The OECD Health Project

Long-term Care for Older People

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Long-Term Care for Older People

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Foreword

This study of long-term care was one of the major components of the OECD Health Project, *which was carried out during 2001-04 to explore key issues in improving the performance of health and long-term care systems.*

Long-term care systems bring together a range of services for people who depend on ongoing help with the activities of daily living caused by chronic conditions of physical or mental disability. Long-term care is assuming a higher profile in health policy debates, partly, as this report shows, because it will likely require a growing share of national expenditures on health in the future. As populations age, growing demand for long-term care is expected, particularly when the baby boom generations reach old age after 2030. Together with current concerns to improve the quality of care and enhance consumer choice, this is likely to pose continuing challenges for national policy-makers in seeking to balance provision of good-quality care with sustainable cost to both public and private budgets. This report concludes with a review of recent national reforms to long-term care financing that aim to balance quality care with equitable payment.

This project was conducted with the invaluable assistance of a network of national experts nominated by the 19 OECD countries taking part in the project: Australia, Austria, Canada, Germany, Hungary, Ireland, Japan, Korea, Luxembourg, Mexico, the Netherlands, New Zealand, Norway, Poland, Spain, Sweden, Switzerland, the United Kingdom and the United States. National experts provided the main input to the study by responding to a questionnaire distributed by the OECD. They also provided valuable comments on the draft report. The Secretariat is grateful to these experts for their sustained commitment and assistance during the course of the long-term care study. The report itself and its conclusions are the responsibility of the OECD and do not necessarily reflect the views of the participating countries and national experts.

This report was prepared by a team in the OECD Social Policy Division led by Manfred Huber and including Patrick Hennessy, Junichi Izumi, Weonjong Kim and Jens Lundsgaard. The team is grateful for the support and advice of colleagues including Martine Durand, John Martin and Peter Scherer, and to Victoria Braithwaite for secretarial support.

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Executive Summary

Governments in OECD countries are faced with growing expectations of their populations for access to better quality long-term care services at affordable costs. When the cohorts of the baby-boom generation will reach the oldest age groups over the next three decades, demand for services will rise steeply. In the meantime, consumers of long-term care are already more reluctant to accept the variability in the quality of care and the wide differences in access to services that currently prevail across OECD countries.

This study reports on latest trends in long-term care policies in 19 OECD countries: Australia, Austria, Canada, Germany, Hungary, Ireland, Japan, Korea, Luxembourg, the Netherlands, New Zealand, Norway, Mexico, Poland, Spain, Sweden, Switzerland, the United Kingdom, and the United States. It studies lessons learnt from countries that undertook major reforms over the past decade. Trends in expenditure, financing and the number of care recipients are analysed. Special attention is given to experience with programmes that offer consumers of services a choice of care options, including in the form of cash benefits. Another focus is on what governments can do to improve quality of services.

Long-term care is a cross-cutting policy issue that brings together a range of services for persons who are dependent on help with basic activities of daily living over an extended period of time. Such activities include bathing, dressing, eating, getting in and out of bed or a chair, moving around and using the bathroom, often in combination with rehabilitation and basic medical services. Long-term care needs are most prevalent for the oldest age groups in OECD countries who are most at risk of long-standing chronic conditions causing physical or mental disability.

An overview of long-term care programmes and expenditure

Among OECD countries, there is a trend towards more universal public provision of long-term care services for those dependent on such care. Several countries have made decisive progress over the past decade in overcoming fragmentation of service delivery and financing across public programmes, regions, or groups of the population. Although in most countries studied the main source of public financing is general taxation, several countries have now opted for a social-insurance-type solution for funding long-term care (Germany, Japan, Luxembourg, and the Netherlands). In other countries, public funding for long-term care is still relatively low, often being restricted to a limited amount of care provided in institutions (*e.g.* Hungary, Korea and Mexico).

But even in countries with relatively comprehensive coverage, spending on long-term care is currently only around 10 to 20% of total spending on health and long-term care together. In addition, there is currently no evidence that long-term care expenditure has grown faster than spending on acute health care – at least after an initial period of introduction of long-term care programmes. High private cost-sharing and informal care provision have

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helped contain costs in the past. The burden of private cost-sharing for care in nursing homes can be high, amounting to 30% or more of total spending in several countries.

For the seven countries in the study that provide universal coverage, the share of publicly funded long-term care in GDP varies from 0.8% to 2.9%. In another twelve countries in which means-testing plays an important role, the spending ratio varies between below 0.2% to 1.5% of GDP. Differences in spending levels for long-term care services are mainly determined by generosity of coverage of services, including differences in the quality of care, such as privacy and amenities in nursing homes. As a result, countries that differ widely in the share of the oldest old group in the total population often have similar public spending levels for long-term care. For the future, OECD countries will have to set aside more resources for long-term care, through a combination of public and private sources.

Towards a continuum of care: bringing services together

Long-term care policies face numerous challenges at the interface with other health and social services, as well as with informal care provided at home by family and friends. Interface problems in the coordination of services of acute, rehabilitative and long-term care can lead both to unsatisfactory outcomes for patients and can also result in inefficient use of resources across health and long-term care systems taken together.

Continuum of care – in the sense of better coordinated care that puts the right mix of services in place – is vital for people receiving care at home and in the community. Enabling older persons to stay at home as long as possible can help greatly to improve the situation of many older persons with care needs, and it is what most want. A key factor in achieving this is to have a broad range of support services available, including respite care in the community together with professional guidance to families.

Policies to improve the continuum of care have been achieved in many countries through a range of measures, including national strategic frameworks to outline broad priorities and goals for policy, sometimes including explicit targets. Successful examples are multidisciplinary care assessment teams, including teams providing advice to households and consumers of services about the available care alternatives and what might be the best choice individually. There is mixed evidence about the cost-efficiency of integrating funding structures for long-term care at local level across health and social budgets and about the benefits of explicit case-management.

Explicit policies with the goal of shifting the balance of long-term care towards more home-based care have enabled more older people, who depend on care, to remain in their own homes. Besides public investment to expand home-care services, this outcome has also been made possible by favourable disability trends among older persons in certain countries and other factors such as the higher incomes of today's retirees and better housing standards.

Besides progress with expansion of services such as respite care in a number of countries, there have been initiatives to support informal carers by granting pension credits for time spent on caring, and payments to carers to compensate for employment income forgone. These policies raise, however, the question of the long-run consequences of providing incentives for carers to leave the labour market, many of whom are women in the age

groups around 50, as their subsequent reintegration in the labour market may be extremely problematic.

Consumer direction and choice in long-term care

For persons who are cared for at home, a variety of cash-benefit programmes have been developed in a number of OECD countries over the past ten years to allow dependent persons and their families more individual choice among care options. These programmes have been designed in various ways: as personal budgets and consumer-directed employment of care assistants, as payments to the person needing care but with a choice on how to spend it in support of care, or, finally, as payments directly to informal care givers in the form of income support.

With personal budgets and consumer-directed employment of care assistants, older persons can employ a personal attendant, frequently with the option that this person can be a relative. Payments to informal care-givers as income support have been designed for the dual purpose of increasing flexibility and mobilising, or at least maintaining, a broader carer potential that enables older persons to stay longer in the community and reduces the need for expensive institutional care.

Some of these programmes are still experimental, covering only a small part of the population. But there exist also several universal programmes designed in this way, which are the main public scheme to provide for publicly funded long-term care (*e.g.*, in Austria and Germany).

These initiatives enable more people with care needs to stay at home as long as possible, by mobilising or sustaining the contribution from informal care. Consumer choice can improve the self-determination and satisfaction of older persons and increase the degree of independent living, even in cases of dependency on long-term care. In general, these programmes are appreciated by older people, for the greater control they get over their life. Surveys have shown that greater choice and consumer direction can contribute to better quality of life at similar cost compared with traditional services, provided these programmes are well targeted to the persons most in need. However, it is essential that sufficient additional services to support care givers are available, such as respite care and counselling since a sufficient supply of care givers is needed if consumer choice is to yield tangible benefits to the frail elderly.

Monitoring and improving the quality of long-term care

There is great variation in quality of long-term care services for older persons. Consequently, quality of services often does not meet the expectations of the public, the users of services and their families. Examples of inadequate care in institutional and community settings are numerous. These include inadequate housing, poor social relationships and lack of privacy in nursing homes; and shortcomings in services such as inadequate treatment of chronic pain, depression, bedsores or the inappropriate use of chemical or physical restraints.

Policies to bring quality in long-term care up to expectations include increasing public spending and initiatives for better regulation of long-term care services, such as by

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establishing quality assessment and monitoring of outcomes. Governments in many countries are now taking a more active role in this respect. But long-term care still lags behind acute health care when it comes to measurement and quality improvement strategies. To improve the situation, more investment in measurement instruments is needed. Countries should move on from setting standards of quality in terms of infrastructure and process to measuring improvement in outcomes and disseminating this information to clients, actual and potential.

There is also the case for making information on the quality of care and the prevalence of adverse outcomes more transparent and accessible to the public on a regular basis. Publicly available information on quality assessment at the level of the provider could lead to improved consumer protection and create a climate of competition for quality, in particular when combined with greater choice on the part of consumers.

It is unlikely that better quality care will be sustainable in the future with current staffing levels in long-term care. This is highlighted by the fact that, according to the responses to the OECD questionnaire, staff shortages and staff qualifications are the number one concern of long-term care policy makers in OECD countries. It is therefore important to address the issue of staff shortages now in order to avoid a further worsening of the situation in many countries. Improving pay and working conditions may be needed in many cases. The object would be to make sure qualified jobs in the care sector remain competitive with alternative jobs in acute health care, against the background of an increasing risk of staff shortages across health and social services.

Countries differ widely in the privacy and amenities available to residents in nursing homes. The number of persons residing in single or double rooms, for example, can range from less than a quarter to almost a hundred percent. Improving the situation in those countries where many people have to share larger rooms, will require substantial investment in new buildings.

Paying for long-term care: current reforms and issues for the future

The large variations in the public coverage of long-term care costs across the OECD countries reflect variations in choice among countries in the way long-term care is financed and provided. A number of countries have introduced new forms of public programmes for long-term care. This has increased overall coverage and consolidated previously fragmented systems of health and social services. Other countries have opted for reforming their existing long-term care systems while maintaining the basic design of a tax-base system with set budgets.

Austria, Germany, Japan and Luxembourg are among the countries which opted for new comprehensive public programmes. With the exception of Austria, these are social insurance programmes, following the basic model of financing for health care adopted in these countries. Some other countries provide comprehensive services that are tax-funded (*e.g.*, the Nordic countries); others stick to means-tested programmes to contain costs (*e.g.* Australia and the United Kingdom). Targeting services more on the population with greatest need and modifying user payments to arrive at a fairer distribution of cost have been a central part of reforms.

For countries which consider moving from a fragmented and incomplete set of public and private long-term care services to a more comprehensive system, there are several lessons from the reform experiences analysed in this study. First, universal systems with population-wide access to long-term care prevent catastrophically high personal costs in the case of dependency for those at risk of expensive care in institutions who cannot receive sufficient care at home. As a result, the need for social assistance programmes to cover private funding gaps has been greatly reduced. Second, a number of strategies have been followed or are currently under consideration to limit the risk of unmanageable cost increases under universal public programmes in the future, when the share of very elderly persons in the population will rise steeply. This includes substantial private cost-sharing, targeting benefits to those most in need, and strategies to prevent or delay the onset of disability in old age. Estimates of future cost increases under alternative scenarios suggest that the financial sustainability of mature long-term care systems critically depends on the success of these measures.

Pensioners are frequently required to contribute to funding long-term care, both by directly contributing to the public system, and in the form of substantial private cost-sharing. Supplementary private insurance could play a stronger role in the future to cover private cost-sharing. Private insurance on top of a basic universal public insurance, for example to pay for the cost of accommodation in nursing homes, covers a risk that is easier to calculate and therefore to insure for the private insurance industry compared to full coverage of the risk of care needs in old age. And it is more affordable for private households.

Finally, when new universal long-term care systems are introduced, it is vital to stabilise or even reduce the number of persons receiving care in institutions. The right mix of support services for home and community-based care is needed to achieve this. This is also important against the background of recent demographic and social trends, such as a growing number of very old persons who live with their spouses, because these trends suggest that informal care in the family will remain one of the most important sources of support, even for very old persons.

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Introduction

Long-term care services are needed by individuals with long-standing physical or mental disability, who have become dependent on assistance with basic activities of daily living, many of whom are in the highest age groups of the population. Long-term care issues are becoming increasingly important on the health and social policy agendas of OECD countries, as policy-makers face continuing increases in public expenditure due to rising demand for long-term care services to meet the needs of growing elderly populations. In addition, the quest for better quality services for older people, for more extensive services to support informal carers, and to make services to both groups more responsive to their choices, have added to concerns about the cost of services and their longer-term sustainability. This has led in recent years to a growing number of national reforms in the financing and delivery of long-term care.

The reform strategies chosen and the experiences of their implementation in OECD countries differ between countries which are at varying stages in the development of services and face different demographic pressures. In some countries, recent reforms have provided improved social protection for older people against the financial consequences of needing extensive long-term care. Some countries have used targeting and increased user payments for some services to focus available resources on the greatest needs. Some countries with a small service base have been concerned about an insufficient supply of services and over-burden on families, while others have been concerned to restrain the growth of the most expensive care, and to better target home care in a way that requires a higher participation from families.

Much has been learned in recent years about how to design a better mix of services for dependent people in order to respond to care needs in flexible ways. However, there is less common ground within and across countries when it comes to the crucial question of "who should pay for what?" The private share of the cost of intensive long-term care can be a huge financial burden for the households concerned. Informal care provided at home by family members, friends, or voluntary organisations is still the most important source of care in all countries. As a result, the public-private mix in the provision of care and the way this is financed varies within and across countries more than is generally the case with other areas of social protection.

This study reviews cross-national developments in long-term care policies, focusing on those aspects that are currently the main focus of reform in OECD countries. The study examines both those reform initiatives that have restructured the financing of long-term care and those that have the aim of improving the delivery of care. As access to services and the way they are paid for are closely linked, these issues have often been linked within the same package of reforms. There is a particular focus in the report on strategies to better integrate care across different sectors and care settings, on policies to introduce more choice and consumer direction, and on initiatives to improve the quality of care.

The continuing growth in the number and share of the oldest people in OECD populations has led to concern about growing expenditure on long-term care services over future decades. Chapter 1 reviews the evidence on cross-country differences in numbers of care recipients and expenditure, indicating key national differences and drivers, and considers the implications of recent projections of future national expenditures on long-term care.

Care needs of older people tend to be complex and call for co-ordinated approaches to provide a continuum of care that is more responsive to the needs of each individual. This continuum has several dimensions: the interaction between acute, rehabilitative and long-term care needs; strategies to boost the provision of care at home; and a greater focus on people with specific needs, such as for people suffering from dementia and their carers. Recent initiatives are introduced and reviewed in Chapter 2, which also sets the scene for a more detailed study of the role of consumer choice and of care allowances in meeting these goals.

Home care continues to be the predominant – and preferred – care setting for the majority of people with care needs. Chapter 3 reviews the movement in several OECD countries towards allowing more individual choice by older people receiving publicly funded long-term care at home, including by employing their own carers or by financial support for care provided by family members and friends.

Concerns over severe quality deficits, particularly within nursing homes providing for those with the greatest needs for care, have been important drivers to recent long-term care reforms. Chapter 4 brings together international evidence on these quality deficits and initiatives to identify and reduce them.

At the heart of a number of major long-term care reforms over recent years has been the question of how to provide wider and more equitable access to long-term care services, within the constraints of financial sustainability. Chapter 5 considers the various reform paths followed by OECD countries, within the context of different national methods for financing health and social services. It shows that a growing number of countries have introduced, or are considering introducing, a new public scheme to provide better protection against the high costs of long-term care. Other countries are making difficult choices about better targeting and amending user payments to arrive at a more sustainable and equitable set of services.

Annex A provides background information on demographic and social trends of ageing populations, including living arrangements of older persons and the role of informal care giving. Short profiles on the long-term care systems of the 19 countries studied are presented in Annex B.

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Box 0.1. **Definitions and glossary of terms**

Terminology in long-term care policy and statistics varies widely between countries. This box presents working definitions elaborated with the aid of the group of experts who supported this study. These are an interim step towards a planned routine data collection on long-term care expenditure and recipients by the OECD Secretariat in the future.

Activities of daily living (ADLs)	*Activities of daily living* are self-care activities that a person must perform every day, such as bathing, dressing, eating, getting in and out of bed or chair, moving around, and using the toilet, and controlling bladder and bowel.
Allowances	*Allowances, cash allowances and cash benefits* are all payments that may be either liable for income taxation or exempt from income taxation.
Care	Frequently used in the study as synonym for *long-term care.*
Consumer direction	The term *consumer direction* refers to arrangements whereby public programmes enable persons needing care or their families to purchase their own care, sometimes including being an employer of a care assistant.
Disabled, or dependent older persons	Older persons whose overall level of functioning is substantially reduced, such that they are likely to require help from a third party, or substantial help from aids and adaptations, in order to fulfil the normal activities of daily life.
Formal long-term care services	Long-term care services supplied by the employees of any organisation, in either the public or private sector, including care provided in institutions like nursing homes, as well as care provided to persons living at home by either professionally trained care assistants, such as nurses, or untrained care assistants.
Home care	Refers to long-term care services that can be provided to patients at home. This includes day-care and respite services and the like. Includes long-term care received in home-like settings, such as assisted living facilities, although statistical systems are in many cases not able to identify these.
Informal care	*Informal care* is the care provided by informal care-givers (also called *informal carers*) such as spouses/partners, other members of the household and other relatives, friends, neighbours and others, usually but not necessarily with an already existing social relationship with the person to whom they provide care. Informal care is usually provided in the home and is typically unpaid.
Institutional care	Long-term care provided in an *institution* which at the same time serves as residence of the care recipient. *Note:* Institutional care should be distinguished from short-term care received in institutions such as *respite care*.
Long-term care	Long-term care is a range of services needed for persons who are dependent on help with basic ADL. This central personal care component is frequently provided in combination with help with basic medical services such as help with wound dressing, pain management, medication, health monitoring, prevention, rehabilitation or services of palliative care.
Long-term care institutions	*Long-term care institutions* are places of collective living where care and accommodation is provided as a package by a public agency, non-profit or private company. Residents may or may not be charged separately for care services and accommodation.
Older persons	All those aged 65 or over.
Nursing home/Nursing home care	Used in this study as synonym for long-term care institution providing nursing and personal care to persons with ADL restrictions.
Private home	Personal residence not specifically designed for people with care needs.
Respite care	*Respite care* is a short-term care arrangement with the primary purpose of giving the carer a short term break from their usual care commitments.

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Chapter 1

An Overview of Long-term Care Programmes and Expenditures

This chapter reviews the evidence on cross-country differences in long-term care programmes and expenditure, indicating key national differences and drivers, and considers the implications of recent projections of future national expenditures on long-term care.

Introduction

Expenditure on health and long-term care are both heavily concentrated on the oldest age groups, which are currently the fastest growing segments of OECD populations. More attention, therefore, needs to be given to finding more efficient ways to respond to the specific care needs of older persons. A better mix of services of preventive, acute, rehabilitative, and long-term care services is needed.

After proposing a working definition of the scope of long-term care services, this chapter first presents a snapshot of long-term care coverage by public programmes. This shows how differences in programme design lead to significant variations in overall spending levels. In particular, there are marked differences between long-term care funding for services in a home/community-based setting and care provided in an institutional setting.[1]

Although data on trends over time are scarcer, some such evidence is also presented about expenditure growth for long-term care. Analysing trends over time is crucial to finding out whether the cost pressures listed above have in the past been matched by corresponding expansions in supply of long-tem care funding. The chapter ends with a cautious note on the underlying assumptions of projection models for future spending growth, and briefly reviews results from recent projections exercises.

The nature of long-term care services

Long-term care brings together a range of services for persons who are dependent on help with basic activities of daily living (ADL) over an extended period of time. Such activities include bathing, dressing, eating, getting in and out of bed or chair, moving around and using the bathroom. These long-term care needs are due to long-standing chronic conditions causing physical or mental disability.

This study distinguishes between long-term care services and medical services, such as interim hospitalisation, medical diagnosis and prescription drugs. An attempt has also been made in this study to separate long-term care services of help with ADL-restrictions (as defined above) from lower-level social care such as housekeeping, meals, transport and social activities.

Demand for long-term care grows exponential with age, and the bulk is concentrated on persons aged 80 years and older. The effect of trends in disability among older people on future demand for long-term care has therefore been at the centre of a number of recent studies, both in countries and internationally. An overview of recent findings is reviewed in Annex A. Although a number of studies agree that favourable disability trends in the future could have a substantial mitigating effect on future demand for long-term care, the fast-growing number of very old persons, in particular relative to the population at working age, is nonetheless expected to increase substantially care needs – and related spending – in the future.

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In all countries, older persons still receive the bulk of help with activities of daily living (together with lower-level care), in their own homes – from informal (unpaid) carers, either family or friends. Formal (paid) services of long-term care are provided in a variety of settings. They can be provided at home and in the community, by professional services of home care, including paid personal assistants. Alternatively, they are delivered in institutions, such as nursing homes and assisted living facilities, for which a wide range of national arrangements and national labels exist.

To support persons who are cared for at home, a number of cash-benefit programmes allowing consumer choice, personal budgets for home care, and care allowances have now been developed in a growing number of the countries studied. As Chapter 3 will show, these can range from experimental programmes, covering a small part of the population to being the main public scheme available to cover long-term care.

The complex interplay of formal and informal long-term care and the wide range of potential service options illustrate that, in addition to ageing per se, there are other factors likely to exert spending pressures. Besides changes in family structure and living conditions of older persons, these include growing public expectations for an increased protection by public programmes against financial risks of dependency and long-term care needs in old age, a broader range of support services for informal care provided at home, and better quality of services, in particular those provided in a nursing-home setting.

A wide range of long-term care coverage by public programmes

Financing of long-term care services is drawn from different sources in OECD countries. A central challenge for reform therefore remains how to organise co-ordinated care for patients across a wide range of long-term care services and settings. This section starts with an overview of the coverage provided by major public programmes for both care in institutions and in a home/community-care setting. The summary discussion of these programmes sets the scene for the more detailed analysis in subsequent chapters throughout the study, including short country profiles in Annex B.

The most significant programmes are set out in Table 1.1, which lists long-term care programmes in OECD countries by type of programme, source of financing, eligibility criteria and the use of private cost-sharing. Programmes in most countries consist of in-kind services for both home care and institutions. But there are a growing number of programmes which offer cash allowances or consumer-directed budgets. In most cases, long-term care programmes serve all age groups (see Box 1.1). Korea and Japan are exceptions in this respect, as well as the US Medicare programme.

In most countries studied, the main source of public financing is taxation. For example, Norway and Sweden both offer universal coverage of long-term care services funded from general taxation, but differ in the cost-sharing required for services provided in nursing homes. A few countries (Germany, Japan, the Netherlands and Luxembourg) have set up a universal social insurance scheme specifically to cover long-term care. Austria has a universal system funded from general taxation, governed by similar regulation. In other countries the main health insurance programme finances a limited amount of care in hospitals in the absence of other programmes, but the total involved is quite small (*e.g.*, Hungary, Korea, Mexico and Poland).

Table 1.1. **Major public programmes covering long-term care in selected OECD countries, 2003**

	Type of care	Programme	Source of fund	Type of benefits	Eligibility criteria[1, 2]	Private cost-sharing
Australia	Institutional care	Residential care	General taxation	In-kind	All ages	There is a standard charge plus a means-tested charge based on income.
	Home care	Community Aged Care Packages (CACP)	General taxation	In-kind	Generally 70+ Means-tested	Users are charged according to ability to pay.
		Home and community care (HACC)	General taxation	In-kind	All ages Means-tested	Users are charged according to ability to pay.
		Care payment	General taxation	Cash	All ages Means-tested	–
		Carer allowance	General taxation	Cash	All ages Universal	–
Austria	Home care	Long-term care allowance	General taxation	Cash	All ages Universal	Users are expected to pay the difference between the benefit and the actual cost.
	Institutional care	Long-term care allowance	General taxation	Cash	All ages Universal	Users are expected to pay the difference between the benefit and the actual cost.
Canada	Home care	Provincial programmes	General taxation	In-kind	All ages Usually means-tested	Means-tests vary between provinces.
	Instutitutional care	Provincial programmes	General taxation	In-kind	All ages Usually means-tested	Means-tests vary between provinces.
Germany	Home care	Social Long-Term Care Insurance	Insurance contribution	In-kind and cash	All ages Universal	No cost-sharing required but out-of-pocket to pay for additional or more expensive services than covered by public insurance was on average EUR 130 per month.
	Institutional care	Social Long-Term Care Insurance	Insurance contribution	In-kind	All ages Universal	Board and lodging is not covered (on average EUR 560 per month); plus service-charges in excess of statutory limit were EUR 313 on average; (these private cost can be covered by means tested social assistance).[3]
Hungary	Home care/ Institutional care	Social protection and social care provision programme	General taxation	In-kind and cash	All ages Means-tested	User payment is set by the institution within the range defined by the local governments.
		Health-care insurance fund financed services	Insurance contribution	In-kind	All ages Universal	"Basic quality" services are free of charge. Patients have to pay for "higher quality" services.
Ireland	Institutional care	Nursing Home Subvention Scheme	General taxation	In-kind	All ages Means-tested	Maximum of EUR 26 000 per year on average (depending on home).
		Public long term care	General taxation	In-kind	All ages Means-tested	Users have to pay up to a maximum of 80% (around EUR 5 500 per year) of the non-contributory old-age pension.
	Home care	Community-based care	General taxation	In-kind	Partly means-tested	Community nursing services are not means-tested and are free of charge, but home helps are means-tested.
Japan	Home care Institutional care	Long-term Care Insurance System	Insurance contribution and general taxation	In-kind	Aged 40-64: disabled by 15 ageing-related diseases aged 65+: all disabilities Universal	Users pay 10% of the cost as co-payment.

Table 1.1. **Major public programmes covering long-term care in selected OECD countries, 2003** *(cont.)*

	Type of care	Programme	Source of fund	Type of benefits	Eligibility criteria[1, 2]	Private cost-sharing
Korea	Home care Institutional care	Social services for the elderly	General taxation	In-kind	65 and over Means-tested	Recipients of social assistance: free of charge. Others: charge varies according to the level of income.
Luxembourg	Home care Institutional care	Dependency insurance	Insurance contribution	In-kind and cash	All ages Universal	Users are to pay the difference between the benefit and the actual cost of care.
Mexico	Institutional care	Specialised services in Geriatrics	General taxation	In-kind	All ages, all people who are insured	
	Home care	Day centres for pensioners and retired	General taxation	In-kind	Insured pensioners and retired people	
Netherlands	Home care	AWBZ	Insurance contributions	Consumer-directed budget[4]	All ages Universal	Income-related co-payments are required.
	Institutional care	AWBZ		In-kind	All ages Universal	Income-related co-payments are required.
New Zealand	Home care	Carer Support	General taxation	In-kind	All ages, means-tested	
		Home Support: home help	General taxation	In-kind	All ages, income tested	
		Home Support: personal care	General taxation		All ages, universal	
	Institutional care	Long-term residential care	General taxation	In-kind	Aged 65 and over, and 50-65 with early onset age-related conditions Means-tested	
Norway	Home care	Public long term care	General taxation	In-kind	All ages Universal	Home nursing care is free of charge. Home help is based on an optimal user-payment (usually NOK 50 per time).
	Institutional care	Public long term care	General taxation	In-kind	All ages Universal	Residents in institution are charged approximately 80% of their income.
Poland	Home care Institutional care	Social services	General taxation	Cash/in-kind	All ages Means-tested	
Spain	Home care Institutional care	Social care programmes at Autonomous Community level	General taxation	In-kind	Means-tested	73% of total long-term care cost was met privately in 1998 according to an estimate.
Sweden	Home care Institutional care	Public long term care	General taxation	In-kind	All ages Universal	Users pay moderate amount of fees set by local governement.
Switzerland	Home care Institutional care	Programmes at Canton level; health promotion for the elderly by Old Age Insurance	Sickness/Old Age Insurance funds and general taxation	Mix of in-kind benefits and benefits in cash	Means-tested for institutional care	High.
United Kingdom	Home care Institutional care	NHS	General taxation	In-kind (nusirng at home and in nursing home)	All ages Universal	Free of charge.
	Home care Institutional care	Social services	General taxation	In-kind	All ages Means-tested	Users are charged accoriding to ability to pay.
	Home care (cash)	Social Security Benefits	General taxation	Cash benefit	All ages Means-tested	

Table 1.1. **Major public programmes covering long-term care in selected OECD countries, 2003** *(cont.)*

	Type of care	Programme	Source of fund	Type of benefits	Eligibility criteria[1, 2]	Private cost-sharing
United States	Home care (in-kind) Institutional care (in-kind)	Medicare	Insurance contributions	In-kind (skilled care only)	Disabled and aged 65+ Universal	Home nursing care: free of charge. Skilled nursing care: up to 20 days USD 0, 20-100 days USD 105 per day, after 101 days 100%.
	Home care (in-kind) Institutional care (in-kind)	Medicaid	General taxation	In-kind	All ages Means-tested	Co-payment can be charged depending on financial status of the recipient.

1. "Means-tested" refers to a test of user's income and/or assets in relation to receipt of personal care (at home) or home care allowance, or in relation to nursing and/or personal care in a nursing home. Generosity of tests varies widely between countries.
2. "Universal" refers to programmes with no income and/or asset test as defined in note 1 above.
3. Cost-sharing in 1998, according to Schneekloth and Müller (2000).
4. By 1 April 2003, the consumer-directed budget has been changed in a cash payment.

Source: OECD's questionnaire on long-term care.

Box 1.1. **Long-term care systems serve all age groups**

Age of the care recipient is in most cases not an eligibility criterion as most programmes aim to link eligibility for certain funding levels of services to the care needs of users, independently of the underlying chronic health condition and without differentiation by age group. The predominant group of users for long-term care services under public programmes, however, is older persons, many of them in the oldest age group. As a rule of thumb, around 80% of users of home-care services and some 90% of nursing home residents are aged 65 and older. It is for this reason that throughout this report the terms "long-term care programmes" and "long-term care for older persons" are often used interchangeably. Where the description and analysis refer to older persons exclusively (such as for the discussion of number of recipients), this will be stated explicitly.

Besides countries that provide universal access to long-term care services, there are those that have a largely means-tested system in which the user is expected to bear all or most of the cost above a certain level of income. In means-tested schemes, the user faces very high costs if their income is above the means-test level, especially on entry to a nursing home. This has led to pressures on governments for reform. A common feature of long-term care programmes frequently is that the nursing home resident has to pay an accommodation charge, unless they are in the social assistance category. In some countries with a public scheme this is linked to retirement income, *e.g.,* 80% of the public pension in Norway, whereas in others the user pays the actual cost unless meeting a low income test. Chapter 5 considers these developments in detail.

As Table 1.1 shows, even under universal public programmes, the requirement for private cost-sharing usually is substantial, although it tends to be spread more evenly among beneficiaries compared to means-tested programmes. Cost-sharing in universal systems either comes as a fixed percentage of cost, or as the difference between the benefit and actual spending.[2] The implications at aggregate level of cost-sharing regulations for the public-private mix of financing are discussed in the following sections on expenditure trends.

Differences in spending levels for long-term care services

Total expenditure on long-term care in the 19 OECD countries covered in this study ranges from below 0.2 to around 3% of GDP. Most countries, however, are clustered in a range between 0.5% and 1.6% of GDP, with only Norway and Sweden having expenditure ratios well above that level (Table 1.2 and Figure 1.1).

The comparison of spending levels across countries reveals that quite different ways of organising and funding long-term care (as sketched in Table 1.1) have lead to similar expenditure outcomes, in terms of overall spending levels. For example, Australia, Canada, Germany, the United Kingdom, and the United States all have spending ratios that lie within a narrow range of 1.2 to 1.4% of GDP. The first lesson from this comparison is therefore that one broad type of programme design need not be associated with different expenditure outcomes than another.

Moreover, countries with similar spending levels may face rather different challenges. This is illustrated by Figure 1.2 which plots overall spending levels against the percentage

Table 1.2. **Public and private expenditure on long-term care as a percentage of GDP, 2000**

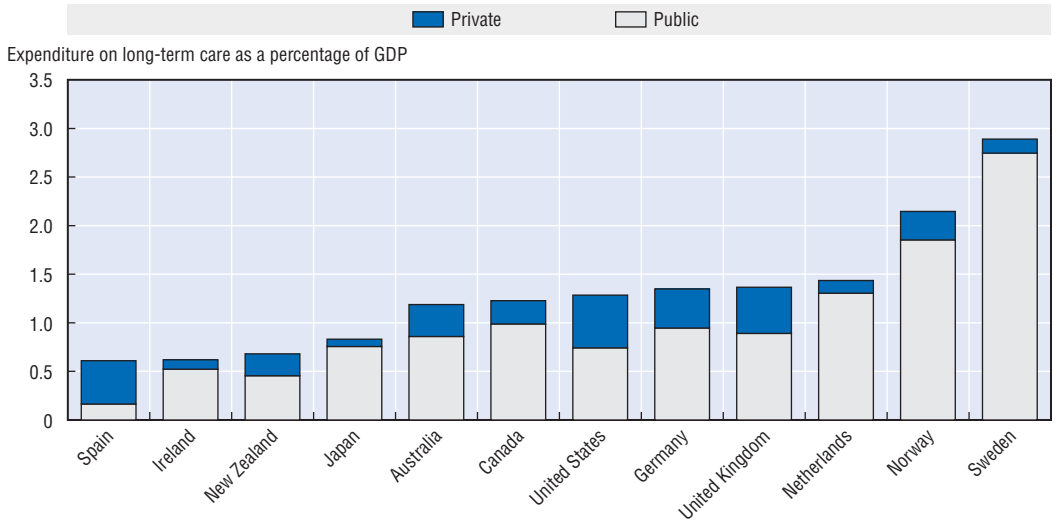
	Total expenditure			Public expenditure			Private expenditure		
	Home care	Institutions	Total	Home care	Institutions	Total	Home care	Institutions	Total
Australia	0.38	0.81	1.19	0.30	0.56	0.86	0.08	0.25	0.33
Austria	n.a.	n.a.	n.a.	n.a.	n.a.	1.32	n.a.	n.a.	n.a.
Canada	0.17	1.06	1.23	0.17	0.82	0.99	n.a.	0.24	0.24
Germany	0.47	0.88	1.35	0.43	0.52	0.95	0.04	0.36	0.40
Hungary	< 0.10	< 0.20	< 0.30	n.a.	n.a.	< 0.20	n.a.	n.a.	< 0.10
Ireland	0.19	0.43	0.62	0.19	0.33	0.52	n.a.	0.10	0.10
Japan	0.25	0.58	0.83	0.25	0.51	0.76	0.00	0.07	0.07
Korea	n.a.	n.a.	< 0.30	< 0.10	< 0.10	< 0.20	n.a.	n.a.	n.a.
Luxembourg	n.a.	n.a.	n.a.	0.15	0.37	0.52	n.a.	n.a.	n.a.
Mexico	n.a.	n.a.	< 0.20	n.a.	n.a.	< 0.10	n.a.	n.a.	< 0.10
Netherlands	0.60	0.83	1.44	0.56	0.75	1.31	0.05	0.08	0.13
New Zealand	0.12	0.56	0.68	0.11	0.34	0.45	0.01	0.22	0.23
Norway	0.69	1.45	2.15	0.66	1.19	1.85	0.03	0.26	0.29
Poland	0.35	0.03	0.38	0.35	0.03	0.37	n.a.	0.00	0.00
Spain	0.23	0.37	0.61	0.05	0.11	0.16	0.18	0.26	0.44
Sweden	0.82	2.07	2.89	0.78	1.96	2.74	0.04	0.10	0.14
Switzerland	0.20	1.34	1.54	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
United Kingdom	0.41	0.96	1.37	0.32	0.58	0.89	0.09	0.38	0.48
United States	0.33	0.96	1.29	0.17	0.58	0.74	0.16	0.39	0.54
Average[1]	0.38	0.88	1.25	0.35	0.64	0.99	0.06	0.19	0.24

Note: Data for Hungary, Korea, Mexico and Poland are only rough indications of magnitude; Data for Australia, Norway, Spain and Sweden are for age group 65+; n.a. = not available.
The notion of "long-term care" used in a national context can be substantially broader, *e.g.,* by including residential homes for older people (*e.g.* the Netherlands, Nordic countries).

1. Average excludes Austria, Hungary, Luxembourg, Korea and Mexico.

Source: Canada, Germany, Hungary, Norway: *OECD Health Data 2004;* Australia: Productivity Commission (2003); Ireland: estimates based on O'Shea (2003) and Mercer Limited (2003); Poland: Kawiorska (2004); Spain: Marin and Casanovas (2001); United States: *OECD Health Data 2004* and GAO (2002); Austria, Japan, Korea, Luxembourg, Mexico, Norway, New Zealand, Sweden, Switzerland, United Kingdom: Secretariat estimates based on replies to the OECD's questionnaire on long-term care. (See Huber, 2005a, for a more detailed documentation of sources and methods.)

Figure 1.1. **Public and private expenditure on long-term care as a percentage of GDP, 2000**



Source: See Table 1.2.

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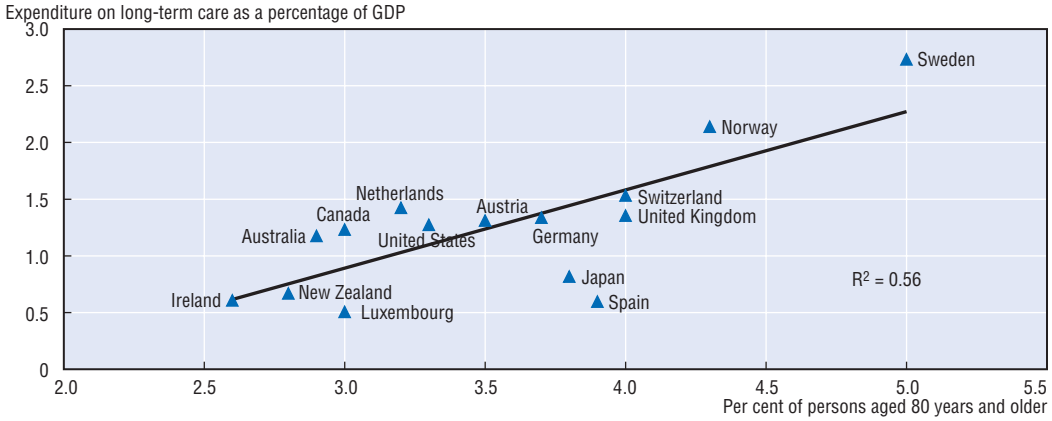
Figure 1.2. **The correlation between total long-term care spending and the population share of the very elderly, 2000**



Source: See Table 1.2 and Table A.1.

of persons aged 80 years and older – the largest group of service users under long-term care programmes.[3] Spain and Ireland, for example, have both similar moderate spending levels and a comparable split between spending for home care *versus* spending on institutional care. However, long-term care financing in Spain is faced with a number of very old persons in the population that is almost 40% higher than in Ireland. In addition, financing for this significantly older population in Spain comes predominantly from private sources. For Ireland, private spending accounts for only one sixth of total spending.

A second conclusion is therefore that countries with significantly different population shares of very old persons often have similar spending levels, which are mainly due to differences in programme design, such as varying public-private mix of funding and, more generally, differences in the division of labour between formal and informal (unpaid) care-giving.

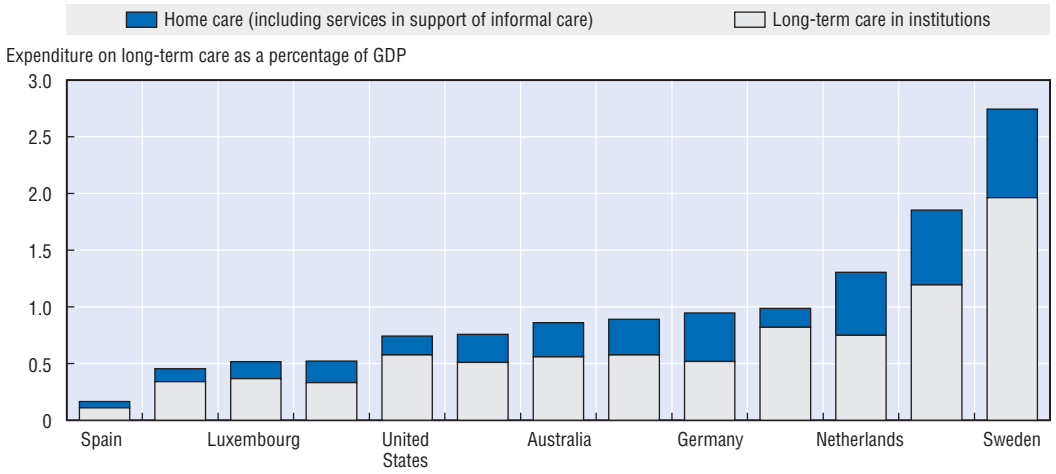
Norway and Sweden stand out in this comparison with substantial higher spending than any other country. Although both countries also have the highest population shares of very old persons, the high expenditure numbers are also due to the generous programme design in both countries. Comparatively high spending levels in these countries are illustrated by the generous services provided for residents in nursing homes. Both countries offer more amenities, such as single room and well-equipped housing infrastructure, compared to other countries (see Table 4.5 in Chapter 4). Higher cost-sharing in Norway may explain part of the lower expenditure ratio compared with Sweden.[4]

Aspects of quality of care may explain part of the differences observed in Table 1.2 and Figure 1.1 for other countries as well. The proportion of single and double-bed rooms in nursing homes has obvious cost implications for all countries. Their number is currently much lower in countries like Japan and Korea, explaining part of the lower expenditure levels for these countries.

Public expenditure on long-term care services

While even universal long-term care programmes currently consume only around 8 to 20% of health and long-term care spending (taken together), several countries start from a

Figure 1.3. **Public expenditure on long-term care as a percentage of GDP, 2000**



Source: See Table 1.2.

much lower level of resources available to meet the demand for long-term care. This is especially the case for some countries that are only just beginning to develop unique long-term care programmes within health and social services. Moreover, public programmes that cover home care are, in many cases, less developed than programmes for long-term care in institutions.

Public funding is the most important source of financing for long-term care services in all countries where data on the public-private mix of funding are available (with the exceptions of Spain and Switzerland). Nonetheless, public spending on long-term care is still relatively low as a proportion of GDP, when compared with other ageing-related expenditures such as pensions or acute health care that are also heavily concentrated on older persons (Figure 1.3). This section looks in more detail at the differences in the way public money is spent on home care *versus* institutional care.

Spending on care in institutions accounts in all countries for over half of public spending on long-term care (Figure 1.4). Public programmes of home care have received increasing attention as the preferred option for most persons with care needs. In addition, the majority of home-care recipients, in particular among older persons, will have in addition to access to public programmes family or friends who support them by providing additional services, the majority of which will be unpaid. Home care is therefore a lower cost alternative to care in institutions, in many cases.

Public policy has consequently over time shifted a larger share of resources to support home-care services in a number of ways: by a larger supply from home-care providers in the community, more support services, such as respite and counselling, to families who care for close relatives, and finally programmes of consumer choice in various forms, as care payments or personal budgets. As a result, home care now accounts in half of the countries, for which data are available, for more than 30% of public resources (Figure 1.4).

Behind these aggregate numbers, there are big differences in the way access to home care is granted. Similar spending levels can either be spread widely, including small

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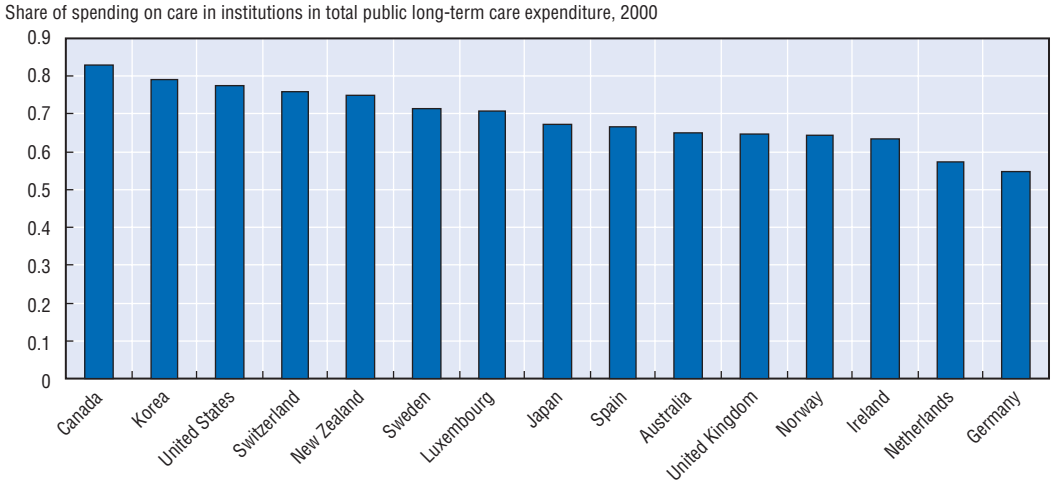
Figure 1.4. **Share of spending on institutional care in total public long-term care expenditure, 2000**



Source: See Table 1.2.

payment for a large number of low-level cases, or be targeted more in favour of those with higher levels of care needs. Chapters 2 and 3 analyse the consequences of these differences in programme design, and Chapter 5 explains trends in reform to better target services to those most in need.

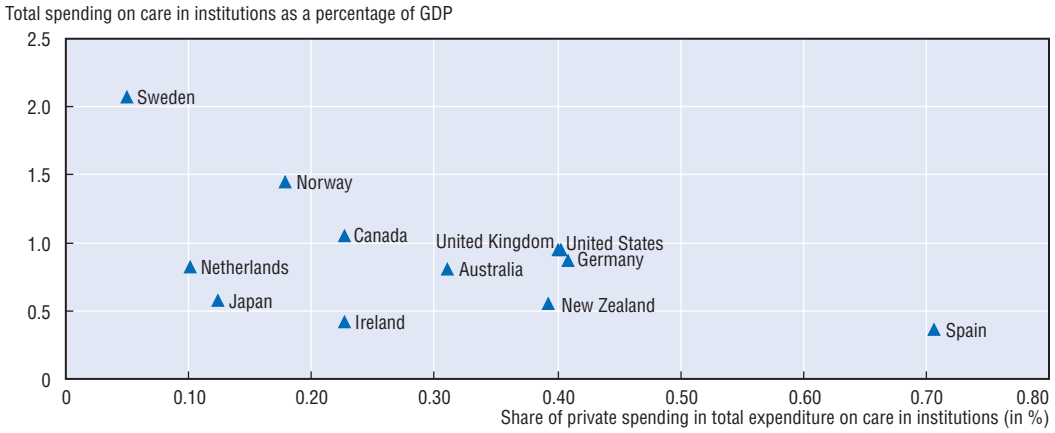
The public-private mix of funding for long-term care services

Private households in most countries share the burden of care, not only by providing informal, unpaid care, but also by making substantial co-payments and/or out-of-pocket spending for care provided under public programmes, both at home or in institutions. Even under universal social insurance systems, long-term care services provided in institutions are usually only partially covered by public programmes and households may be required to contribute to the cost of board and lodging. In most countries, users are also charged for nursing and personal care, following a means-test. Moreover, households that can afford to pay for them may decide to buy services additional to those provided under public programmes, directly from private providers.

In general, private spending plays a more important role for funding long-term care provided in institutions than for home care. Because these private expenditures are concentrated on a relatively small number of households, they can represent a heavy financial burden on individual households concerned (see, *e.g.,* the cost-sharing rates for Germany, Ireland, and Spain in the last column of Table 1.1).

The burden of private expenditure in nursing homes can be substantial for individual households and is an important source of funding for care in institutions, contributing 30% or more of total spending in several countries (Australia, Germany, New Zealand, United Kingdom and the United States). As Figure 1.5 shows, countries at different spending levels on care in institutions vary widely in the share of private spending contributed by households (and, in the case of the Unites States, by private insurance).[5]

Figure 1.5. **The role of private spending on care in institutions**



Source: See Table 1.2.

Substantial private cost-sharing, in particular for nursing home care, and the availability of informal care as a major source of support, are two of the main reasons why countries with different programme designs and different old-age population shares have been able to contain costs, sometimes arriving at quite similar spending levels.

Trends in public expenditure on long-term care

There is a widely shared perception that expenditure growth will accelerate over the next 20 to 30 years, mainly as a result of larger numbers of older persons, and a steep increase in the numbers of the oldest-old. However, in the cross-sectional view explored above, the empirical evidence suggests that differences in programme design (such as generosity of funding and level of cost-sharing, quality of services, the way services are targeted to those most in need or spread widely to include lower-care cases) play a more important role in explaining differences in current spending levels than demand for services measured mechanically by population age structure.

This section looks into time trends to shed more light on the most important cost drivers that will likely continue to prevail in the future. The caveat here is that data on time trends are even scarcer than for cross-sectional analysis and limited comparability over time an additional concern (Box 1.2).

For mature long-term care systems, public spending has remained fairly stable as a share of total public expenditure on health and long-term care in several countries over the period since 1990 (Figure 1.6). The main growth of long-term care spending took place during the initial phase of setting new social programmes up (Germany, Japan, and Luxembourg). Where, however, a system was in place for a longer period of time, no "cost explosion" relative to acute care spending has occurred.

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Box 1.2. **What can we learn from future projections of spending on long-term care?**

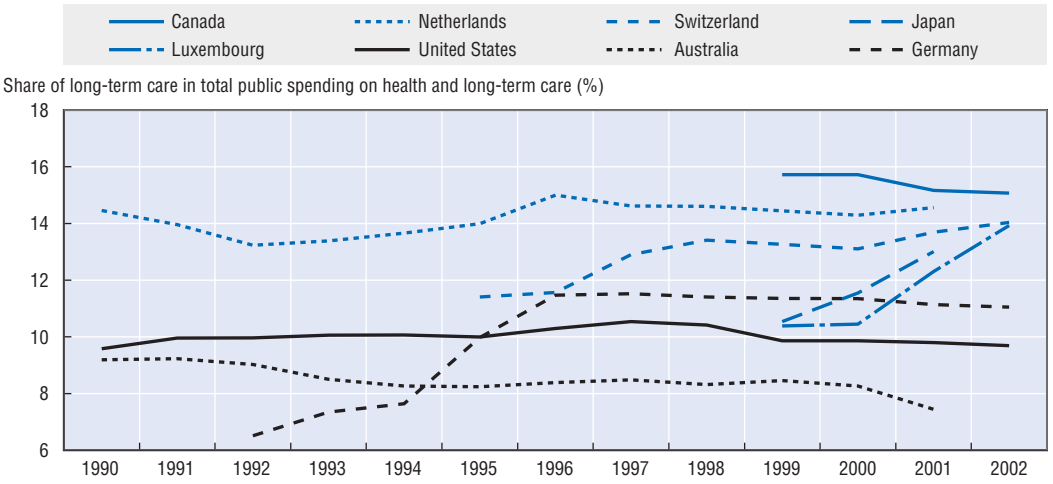
National reviews of long-term care policies and strategies for reforms frequently look into projection models to learn more about the likely outcomes of changes in the parameters of long-term care systems and of expected trends in the demographic and socio-economic environment. At the core of most of these models is a demographic mechanism based on age-specific utilisation and/or expenditure rates and a model of demographic change by age groups. In its simplest versions, few other parameters (such as relative prices of services and assumptions on overall economic growth) are used to produce time paths for future expenditure growth. However, as the discussion of observed trends over time in this chapter illustrates, there is little evidence to support the assumption that changes in the age structure are the predominant driver of growth in public spending on long-term care.

This has also been recognised by a number of recent national projects and international initiatives which have developed more refined models in order to improve the reliability of long-term care projection exercises. A previous study for the OECD showed that the assumption of constant disability rates and constant relative expenditure within age groups led to higher projected future expenditure than projections that take into account evidence on declining disability over time (Jacobzone *et al.,* 1999). More recent results from a number of countries also support the proposition that disability rates in older age are declining, and consequently suggest slower growth in projected costs of long-term care in the future (see, *e.g.*, Lagergren and Batljan, 2000, for Sweden; Manton and Gu, 2001; Knickman and Snell, 2002, for the United States). There is, however, some uncertainty about the trend decline in disability rates. This trend is not observed in all countries, and the rate is very different across countries.

The degree to which estimates of future long-term care costs are highly sensitive to trends in disability is further illustrated by a recent study carried out for the European Commission covering Germany, Italy, Spain and the United Kingdom (Comas-Herrera and Wittenberg, 2003). This study shows that a delay in dependency of one year for each year of additional life expectancy would reduce projected long-term care costs by over half in three of these four countries, compared to alternative estimates. Significant reductions in future projected costs would arise even if dependency were only to be deferred for six months for each additional year of life expectancy.

Projections of long-term care spending rates are also highly sensitive to assumptions about overall productivity trends in the economy, labour market participation, trends in the availability of informal care givers, and population growth. Experience over the past 20 years has shown how difficult it can be to project the wider outcomes of demographic ageing with any accuracy. However, the modelling of future long-term care costs is a developing art (rather than science) and has already helped to indicate which variations in underlying causes are the most sensitive and where public policies may help to influence outcomes in future years. Annex A of this report considers in more detail the trends in disability and informal care that may impact on demand and supply of long-term care in future decades.

Figure 1.6. **Trends in public spending on long-term care, 1990-2002**



Note: Australia and United States: expenditure in institutions only.

Source: OECD Health Data 2004.

Notes

1. The data set on expenditure and financing presented in this chapter brings together the most comprehensive picture currently available for a cross-sectional analysis. It builds on recent progress with health accounts and on detailed replies from participating countries to a questionnaire for this study (for details on sources and methods, see OECD, 2004b). Data have been harmonised, therefore may differ substantially from nationally published data.
2. The borderline between means-tested programmes and "universal" programmes can be blurred. If cost-sharing under universal programmes is high, some households will not be able to cover their cost. They may then become eligible for means-tested social assistance to fill the financial gap, for example to cover the cost of accommodation in nursing homes.
3. The prevalence of functional limitations grows exponentially with age which leaves room for different cut-off points for analytical purposes. 80+ is a frequent choice in the research literature. However, other age-limits have been proposed. The benchmark for *Residential Aged Care* in Australia, for example, foresees that availability of care places increases in line with the number of persons aged 70 years and older (see Annex B).
4. The case of oil-rich Norway (with the third highest per capita GDP of OECD countries), is also a reminder that in comparing expenditure ratios one should not forget the large differences in the underlying GDP denominators.
5. This is also the case when demographic differences are taken into account, *e.g.* by standardising, expenditure levels by the share of very old persons (aged 80 years and above) in the population, relative to an OECD average share of about 3%.

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Chapter 2

Towards a Continuum of Care: Bringing Services Together

Care needs of older people tend to be complex and call for co-ordinated approaches to provide a continuum of care that is more responsive to the needs of each individual. This continuum has several dimensions: the interaction between acute, rehabilitative and long-term care needs; strategies to boost the provision of care at home; and a greater focus on people with specific needs, such as for people suffering from dementia and their carers. Recent initiatives are introduced and reviewed in this chapter, which also sets the scene for a more detailed study of the role of consumer choice and of care allowances in meeting these goals.

Introduction

Chapter 1 has shown the scale of investments in long-term care services in OECD countries, and indicated that this is likely to increase in future decades. However, concerns have all too frequently been expressed by both users of services and administrations that these services are not always well-co-ordinated and so have a less-than-optimal impact. For example, a frequent criticism of these services from users and their families is that, whatever the quality of individual services, there is insufficient communication between them. This may leave users and families having to deal with different services with separate entry criteria and priorities. From the point of view of national administrations, this lack of co-ordination may also result in less-than-optimal use of resources, for example, inappropriate use of more expensive services such as care institutions, or lack of access to home care and rehabilitation services that would allow an older patient to be discharged more speedily from hospital.

This chapter reviews recent OECD country policies that have aimed to improve the co-ordination and fit between these separate services, to the benefit of users and the overall effectiveness of national investments in these services. First, it considers policies to improve the co-ordination of services, looking at national strategic frameworks, more integrated delivery structures and realignment of long-term care financing as ways to improve the combined contribution of services. Secondly, the chapter looks at measures taken in pursuit of one of the main objectives of better co-ordinated services, namely, that of maintaining a greater number of older disabled people in their own homes in preference to care institutions. Finally, it discusses what has proved to be a vital component of policies with this aim – support for informal carers to enable them to provide their own essential contribution to the continuum of care that older people need.

The continuum of care

One concept that has been developed to provide a measure of how successfully different health and social services fit together is that of the continuum of care. In this view, success must be measured by how well the services fit together at the level of the individual patient. Since patients have different conditions and disabilities, and are receiving care in different circumstances, there is no single continuum as such, but one for each patient, requiring services to take a holistic view of their needs.

This can be illustrated by the simplified continuum of interventions shown in Table 2.1 for two major age-related disabling conditions, namely, stroke and dementia. The services that may be needed at any one time for those suffering from each of these conditions are for the most part different. Those with stroke may require rehabilitative services to restore some bodily functioning, and, unless the effects are severe, may be enabled to stay in their own home, most probably with help from informal or formal care. By contrast, those with dementia may be able to be treated with drugs to slow down the onset of symptoms but will not see a recovery of functioning. If they have informal carers,

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Table 2.1. **Interventions on a continuum-of-care for stroke and dementia patients**

Type of intervention	Potential benefits in the case of:	
	Stroke	Dementia
Prevention through risk management	Yes	No
Controlling severity of symptoms through drugs	Limited	Limited
Restoring functioning through drugs	Limited	No
Restoring functioning through physiotherapy	Yes	No
Occupational therapy to help patient to help themselves	Yes	No
Advice and help to enable patient to help themselves	Yes	Very limited
Advice and counselling to family carer	If necessary	Essential
Post-acute hospital care	Yes, where hospital treatment was required	Does not apply
Personal care service in own home	Yes, where symptoms severe but patient can remain at home	Yes when condition has become severe but patient can remain at home
Admission to long-term residential care	In severe cases where rehabilitation unlikely and home care not possible	Yes unless family carer can provide extensive palliative care
End-of-life care	In severe cases only	Yes

Source: Adapted from Moon *et al.* (2003), "Stroke Care in OECD Countries: A Comparison of Treatment, Costs and Outcomes in 17 Countries", OECD Health Working Papers No. 5, OECD, Paris; Moïse, P., M. Schwarzinger and M.Y. Um (2004), "Dementia Care in 9 OECD Countries: A comparative analysis", OECD Health Working Papers No. 13, OECD, Paris.

they will require a great deal of counselling and support. If this support is not available, institutional care is most likely to be necessary beyond a certain stage.

The policy aim behind the continuum-of-care approach is then to have services managed and financed in a way that achieves:

- First, a more co-ordinated input of the range of services required by service users and families *atany one point in time*. This applies particularly when the service user is receiving care in their own home, as a number of different services may need to work together to provide appropriate care and maintain the service user in that setting.
- Secondly, better management of transitions between services and service settings, as the patient's needs change and develop *over time*. In policy terms there has been a particular concern to achieve smooth transitions between the major service settings of the user's own home, acute hospital and nursing home.

The potential complexity of interactions between services has led a number of countries to introduce measures designed to make services work together more effectively and to manage transitions between services more efficiently, both for benefit of the user and for a better use of resources. This does not necessarily mean having all services integrated into one organisation; indeed, in no OECD country are all acute and long-term care services integrated in one organisation country-wide, although there are a number of area-based initiatives to test ways of doing so.

National measures to improve the continuum of care

Long-term care services are delivered in OECD countries at local level, frequently managed by sub-national levels of government or agencies. However, the framework within which these local governments and agencies operate is to varying degrees set by national government legislation and regulation. There are three aspects of long-term care

policy on which national governments often take the initiative in an effort to influence the outcomes of long-term care delivery:

- First, taking the lead in consulting relevant national and local stakeholders and preparing a strategic framework that sets out agreed goals and priorities.
- Secondly, reforming government or other institutional structures to enable a more integrated approach to the delivery of care.
- Thirdly, realigning the flow of long-term care finance, and the terms on which it is made available, in order to influence the balance of care received.[1]

This chapter now considers recent national initiatives in these three areas, summarised in Table 2.2, to show how each may contribute to improving the continuum of care.

Setting the strategic framework

A growing number of OECD countries have sought to improve the linkages between agencies providing health and long-term care services for older people by negotiating and publishing a strategic framework that sets out agreed national goals and priorities. These are designed to ensure that service providers, financing agencies, levels of government and other stakeholders have a common approach to providing services and also that the users and their families, or advocacy groups working on their behalf, are able to see what services will be made available in which circumstances. As long-term care is usually a devolved service, run by sub-national agencies or levels of government, these national standards may also indicate what services should be provided in all parts of the country.

These national strategic plans may operate at several levels:

- They may set out broad priorities and goals for policy, *e.g.*, the plans in Australia and New Zealand.
- They may in addition set targets for service provision and the resources that will be put in place to achieve these. These usually have a programme to be achieved within a set time frame, *e.g.*, Japan, Norway, Spain, Sweden and the United Kingdom.
- They may aim to provide a comprehensive framework for service provision, including detailed service guidelines, *e.g.*, as in the United Kingdom.

All these approaches can form a very important step in moving towards a more integrated continuum of care, setting out common aims for services and enabling clear advice to be given to users and their families by all those involved in service provision. If users are to receive more integrated service, each service provider needs be aware of the resources and priorities of other services in addition to their own. These frameworks, if incorporating joint targets, may also provide a basis for monitoring progress with implementation and achievements. However, if the frameworks contain few specific targets in pursuit of shared values and aims, they may have less impact.

Towards more integrated delivery structures

Table 2.2 also sets out a range of administrative initiatives and reforms that OECD countries have implemented with the aim of improving the continuum of care. These vary from co-ordinating mechanisms to provide a bridge between services and users (sometimes called "single entry points") through area-based experiments in service integration, all the way to structural reforms bringing together services at a similar level of government.

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Table 2.2. **Measures introduced in OECD countries to improve the continuum of care**

	National strategic frameworks	More integrated delivery structures	Realignment of long-term care finance
Australia	National Strategy for an Ageing Australia (2001)	Aged Care Assessment Teams (ACATs); Co-ordinated care trials; Home and Community Care Programme	Integrated assessment and payment scale for care homes (1997) designed to support ageing in one place
Austria			Integrated system of Long-Term Care Allowances (1993) designed to support informal care
Canada	Collaborative strategy for home and community care (2002)	CHOICE (Alberta); SIPA (Montreal)	
Germany			Long-Term Care Insurance (1995) designed to support informal care
Japan	Gold Plan 2 (2000)	Care managers co-ordinate delivery of care (post 2000)	Long-Term Care Insurance (2000) designed to support growth of specialised LTC services
The Netherlands		Local assessment teams	
New Zealand	Health of Older People Strategy (2002)	Integration of acute and long-term care delivery at District Health Board level (2003)	Integration of acute and long-term care funding at District Health Board level (2003)
Norway	Action Plan for the Elderly (1998)	Long-term care delivery integrated at local government level	Long-term care financing integrated at local government level
Spain	Gerontological Plan (2000-2005)	Devolution and integration of health and social services at regional level (post 2002)	Integration of health and social services funding at regional level (post 2002)
Sweden	National Action Plan on Policy for the Elderly (1998)	Integration of primary health care and long-term care at municipality level (post 1991)	Integration of acute health and long-term care funding at municipality level (post 1991); Hospitals may charge local governments when elderly patients cannot be discharged through lack of a long-term care package
United Kingdom	National Service Framework for Older People (2001)	Care management by local governments (post 1993); Single Assessment Process (from 2004)	Most funding focused on local governments (post 1993); Hospitals may charge local governments when elderly patients cannot be discharged through lack of a long-term care package
United States		Social/Health Maintenance Organisations (S/HMOs) (evaluation report 2003)	Social/Health Maintenance Organisations (S/HMOs) (evaluation report 2003)

Source: OECD's questionnaire on long-term care.

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A number of countries have introduced a co-ordinating mechanism to improve the continuum of care. Australia, for example, has for some years employed *Aged Care Assessment Teams* (ACATs) to bring multi-disciplinary assessment to bear on those who may need to enter a form of institutional care. From managing this transition they have come to play a wider role, also advising where an intensive home-care package may be a suitable alternative. The Netherlands has used local assessment agencies to provide advice and access to home-care and institutional services, and they now also operate in an advisory role to those who opt to have a consumer-directed budget instead of direct provision of services (see Chapter 3 for more details). Care managers are employed at the local level in Japan and the United Kingdom to co-ordinate the response to those needing care and provide an element of continuity in managing transitions within care.

These co-ordinating mechanisms have shown a degree of success and become an established feature of the care system in several countries. In Australia, for example, ACATs successfully act as gatekeepers and are responsible for insuring that services and Australian Government expenditure are targeted to people genuinely in need. They have helped tilt the balance of care towards more intensive home care. In England, the introduction of care management was one important factor in the "community care" reforms of 1993, following which there has, since the mid-1990s, been a shift in the balance of care involving a reduction in nursing home places and an increase in intensive home-care places. The introduction of care management was informed by the experience of a series of case management trials in the 1980s and early 1990s in a number of countries (see Davies in OECD, 1994, for details; and Challis, 1999, for developments in care management after the reforms). Following on from this experience, the United Kingdom in 2004 implemented a *Joint Assessment Process* for health and social care for older people.

The UK "community care" reforms also involved a more fundamental reform that integrated the provision of most long-term services at local government level, replacing a system divided between local government social services and the national social assistance system. More recently, from 2002 local NHS bodies and local governments may set up Care Trusts to provide integrated health and social care for groups including the elderly. Other countries that have integrated the management of long-term care at local government level include Norway, and, following reforms in 1991, Sweden. In both cases primary health care is integrated at the same level. New Zealand has, from 2003, integrated the provision of health and social services to older and disabled people at the level of the recently-established District Health Boards. In Spain, there has been a process of devolution to the regions (autonomous communities) such that, from 2002, health and social services are integrated at the regional government level.

There have been a number of initiatives that aim to replicate this type of structural integration in local areas without reforming the national health and long-term care systems as such. These include:

- In Australia, the Co-ordinated Care Trials in twelve areas, four of which focused on people over 65 with complex needs.
- In Canada, the CHOICE programme in Alberta and SIPA (Système de soins intégrés pour personnes âgées) in Montreal.
- In the United States, the Programme of All-Inclusive Care for the Elderly (PACE) and the experimental Social/Health Maintenance Organisations (S/HMOs).

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While these local area initiatives differ in their organisation and links to the wider health system, all share a number of features: service co-ordination or case management, with multi-disciplinary assessment; devolved budgets bringing together separate funding streams; either direct management of the relevant services or power to commission these from providers; and a single entry point for users of services and their families.

All of these features appeared to be important in the outcomes that were achieved (for evaluations of these initiatives, see: for Australia, Silagy *et al.*, 2001; for Canada and the United States, Johri *et al.*, 2003, and Kodner, 2003; for the United States, Thompson, 2002). Results varied between the different initiatives but included reductions in hospital bed days and deferral or reduction in use of institutional long-term care. However, not all of these local initiatives succeeded in achieving these goals, and most of them were unable to do so without exceeding the cost limits per head set for the trial period. In essence this was because cost savings achieved in hospital bed days and nursing home use did not always exceed the additional costs in community services supplied and the costs of the co-ordinating mechanism itself.

Case management and multi-disciplinary assessment are themselves an added cost to the existing system and acute health and long-term care financing agencies generally expect that they will at least pay for themselves. Indeed, it is fair to say that the originators of these schemes tended to anticipate more opportunities for substitution of lower-cost services than were always found to be possible, particularly in a situation where new expert co-ordinators and assessors were also identifying unmet need for community services. Case managers and geriatricians are also scarce resources within health and social care systems and their use has to be carefully targeted to the more complex cases where their input can be most effective.

However, the positive results achieved in many cases provide lessons for future schemes to build upon. Two particular lessons are that: *i*) it is important to involve the patient's own general practitioner in the assessment process – this was shown particularly in the Australian and Canadian examples; and *ii*) the presence of a single point of entry was itself a valued benefit to service users and their families. In all cases users and their families generally experienced greater assurance and reduced insecurity from the presence of a single co-ordinator. This may be difficult to cost but is a very positive outcome in itself and a compelling reason to continue to develop new means of providing a better point of entry to care services for users and their families.

Realigning long-term care finance

The way that long-term care is financed – which agencies fund which services, and on what terms – is likely to influence the balance of services being received. The organisation and terms of funding can either impede or enable progress towards the desirable balance of services. A number of countries in the current study, *e.g.*, Austria, Hungary, Spain and Poland, have reported recent problems arising from the boundaries between health and social service financing. These have included different assessment criteria for similar services but paid for from different budgets. This can lead to difficulties in arranging a package of services, difficulties in transferring patients from one to another service, and consequently to a lack of equity in outcomes for patients in similar circumstances.

New Zealand, Sweden and England provide examples for policies to address this problem. Sweden and England introduced more integrated funding in the early 1990s – in

Sweden focusing primary health care and long-term care on municipalities, and in England focusing most long-term care funding on local governments, a process continued with further transfers in later years. In both cases this facilitated a shift in the balance of care as local government care managers were able to exercise more control of the flow of funds. In both countries there has been a shift towards more intensive home care and away from institutional care. In England the number of nursing home beds has begun to decline in recent years and the number of intensive home-care places is increasing.

Both countries have also made it possible for hospitals to charge local governments where discharges of elderly hospital patients are delayed because a suitable long-term care package has not been arranged in time. Following this move in 1991, the number of so-called "bed blockers" was significantly reduced in Sweden, and following a similar move in England in 2003 the number of "bed blockers" is declining.

New Zealand completed in 2003 a phased reform integrating the funding of long-term care at District Health Board level, with the aim of facilitating a more effective use of acute and long-term care services and smoother management of transitions between them.

The new schemes for long-term care insurance in several countries have also been designed in such a way as to enable benefits to be used in a flexible way across the care spectrum. New schemes in Germany, Japan and Luxembourg enable the benefits and services to support home-based care as well as institutional care. In addition, Austria and Germany pay care allowances as part of their public long-term care financing schemes, with the aim of supporting informal care as well as formal care services.

The OECD countries have therefore adopted a range of measures in recent years to enable services to be provided in a more co-ordinated way across the continuum of care. One of the main aims in doing so has been to shift the balance of care towards maintaining more disabled older people at home, and to provide more help to family carers. The rest of this chapter considers initiatives specifically directed at these two related goals.

Shifting the balance towards home-based care

All OECD countries are agreed on the general policy direction of aiming to maintain disabled older people in their homes where possible rather than in care institutions. This reflects the expressed wishes of older people themselves. This objective has been termed "ageing in place". OECD Social Policy Ministers agreed on this common priority over a decade ago (OECD, 1994).

Over the past decade, there has been considerable investment in home-care services, coupled with an improvement in knowledge about which service inputs will be most effective. It has also become generally accepted that once an older person has significant disabilities, the contribution of a family carer or carers will be key to maintaining that older person at home.

First, this section sets out the current situation and, where data permit, the trends in the use of institutional and home-care services. Then, it reviews national measures directed at maintaining the more disabled older person at home, with a particular focus on the need to provide support to family carers as well as services for the older person.

Table 2.3 shows considerable variation between countries in the receipt of institutional and home-care services and cash benefits. In relation to institutional care, some of the apparent variation between countries in the level of use of care institutions is undoubtedly due to remaining differences in the definition of care institutions. In the case

Table 2.3. **Recipients of institutional and home-care services aged 65 and over**

	Year	%65+ receiving long-term care in an institution	Year	%65+ receiving home care benefits
Australia	1995	5.7		
	2000	5.5	2000	14.7
	2003	5.3		
Austria	1996/97	3.8	1997	14.4
	2000	3.6	2000	14.8
Canada	1998	3.7		n.a.
Germany	1997	3.3	1997	7.3
	2003	3.9	2003	7.1
Hungary			1995	5.1
	2000	n.a.	2000	4.5
Ireland	2000	4.6	2000	ca. 5%
Japan	2000	3.2	2000	5.5
Korea	2000	0.2	2000	0.2
Luxembourg	2001	3.8	2001	4.3
	2003	4.0	2003	4.8
Netherlands			1990	8.4
	2000	2.4	2000	12.3
New Zealand	2000	5.9	2000	5.2
Norway	1991	6.2	1992	17.6
	1995	5.9	1995	16.0
	2000	6.0	2000	18.0
Sweden	1991	6.4	1990	13.4
	1995	8.8	1995	8.9
	2000	7.9	2000	9.1
Switzerland	2000	7.0	2000	5.4
United Kingdom	2000	5.1	2002	20.3
United States	1973-74	4.5		
	1985	4.6	1992	3.0
	1995	4.2	1996	5.3
	1999	4.3	2000	2.8

Source: Huber, M. (2005b), "Long-term Care: Services, Eligibility, and Recipients", OECD Health Working Papers, OECD, Paris, forthcoming.

of those countries with lower levels of institutional use – Austria, Canada, Germany, Ireland, Japan, Luxembourg and the United States – this refers exclusively to places in nursing homes or similar institutions, where nursing is provided by professional nursing staff. In those countries with a higher level of institutional use, the category is more mixed, and includes some homes where residents may receive only social care. Direct comparisons across countries should therefore be made with great caution.

In relation to the trend in nursing home use, the most lengthy time series relates to the United States, and shows a small decline in the rate of nursing home use among those aged 65 and over during the past 20 years. More recent declines in this ratio are also observable in Australia, Austria, and Norway. Both Germany and Luxembourg show a rising trend in nursing home use, apparently fuelled by the introduction of long-term care insurance.

These examples show there is no inexorable upward trend in the rate of nursing home use as the population ages. In general, the level is fairly stable as a proportion of the older population. But as the older population is itself ageing, this implies reducing rates of use at

Table 2.4. **Decreasing rates of nursing home use in the United States, 1985 to 1999**

Rate of nursing home residence among persons age 65 or older, by age and gender group, 1985, 1995, 1997 and 1999 (per 1 000)

	1985	1995	1997	1999
TOTAL				
65 or older	54	46	45	43
65 to 74	13	10	11	11
75 to 84	58	46	46	43
85 or older	220	199	192	183
MEN				
65 or older	39	33	32	31
65 to 74	11	10	10	10
75 to 84	43	33	35	31
85 or older	146	131	119	117
WOMEN				
65 or older	62	52	52	50
65 to 74	14	11	12	11
75 to 84	66	54	53	51
85 or older	250	225	222	211

Note: Rates for 65 or older category are age-adjusted using the 2000 standard population. In 1997 population, figures are adjusted for net underenumeration using the 1990 National Population Adjustment Matrix from the US Census Bureau.

Reference population: These data refer to the resident population. Persons residing in personal care or domiciliary care homes are excluded.

Source: US National Nursing Home Survey.

each age within that older population. Age-specific rates of nursing home use are necessary to reveal the true trend. These were reported in OECD (1996a) for eight OECD countries. These data indicated that since 1980 the age-specific rate of nursing home use had declined in seven out of eight countries studied. Table 2.4 shows this trend has, for example, continued through the 1990s in the United States. At each age level, the rate of nursing home use has declined, with a higher proportion of the age group remaining in their own homes. This trend is significant as it shows that, in the more aged OECD countries, there is no demographic imperative whereby nursing home places will be needed at the same rate for each age group in future as today. Projections of future need for nursing home beds based on current usage may therefore exaggerate future requirements, and overlook the trend towards very elderly people remaining at home.

What is behind the trend to lower nursing home use and remaining at home? Certainly the growing well-being of older people is a major influence. As is set out in Annex A, the level of health and independence of older people is growing, even while average age span lengthens. The age at which help is needed is later on average. Older people are also on average becoming more affluent and living in better housing, where care may be delivered *in situ* rather than requiring a move elsewhere. There is a small but growing sector of supported living arrangements. Home-care services and benefits clearly have played some role although, as will be seen, it is not easy to discern a consistent trend.

Finally, it should be noted that this is happening in spite of the often-predicted decline in informal care by family members in developed countries. On the contrary, many more very elderly people are living at home and receiving such care in the "older" OECD

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countries today than in former years, although social trends in the more rapidly ageing countries seem likely to reduce the currently high level of co-resident care by families (see Annex A).

Looking at receipt of home-care services and benefits in Table 2.3, wide variations are discernable between countries, more so than with nursing home use and indications are that this does reflect more divergence in policies between these countries, rather than in some cases being definitional, as with care institutions. Countries such as Norway and Sweden have for a number of years had more extensive home-care provision than other OECD countries. Others such as Australia, Austria and the Netherlands have expanded provision in recent years.

Both Sweden and the United Kingdom have recently reduced the breadth of distribution of public home help, although not the total amount supplied: it has increasingly been focused on the most disabled people, as experience has shown home help is more effective in keeping this group out of nursing homes when more intensive help is provided. The sharp drop from 1996 to 2000 in home-care recipients shown in the US numbers from the National Home and Hospice Care Service are mainly a result of the Balanced Budget Act of 1997 which mandated a major overhaul in Medicare payment for home health care (Murtaugh *et al*., 2003) There is some evidence that at least part of this decline has since 1999 been compensated by a shift of home care towards other services, including consumer-directed home-care programmes, discussed below. The cash allowance scheme in Austria is of noticeably wide application and represents a significant national investment to maintain older people at home by supporting informal carers.

Recent initiatives to support more disabled older people at home

It is likely that the OECD countries will have to develop and apply more extensive measures to enable the more severely disabled older people to remain at home. Firstly, this is a likely consequence of reining in the use of nursing homes. In addition, the growth in numbers in the very oldest age groups is likely to generate increasing numbers with severe disabilities, even if the overall trend in disability continues to decline on average (see Annex A). Recent initiatives to support the more disabled elderly at home are therefore doubly significant, as similar measures are likely to be increasingly necessary if the policy aim of "ageing in place" is to be sustained. Selected national measures are set out in Table 2.5.

A number of countries have taken steps to make more intensive home care available as an alternative to institutionalisation. Australia has for some years provided *Community Aged Care Packages* as a community alternative for frail older people whose dependency and complex care needs would quality them for entry to an aged care home for low-level care. More recently the *Extended Aged Care at Home* programme has been introduced to provide high-level care to people in their own homes. Sweden and the United Kingdom have both developed a more targeted approach to public home care, such that more hours of care are now being provided, but to fewer, more disabled people. The United Kingdom has also promoted intensive home-care packages. An increase in the number of elderly receiving these packages has been made a performance target for local governments: as a result there has been a strong upward trend from a small initial total, coinciding with reduced numbers in nursing home beds.

The Medicaid programme in the United States has allowed an increasing number of waivers to be introduced by different states. These allow states to use the Medicaid

Table 2.5. **Recent initiatives to support more disabled older people at home**

Australia	Community Aged Care Packages (from 1985; reformed in 1997); Extended Aged Care Packages (from 1997; with increased funding in recent years).
Austria	Long-Term Care Allowances (post 1993) enable disabled older people to buy home care or pay informal carers.
Canada	National Evaluation of Home Care (concluded 2002); Collaborative Strategy for Home and Community Care (2002).
Germany	Long-Term Care Insurance provides choice for the person eligible for benefits to buy professional home care services as well as to opt for allowances to reward informal carers.
Japan	Long-Term Care Insurance (post 2000) provides disabled older person with choice of home care providers.
Luxembourg	Long-Term Care Insurance (post 1999) provides disabled person with choice of home care providers or an allowance to pay for home care/informal carers.
Netherlands	Long-Term Care Insurance provides disabled older person with home care services or (post 2003) consumer-directed budget.
New Zealand	Ageing in Place initiatives (these provide packages of support to enable older people to remain at home).
Sweden	Increasing targeting of home care on most disabled.
United Kingdom	Local governments have target to increase number of intensive home care packages (post 2000).
United States	Medicaid waivers; "Money follows the person" and "Balancing" initiatives in several States (2003/04).

Source: OECD's questionnaire on long-term care.

programme, which is intended primarily to support nursing home costs, to be used to provide alternatives to institutionalisation, where these can be shown to be effective and are subject to evaluation (see Lutzky *et al.*, 2000, for a review). The potential scope of waivers has also been broadened over time. From 2003 the United States also encouraged states to use long-term care funds differently through the "Money follows the patient" and "Balancing" initiatives, the former allowing institutional funding to continue to allow a long-term care resident to be re-housed in the community.

Austria, Germany, Japan and Luxembourg have all in recent years introduced schemes to direct high levels of resources to disabled older people at home. In the case of Austria, this is in the form of cash payments, in the case of Japan in the form of provision of services, while Germany and Luxembourg offer a choice between cash benefits and in-kind services. Experience with cash allowances for home care is considered in detail in Chapter 3, but considerably more disabled older people living at home are now receiving support.

These payments are in part intended to support family carers. Experience with more intensive care schemes has generally been that the active participation of a family carer is an essential ingredient. This has been made a condition of the Australian *Extended Aged Care at Home* packages, as only if the family carer is fully signed up to the scheme has it been a success. Supporting more disabled older people at home seems likely to involve a major effort to involve and support family carers.

Finally, it should be noted that there is considerable scope for the development and application of assistive technology to make the homes of disabled older people more able to support care, either self-care or by others (see, for the Netherlands and for the United Kingdom, Tinker *et al.*, 1999). If disabled older people are to stay at home, this may call for a capital investment as well as the human investment of care, to substitute for the capital investment that will be called for in nursing homes.[2]

Services to support carers

If continuity of care is to be offered to older people in their own homes, co-resident family members and other informal carers will also need support. While many countries now have initiatives to support family carers, it should be recalled that in terms of longer-

term policy development, home-care services were usually initially directed away from family carers. Most home-care services were initially provided to help older people living on their own, without a co-resident family carer, with the aim of delaying or preventing a move into a nursing home or social home. This is still the case in countries such as Korea, Mexico and Spain that have limited home-care services available to distribute.

In part this reflected ongoing changes in living arrangements (see Annex A), as more older people were found to be living on their own rather than as part of a wider household. Providing home-care services to support older people living alone was a response to this demographic change. However, as countries had more experience of home-care services and a better information base, it emerged that targeting on older people alone is in fact targeting on the group least likely to be able to be maintained outside of institutional care in the event of severe disability. Most schemes aiming to maintain more severely disabled older people at home in fact rely heavily on informal carers, sometimes living-in or otherwise nearby, to be successful (see OECD, 1996a; Jacobzone *et al.*, 1999; Wainwright, 2003). This has prompted a re-think in targeting to older people but also a re-assessment of the assumption that family carers could be left to provide necessary care on their own. The growing evidence of carer burden added a welfare argument to provide more services to carers rather than directing services away from them.

One concern that may have inhibited supply of services to older people with carers, even in the light of the positive outcomes outlined above, is that supplying formal services may lead to a reduction in the supply of family care. However, while home-care services to older people living alone may "substitute" in the broader sense for family care that those older people may have received had they been living in a larger household, there is no evidence that families withdraw from caring when formal services are supplied. They may change the nature of their input, but in terms of total hours of care, if anything the evidence points to family carers providing rather more hours of care when formal services are provided as well (see a recent review of evidence by Penning, 2002).

A number of policies have been adopted as countries seek to build upon and support the efforts of family carers:

- Firstly, some countries have published a national strategy setting out the needs of carers and the role of various services in providing support for them, *e.g.*, Australia, the United Kingdom and the United States.
- Second, some countries have given carers a statutory right to receive an assessment of their need for services in addition to services for older people, *e.g.*, the United Kingdom.
- Thirdly, many countries have introduced respite-care services to provide carers with a break from caring responsibilities. Normally this is dependent on assessment and local resources.
- Fourthly, some countries, *e.g.*, Germany and the United Kingdom, now give pension credits to enable those out of the labour market due to caring to maintain pension rights.
- Finally, several countries, including Australia, Canada, Ireland, Sweden and the United Kingdom, have introduced payments to carers to compensate for employment income forgone due to caring (see Chapter 3).

Respite care is one of the most important services for carers. This can take the form of day care to provide daily respite or short-term residential care. Two recent developments

that have been found particularly helpful to informal carers of people with dementia are more intensive home-respite services and group living homes (Moïse *et al.*, 2004).

Provision of respite care has seen significant growth in OECD countries in recent years. For example, Australia quadrupled expenditure on respite care between 1996/97 and 2002/03, and Germany has introduced a right to four weeks of respite for carers of severely disabled persons as part of long-term care insurance. However, potential demand for respite care remains considerably higher than provision in most countries; for example, reported demand for respite care in Canada is around four times the current use of this service.[3]

Most services to carers are being expanded from a low base. For example, around three quarters of carers in a survey in Austria reported feeling over-burdened at times, and only around 14% of carers were receiving any formal service help.[4] While policy perspectives now normally incorporate the needs and views of carers, services may still be in short supply. The availability of services for carers can also vary significantly between jurisdictions, *e.g.*, as reported for the United States (Montgomery and Feinberg, 2003).

Conclusions

The varying needs of long-term care users and the number of different services that may be needed requires significant efforts from OECD countries to make services work better together. This does not necessarily imply having all services integrated into one service, but it does require having a shared vision of goals and priorities, to have effective means of co-ordinating across services and the alignment of funding streams to ensure appropriate use of services. Although delivery of long-term care is usually a local responsibility, national governments need to take the lead in ensuring these preconditions of effective integration are met.

More disabled older people are living in their own homes. This is partly due to lower levels of disability and other factors such as higher incomes and better housing, but expanded investment in home-care services has played a significant role. There is greater awareness of the need to target more home-care services on the most disabled if they are to help to keep the disabled elderly out of institutional care, and a number of countries have launched initiatives to do so. However, these efforts call for a substantial input from informal carers.

Informal carers cannot be taken for granted as a resource, but require support in a number of ways, for example, with specialised home-visiting services and respite care, and help to combine work and caring rather than leave the labour market on a long-term basis.

There is considerable scope for better evaluation of many initiatives to improve the continuum of care and maintain more disabled elderly people at home. Evaluations in some countries, *e.g.*, as reported by Doty (2000) for the United States, have indicated the difficulties in achieving all the targets set for expanded home-care services, particularly that of having a lower cost per case than comparable institutional costs. However, evaluation in others, *e.g.*, as reported for Canada by Hollander and Chappell (2002), found that home-care programmes have been able to deliver care even to those with higher needs at lower cost than nursing homes. In part, this may be because of different starting points in distribution and cost of services. However, as more disabled people will need to be supported at home in the future, continued efforts to evaluate the outcome of home-care investments, in either cash or services, will be vital.

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Notes

1. This is different from reforming long-term care finance to raise new sources of finance or to change the impact of financing on the users. These reforms are considered in Chapter 5.
2. For a full review of the contribution of housing programmes to the support of older people, see OECD (2003a).
3. Canadian reply to OECD's questionnaire on long-term care.
4. Austrian reply to OECD's questionnaire on long-term care.

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Chapter 3

Consumer Direction and Choice in Long-term Care

Home care continues to be the predominant – and preferred – care setting for the majority of people with care needs. This chapter reviews the movement in several OECD countries towards allowing more individual choice by older people receiving publicly funded long-term care at home, including by employing their own carers or by financial support for care provided by family members and friends.

Introduction

In many OECD countries there is a move towards allowing more individual choice for older persons receiving publicly funded long-term care at home. Having more flexibility in terms of how to receive care can increase the older person's self-determination and that of their informal care-givers. For example, having a choice among alternative care providers empowers older persons as consumers and may help strengthen the role of households in the care-management process, provided that households have ready access to the necessary information to make informed choices, which may involve professional help for care assessment and ongoing monitoring at regular intervals.

With direct cash payments or allowances for informal care, older persons are given the option of employing a personal attendant, frequently with the possibility that this person can be a relative. This may serve a dual purpose of increasing flexibility and mobilising, or at least maintaining, a broad carer potential enabling older persons to stay longer in the community and reduce the need for expensive institutional care. Again, there will usually be the need for some professional advice and monitoring in order for these schemes to achieve these goals.

The OECD country with the longest experience of developing consumer-directed care is the United States, where some programmes have been in place for over 20 years (Box 3.1). Even in countries with relatively extensive long-term care services, most long-term care is still provided by unpaid informal care-givers. In Sweden, for example, which has comparatively high expenditure on public services, an estimated two-thirds of the total volume of long-term care is provided informally by relatives, friends and others (Johansson, 2000). The role of informal care is therefore important in its own right and is increasingly recognised by policymakers in OECD countries. Arrangements to increase choice and flexibility in long-term care often overlap with those to support informal care-giving more generally, and therefore payments for informal care are included in the focus of this chapter.

This chapter explores arrangements that allow long-term care users much greater choice, to the extent of enabling them to decide how a care budget or allowance should be spent. It is based on Lundsgaard (2005) and describes the prevalence of such arrangements in OECD countries and reviews the outcomes in terms of flexibility, care quality and consumer satisfaction. The focus is on long-term care users in their own homes, as this is both the preference of the great majority of users and the focus of most existing schemes of consumer choice. The types of schemes considered are:

- personal budgets and consumer-directed employment of care assistants;
- payments to the person needing care who can spend it as she/he likes, but has to acquire sufficient care; and
- payments to informal care-givers as income support.

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Box 3.1. **Consumer-directed care programmes in the United States**

The *US National Institute on Consumer-directed Long-term Care* defined consumer direction as "a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive".

Consumer direction is a concept that has been increasingly embraced by US states in recent years. Some programmes, such as those in Colorado, Michigan and Oregon, have been running for over 20 years. By 2001, all but two states offered some consumer-directed programme, with almost half a million people being served in total. A survey for this year identified a total of 139 programmes, 65% of which relied in whole or in part on Medicaid funding, either through Medicaid Home and Community-Based waiver programs or through the Medicaid Personal Care programme. The remaining programmes were funded by state general revenues or the federal Social Services Block Grant. The number of participants varied widely from as few as five participants to almost a quarter of a million in the California In-Home Supportive Services programme.

State consumer-directed programmes are extremely varied in the number and range of tasks for which the consumer may assume responsibility. They generally follow one of three models: *direct pay*, in which the consumer is the employer of record and has full hiring, firing, tax and payroll responsibilities; *fiscal intermediary*, where a designated agency handles payroll and taxes and the consumer selects and manages the employee; and *supportive intermediary*, in which a public agency provides supportive services such as recruitment assistance, criminal background checks and training.

One combination of direct pay and fiscal intermediary models is the three-year *Cash and Counseling* Medicaid demonstration project in Arkansas, New Jersey and Florida, with funding from the Robert Wood Johnson Foundation and the US Department of Health and Human Services. In this project Medicaid beneficiaries select their personal care worker and may choose to receive cash to pay the worker or use an intermediary as employer. Counseling helps the consumers with tasks such as managing the cash, handling payroll and taxes and recruitment.

The California In-Home Supportive Services programme and the *Cash and Counseling* demonstration projects are subject to extensive evaluation, generating valuable information about the experiences of older consumers with this model of service. The *Cash and Counseling* demonstrations have concluded that these programmes improve access to care and users' satisfaction. Arkansas' experience shows that the substantially higher per-capita spending on Medical Personal Care Services by recipients of the *Cash and Counseling* programme is to a large extent offset by savings in their expenditure on other Medicaid spending, such as home health and nursing facilities (Dale *et al.*, 2004; Foster *et al.*, 2003; and Phillips *et al.*, 2003).

Source: Heumann (2003); for a recent assessment of California IHSS, see CWDA (2003).

Arrangements to increase consumer-direction and choice when receiving long-term care at home

A number of different arrangements are used in OECD countries to allow more consumer direction and choice for persons receiving long-term care at home. Although they differ in many respects they can usefully be subdivided into the three main groups shown in Panels A-C, Table 3.1.

Personal budgets and consumer-directed employment of care assistants

As an alternative to provision of formal home care via a single designated agency, other arrangements can strengthen the position of older persons as active consumers,

Table 3.1. **Personal budgets, consumer-directed care and payments for informal care**

Information refers to most recent year available, often 2004 for rules and payment levels, but typically 2002 or 2003 for the number of users

	Programme	Description	Can relatives be employed or supported?	Monthly payment levels			Share of 65+ population receiving support %
				Lowest	Main or average	Highest	
				% of private consumption per capita[1] Monthly amount in nat. currency and USD PPP			
A. Personal budgets and consumer-directed employment of care assistants							
Netherlands	Personal Budget for Care and Nursing *Persoons-gebonden budget*	Personal budgets can purchase agency care, directly employ a care assistant and also pay some cash for appliances and informal care.	Yes,[2] but not if living together.	The size of each budget is equal to what would have been the public expenditure on formal services net of user charges less an "efficiency deduction" of 15-20%.			0.8[3]
Norway	Care Wage *Omsorgslønn*	Pays relatives or others for caring when this is considered better than agency care. Typically 3-10 hrs/week.	Yes	The carer is paid for a given number of hours typically using the hourly wage of a care assistant in the public agency.			0.3
Sweden	Carer's Salary *Anställda anhörige*	The person giving care is treated as employed by the public agency. Scheme used in remote areas.	Yes, but not if older than 65 years.	Person giving care is paid a salary similar to care assistants in the public agency and has similar social security protection.			0.1
United Kingdom	Direct Payments	New scheme. Older persons eligible for care can now choose a direct payment for purchase of care.	Yes,[4] but not if living together.	Same as the net costs of the services assessed as required.			0.04[5]
United States	Consumer-directed Home Care	Consumers can hire and supervise a personal care assistant who will be paid by Medicaid for a specific number of hours.	Most prg. allow relatives but not spouses.	Payment levels vary across prg.s reaching up to USD 2 760 a month in Kansas' HCBSFE prg. and up to 66 hrs/week in California's IHSS prg.			0.5
UnitedStates[6]	Cash and Counseling	Demonstration and Evaluation prg. in Arkansas, Florida and New Jersey. Budget can pay also for home adaptation etc.	Yes	20% USD 400	36% USD 723	69% USD 1 400	Experimental with 1 000-2 000 older persons in each state.
B. Payments to the person needing care who can spend it as she/he likes, but has to acquire sufficient care							
Austria[7, 8]	Cash Allowance for Care *Pflegegeld*	All public support for home care is through this allowance. Recipients can purchase formal care if they wish.	Yes	13% EUR 145; USD 154	35% EUR 405; USD 430	132% EUR 1 532; USD 1 626	20.5
Germany[7]	Cash Allowance for Care *Pflegegeld*	Under the long-term care insurance, recipients can choose between care in-kind and this allowance.	Yes	18% EUR 205; USD 209	27% EUR 311; USD 317	57% EUR 665; USD 678	6.4
Luxembourg	Cash Allowance *Prestations en espèces*	Under the long-term care insurance, recipients can choose to replace the first 7 hrs/week of care in-kind by this allowance.	Yes	15% EUR 267; USD 272	39% EUR 679; USD 693	63% EUR 1 100; USD 1 122	3.8

Table 3.1. **Personal budgets, consumer-directed care and payments for informal care** *(cont.)*

Information refers to most recent year available, often 2004 for rules and payment levels, but typically 2002 or 2003 for the number of users

	Programme	Description		Can relatives be employed or supported?	Monthly payment levels			Share of 65+ population receiving support %
					Lowest	Main or average	Highest	
					% of private consumption per capita[1] Monthly amount in nat. currency and USD PPP			
Sweden	Attendance Allowance *Anhørig bidrag*	Cash payment to the dependent who can then pay informal caregivers. Minimum care need of 17 hrs/week.		Yes		52% SEK 5 000; USD 515		0.1
United Kingdom[9]	Attendance Allowance	A cash benefit to persons aged 65+ who have been needing care for at least six month.		Yes	16% GBP 170; USD 266		24% GBP 255; USD 399	19.3
C. Payments to informal caregivers as income support								
Australia[10]	Carer Payment	For people who cannot support themselves because of caring responibilities.	Yes	Yes		53% AUD 934; AUD 682		0.9
Australia[10]	Carer Allowance	For people who live with and care for somebody at home.	No	Yes		11% AUD 191; AUD 139		4.0
Canada	Compassionate Care Benefit	A short-term beneft for persons caring for somebody with a terminal condition.	No[11]	Yes	Pays 55% of normal employment income. Max payment is CAD 1 790; USD 1 467 per month.			New scheme introduced 2004.
Ireland[12]	Carer's Allowance	For carers with low income who live with and look after people needing full-time care.	Yes	Yes	Nil		50% EUR 683; USD 683	
Ireland[13]	Carer's Benefit	A payment to insured persons leaving work temporarily to care for someone needing full-time care.	No	Yes		47% EUR 649; USD 649		
Japan[14]	Allowance for Families Caring for Elderly	Only if low-income family, heavy care needs and not receiving support from the long-term care insurance.	Yes	Yes		5% JPY 8 333; USD 60		Not known because new scheme.
Sweden	Care Leave	Statutory right to take leave from work for up to 60 days when caring for a terminally ill relative.	No	Must be a relative or close friend.	Pays 80% of normal employment income.			
United Kingdom	Carer's Allowance	For persons with low income caring 35+ hrs/week for someone receiving Attendance Allowance (see panel B).[15]	Yes	Yes		18% GBP 192; USD 300		

Table 3.1. **Personal budgets, consumer-directed care and payments for informal care** *(cont.)*

Information refers to most recent year available, often 2004 for rules and payment levels, but typically 2002 or 2003 for the number of users

1. Share of household final consumption expenditure per capita as calculated in the national accounts statistics, which is roughly equal to average disposable income per capita. Payment levels in USD at purchasing power parity (PPP) is calculated using 2003 exchange rates. For comparability across programmes, all amounts are monthly even if some programmes determine payments levels on a weekly basis.
2. If the person needing care lives together with healthy adult relatives then they are obliged to do the necessary housekeeping tasks irrespective of whether they are in working age or have retired. Relatives living in the same household can therefore only be employed to provide care beyond these functions. In practice, employment of relatives living in the same household is seen mostly for adult disabled and only rarely for care provided to older persons.
3. Personal Budgets were introduced in 1995 and grew to a total of 23 000 users in the year 2000 and 54 000 in 2003. In 2003, about a third of all users were older persons which corresponds to 0.8% of the population aged 65+ as shown in the table.
4. With an adjustment of legislation from April 2002, people can use their direct payment to pay a relative who lives with them, but only in exceptional circumstances where they and their local council consider that this is the only satisfactory way of meeting their care needs.
5. Since Direct Payments were introduced in 2000 or older persons also, the number of users in England aged 65 and over has grown from only 500 in year 2000/01 to 2 700 in 2002/03 corresponding to 0.04% of the population aged 65+.
6. The average monthly payment levels differ in the three states involved, from USD 400 in Arkansas, and USD 723 in Florida to USD 1 400 in New Jersey.
7. The middle-column "Main or average" shows a weighted average of payment levels received by beneficiaries aged 65+. "Lowest" and "Highest" show bottom and top of payment scale.
8. Based on Nemeth and Pochobradsky (2002), it is estimated that only around 7% of the persons aged 65+ use part of their Cash Allowance to purchase formal care at home, while very few spend all on formal services.
9. Depending on individual circumstances, the payment levels vary more than indicated by the typical low- and high-level payments shown in the table.
10. Data for the number of recipients refer to June 2002 while payment levels are those that came into force by 1 January 2003. The Carer Payment will under most circumstances be liable for taxation when caring for an older person. Carer Allowance is newer taxed. If Carer Payment is received by both in a couple, the monthly payment level is AUD 780 per recipient corresponding to 45% of private consumption per capita.
11. As the level of payments is calculated as a percentage of normal employment income, it will grow with income in the interval below the ceiling. For persons with low income and children there is, however, a family supplement.
12. The maximum amount shown in the table applies for a person aged 66 or over and with very little income giving care to one person. If caring for more than one person, the maximum is EUR 1 026 per month. For caregivers aged under 66 years the allowance is reduced by EUR 79-118, while for each dependent child it is raised by EUR 36-73 per month.
13. The amount shown in the table applies, irrespective of income and assets, for a person giving care to one person. If caring for more than one person, the benefit is EUR 973 per month, and for each dependent child the benefit is raised by EUR 36-73 per month.
14. This scheme plays a limited role in the overall long-term care provision.
15. In 2002, the Carer's Allowance has been made available also for care-givers aged 65 and over. The payment is only available for persons with disposable income below GBP 342; EUR 536 a month where disposable income is calculated net of spending on respite care, etc. The benefit is taxable.

Source: Based on replies to the OECD's questionnaire on long-term care and national sources.

making their individual demands clearer. Older persons needing care can be given a personal budget to purchase care from alternative competing agencies, or they and their families can be allowed to employ a personal care assistant directly and thereby be able to "hire and fire", schedule, and supervise – in other words direct – care provision.

The Personal Budgets scheme in the Netherlands is the most extensive of its type. In 2003, 0.8% of the population aged 65 or over received home care via a personal budget – compared to 7.4% receiving some form of formal care at home.

In all of the programmes listed in Table 3.1, Panel A, care assistants have a formal employment contract, even if they are relatives of the person receiving care. Therefore, care assistants are typically paid for a specified number of hours. They can provide care to several persons at the same time and their wage does not depend on what income they have from other sources. The level of care needs covered by these programmes varies from typically 3-10 hours per week for the Norwegian *Care Wage* up to a maximum of 66 hours per week for the Californian *In-Home Supportive Services* programme. The UK *Direct Payments* scheme was first extended to older people in 2000 and two years later provided help to around 3 000 persons aged 65 and over. Older people needing home-based long-term care have a right to ask for direct payments to the value of their assessed need for services and these can be used to pay relatives and friends as care assistants provided that they are not living together. Experience in more long-lived consumer-directed schemes in other countries has been that relatives and friends typically provide more hours of care than they are paid for.

Personal budgets may also allow the person to combine care with purchase of physical aids such as a special bed or chair and can generally support very flexible solutions. This is one important aspect where the *Cash and Counselling* programme differs from other consumer-directed home-care programmes in the United States. In the Netherlands, a limited amount can be made directly available to the person who does not need to account for how it is spent, and from this amount some informal help may also be compensated.[1]

Payments to the person needing care to spend it as she/he prefers

Some countries give older persons needing care the option of getting cash to finance some of their expenditure on long-term care (Table 3.1, Panel B). In Germany, persons receiving support from public long-term care insurance can choose between services in-kind and the *Cash Allowance for Care* (or any combination of the two), and in Luxembourg those entitled to home care under the long-term care insurance may take part of this as a cash benefit rather than services or everything as cash if eligible for seven hours weekly or less. In both cases the cash alternative is set at a lower level than the value of the services. In Austria, all public support for long-term care to persons living at home is given as cash. A substantial share of these cash payments is used to compensate informal care-givers or simply enters the household budget when care is provided by co-habiting relatives.

While there are no explicit restrictions on how the German *Cash Allowance for Care* is spent, the older person and their relatives are nevertheless obliged to acquire sufficient care, as is the case also with cash allowances from the Luxembourg *Dependency Insurance*. The health condition and wellbeing of recipients of the German *Cash Allowance for Care* is reviewed every three or six months. If older people are found to be receiving insufficient care in light of their needs, the authorities must make some in-kind provision of care services, in which case the cash allowance will be withdrawn. There are no restrictions on how the UK *Attendance Allowance* is spent.

Compared to those schemes listed in Panel A, most of the schemes in Panel B are quite extensive. The Austrian and German *Cash Allowance for Care* provide support to 20.5% and 5.7% respectively of the population aged 65 or over. The payment levels vary considerably depending on need, with averages of 35% and 27% of private consumption per capita. When these payments are passed on to informal care-givers, they are not taxed as income for the care-giver, as indeed the relationship between the care-giver and the older person remains informal, often being within the family.[2] The UK *Attendance Allowance* provides support to as many as the Austrian scheme, but with a much lower maximum benefit.

Payments to informal care givers as income support

A number of OECD countries have various forms of payments to informal care-givers in order to partly compensate them for the loss of income while providing care and to enable the care-giver to reduce other work activities (Table 3.1, Panel C). Some of these allowances or cash benefits pay around half of the average private consumption per person, while the Swedish temporary *Care Leave* pays more than that. Other cash allowances, however, give only a limited supplement to the income of a household; for example, the Japanese *Allowance for Families Caring for Elderly* pays an amount equal to 5% of average private consumption per person.[3]

The essential difference from consumer or client employment of a care assistant is that income support is not meant to fully compensate care-givers for the value of their work. Rather they are meant to sustain a minimum level of income for persons who are unable to have a normal full-time job due to providing care for somebody who is near to them such as a relative or near friend. Therefore, some schemes are only available for low-income carers, *e.g.*, the Australian *Carer Payment,* the Irish *Carer's Allowance* and the Japanese *Allowance for Families Caring for an Elderly Person*. To be eligible for support, the income and asset criteria may also take into account the income and assets of the carer's spouse or partner and thereby exclude carers from middle- or high-income families. This applies to the UK *Carer's Allowance*. Also, payments from these schemes are often combined with other forms of public income support.[4] Other schemes are build into labour market institutions and provide an option for a temporary leave from work. As such they are available to persons at all income levels. The Canadian *Compassionate Care Benefit* and the Swedish *Care Leave* replace 55% and 80% of the caregiver's previous or normal employment income up to a maximum, while the Irish *Carer's Benefit* pays the same amount to all recipients.

Finally, some schemes are meant to reward or recognise the work of informal care-givers caring for persons with less severe needs, for example the Australian *Carer Allowance*. Eligibility is therefore conditioned only on the provision of care, not on the income or assets of care-givers. Giving the limited amount of the *Carer Allowance* to a wide group of persons living with, and caring for, an older person at home – equal in number to 4% of the population aged 65 or more – creates an extra incentive for the family not to seek institutionalisation that would entail larger public expenses.

In Japan, local authorities may decide if they wish to use a central government grant to support informal care, including the *Allowance for Families Caring for an Elderly Person*. This allowance has been introduced very recently and it is expected to play a minor role. The major policy direction is to expand in-kind benefits through *Long-Term Care Insurance* (see Chapter 5).

The review above shows how vastly different the programmes allowing choice in home care are across countries – both in terms of their structure and their size, ranging from the extensive *Cash Allowance for Care* in Austria to small and experimental programmes in some other countries. Even where seemingly similar arrangements have been put in place, the underlying policy goals for their introduction may not have been the same, taking into account different starting positions and policy context. Different aspects of programme design that cut across the various schemes listed under the three categories in Table 3.1 are now considered.

Aspects of programme design

How many persons receive support under these schemes?

In addition to variations in the extensiveness of schemes at a national level, there is also variation across regions and local areas in their application. In the United States, the number of persons receiving consumer-directed home care based on public funding varies strongly across states reflecting differences in the organisation and provision of services even under the federally subsidised Medicaid programme. A majority of the 139 programmes counted in a recent survey serve 1 000 or fewer participants, often on an experimental basis. 20% in fact serve 100 or fewer participants. Only 12% serve more than 5 000 persons. California's In-Home Supportive Services Program accounts for around half of all of the estimated participants in consumer-directed programmes in the United States (Doty and Flanagan, 2002). The latter programme itself has two sub-programmes: one Medicaid-funded, and one state-funded. Programmes not only differ widely in the number of persons involved, but also in the extent to which state agencies provide support to consumers in their tasks of organising their care such as handling payroll and tax matters involved in hiring care assistants.

Likewise in Norway, the number of persons receiving *Care Wage* varies considerably across local governments even though the programme is based on national regulations. While in the average local government, the number of persons receiving *Care Wage* corresponds to 4.25% of the total number of persons receiving home care, this share is over 10% in 26 out of 404 local governments. The UK scheme of *Direct Payments* has been slow to attract many older applicants, it would appear, because local governments have been slow to offer this option to older people (Wiener *et al.*, 2003). Central government has therefore set up a development fund to enable community organisations to receive grant aid to enable them to provide advice and assistance to potential and actual applicants for *Direct Payments*.

What is the interaction with other forms of long-term care: are these schemes integrated or separate?

Some of the schemes analysed here are directly integrated with other arrangements for long-term care in the sense that there is a unique procedure for determining eligibility for support from public and social insurance programmes. A person found eligible is allocated a given level of support expressed as a particular set of services, a number of hours weekly or an amount of money. From thereon the person needing care can choose how to obtain care and how to "spend" the support for which she/he has been found eligible; either from an agency designated by the public authorities or insurance programme, from an alternative agency or self-employed care assistant, by employing a personal care assistant her/himself or possibly receive a cash allowance to support informal care. The German long-term care insurance comes close to this description.

The Dutch system has evolved to become more integrated and rights-based. When the Netherlands introduced personal budgets for care and nursing in 1995,[5] those eligible for at least three months of home care could apply to have a personal budget instead of care services in-kind, but within an annual cap on total national spending *via* personal budgets. This limitation has gradually been relaxed, and from 2001 there has been an open-ended subsidy which has made the personal budget system function as if it were an entitlement for those eligible for long-term care. Following the reform of the Dutch long-term care insurance scheme in April 2003, all those who qualify for home-based long-term care can opt for a personal budget (Huijbers, 2003). At the same time, a new eligibility assessment protocol has become obligatory, specifying care needs of each individual in terms of seven functional types of service: home help, personal care, nursing, supporting supervision, activating/advising supervision, treatment, and residential care. For these types of care, those eligible for help from the public insurance scheme may make their own contracts with providers, or use the resource to reimburse an informal carer. For care providers, this means that they now have to take individual needs as the point of departure, rather than their own supply of services. At the same time, new types of providers have been approved and existing approvals have been broadened, such as by allowing residential care facilities to offer home-care services as well. The option of employing a relative or friend (as 21% of budget holders did in 1999) is thereby fully integrated with the options of contracting with a self-employed care assistant (as 44% did), with one of the traditional non-profit home-care agencies (as 23% did) or with one of the new private firms providing home care (as 27% of budget holders did in 1999).[6]

Is there a legal right to consumer-directed care rather than services from a single agency?

Cash allowances and income support payments are typically based on clear-cut criteria and persons who satisfy these criteria have a right to benefit. Access to other schemes may be more restricted and depend on judgements made by assessment teams and local authorities. In Norway, there is no legal right to benefit from the *Care Wage* scheme. Even if an older person agrees with a relative and prefers to rely on informal care, she or he can only benefit from the *Care Wage* if the local authorities consider this a better alternative than formal care provided by its own agency. The older person's assessment of the quality of care provided by the local authority's agency is not sufficient. Considerable variation in the number of care-givers under the scheme could indicate that this access criterion is applied differently in different localities.

Character of the employment relation and conditions for informal care-givers

Only the programmes listed in Panel A of Table 3.1 involve a formal employment relationship, but for some other programmes informal carers have some of the entitlements that an employed person would normally have, for example pension entitlements in Germany.

In the United States, tax law requires that all consumer-directed care assistants are treated as employees rather than as self-employed. It implies that they are subject to federal and state laws concerning working hours and minimum wages, and many of these personal care assistants must be covered for unemployment and worker's compensation in case of work-related injury. As with all employees, consumer-employed care assistants

must be covered by social security, with contributions being paid partly by the care assistant and partly by the public programme.

In Norway, the exact type of employment relationship of care-givers under the *Care Wage* scheme varies across local governments. In some places, it is a normal employment relationship similar to that of care assistants working for the municipal homecare agency. But in most places it is a looser free-lance contract under which the care-giver has fewer rights than normal employees. In both cases, care-givers are paid for a given number of hours per week typically based on the hourly wages of municipal care assistants and they have pension rights. In spite of this, the law states that the payment is not meant to reflect fully the extent of care given, and care-givers typically work more hours than explicitly paid for.

In the Netherlands, a formal contract is required, even if the person giving care is a relative, as the care recipient is considered an employer. Care assistants are entitled (like anyone else) to national insurance schemes, such as the *State Old Age Pension* (AOW) and sickness insurance.

Respite care

As has been discussed in Chapter 2, periods of holidays or respite care are essential to avoid overburdening informal care-givers. This raises issues of eligibility for payments and of alternative care arrangements during such periods. Arrangements can differ across countries. Australia, for example, allows persons giving care to continue receiving *Carer Allowance* or *Carer Payment* during a break from their care work of up to 63 days in a calendar year, either for continuous or broken periods. Respite care is also part of the benefit package in Austria and Germany and the extent of these benefits has recently increased considerably in Germany. In addition, as Chapter 2 has indicated, a number of other countries provide respite care as a local service to carers, without it being given the status of a legal right to benefit.

Outcomes: what is the experience with choice of carer and payments for care?

In assessing the outcomes from the schemes considered in this chapter, it needs to be borne in mind that there have been a number of different objectives sought from their introduction. These have included:

- empowering older people by giving them the choice of buying care that better suits their needs;
- sustaining the independent living of older people and thereby avoiding costly institutionalisation;
- developing a more diversified sector of formal care providers and creating new and better quality jobs in the sector;
- promoting and rewarding the contribution of informal caregivers;
- helping to reconcile work and family life for informal caregivers.

This chapter now reviews the evidence of the impact of schemes on these dimensions, bearing in mind that some of the schemes are of fairly recent introduction.

Empowerment and independent living

When people needing care have several options, the choices they make can indicate what works well and/or what will best meet their needs. The explicit choice between

services in-kind and a cash payment or a combination of the two open to persons receiving support from the German long-term care insurance is a case in point, as older people have a *right* to choose and do not have to go through additional extensive administrative procedures if desiring one option rather than the other. Initially, only 15% of the persons receiving care at home chose to have services in-kind only, with the rest choosing cash only or a combination of both. While overall the proportion choosing the cash allowance only has been declining gradually since the scheme's introduction in 1995, it is still above two-thirds of all beneficiaries.

However, a survey in 1998 showed that the preference for cash only is most marked at the lowest level of disability (level 1), at which 82% chose cash only. At the highest assessed level (level 3), this proportion falls to 64% and 25% chose a mix of cash and care, compared to only 8% at level 1. The benefit is therefore being used in different ways by groups with different needs, which is one of the objectives of the scheme.

Flexibility and self-determination are important since long-term care involves the most intimate aspects of a person's life: dressing, bathing, toileting. The importance of self-determination was shown in a study of the Personal Budget scheme in the Netherlands, which found that while care quality is similar when persons needing care are referred administratively to a designated agency, those receiving care *via* a personal budget feel less dependent because they have more control over when care is provided and notably by whom (Miltenburg and Ramakers, 1999). Similar outcomes have been found in the initial findings of the *Cash and Counselling* demonstration in the United States. Foster *et al.* (2003) report that, in the Arkansas pilot, the level of consumer satisfaction was higher among those with personal budgets by comparison with those receiving agency-directed care. Those with personal budgets also showed reduced unmet needs by comparison with agency-directed care.

There may be concern that allowing older people to find and employ their own care assistant may create a risk for vulnerable older people, particularly those with cognitive impairments, of receiving poor service from an untrained or neglectful care assistant. However, studies of the quality of care provided to those receiving the Austrian *Cash Allowance for Care* – a system that goes further than in other OECD countries towards leaving it to older persons and their families to find appropriate care – have found very few cases of poor-quality care (Badelt *et al.*, 1997; Nemeth and Pochobradsky, 2002). Likewise, the experience of the United States Cash and Counselling demonstration in Arkansas has been that the introduction of consumer-directed care did not have any adverse effects on the participants' health and safety (Foster *et al.*, 2003). Apparently, the informal support and surveillance from relatives and others in the community has been sufficient to avoid this. But it remains essential for public authorities to monitor the conditions of vulnerable older persons, both those with and without co-resident carers.

To some extent, some of the flexibility aimed for with personal budgets can be achieved via the dialogue between the person needing care and the authorities assessing eligibility. Many countries will offer service users a choice between approved providers. This includes both countries – Japan and Luxembourg – that have introduced new public schemes to cover long-term care costs in the past decade in the form of in-kind services rather than cash (see Chapter 5). In Norway, it is also a central principle to allow the care recipient to influence the way their care is received, while retaining the final decision with the local government.

Developing a more diversified long-term care sector

Personal budgets, consumer-directed employment and cash allowances are essentially arrangements for the demand-side. For them to work well, it is important that the supply-side or infrastructure can adjust and develop. The experience during the first years with comprehensive systems of *Cash Allowances for Care* in Austria and Germany during the 1990s illustrates the need for allowances to be backed up with a support system of professional home-care services, both to reduce the workload on family caregivers or for respite care.

The role which professional services can play to serve as partners for providing information and for educating and training informal carers is important. There is some evidence that the Austrian and German care allowance systems developed in this direction, but more slowly than expected by policy makers. In Germany, for example, three years after the introduction of the long-term care insurance in 1995, only 10% of all informal caregivers reported having attended a basic training course on caregiving that is offered for free (Schneekloth and Müller, 2000), although evidence suggests the situation has improved since then.

Progress in the expansion and strengthening of the market for professional home-care services (including respite care) to support informal care was achieved in both cases. The mix between informal and formal services which consumers in Germany have chosen is moving slowly towards more demand for formal services. But the share of professional services chosen is still below what had been expected to result from the introduction of care allowance systems with full freedom-of-choice over the individual mix of benefits.

Supporting informal care

The economic rationale for paying informal care givers depends much on their labour market attachment. For persons that would otherwise be employed, payments for informal care, such as within a leave scheme, represent an insurance against the loss of employment income they incur while providing care. Such payments allow families to choose informal care, and to the extent that such care replaces more expensive care that would have been provided formally and publicly funded, the effect on public finances may be positive.

Much, however, depends on the labour market impacts. Particularly for those with a loose attachment to the labour market, a prolonged period of leave can lead to subsequent unemployment as their skills or human capital may gradually deteriorate. Women in their 50s taking leave to care for a parent or parent-in-law may frequently be at high risk in this regard. High payments to informal caregivers may therefore produce an unemployment or low-income trap by reducing the incentive for lower-skilled caregivers to retain contact with the labour market. Active assistance to help long-term caregivers to find paid employment when caring ceases, together with a carer-friendly work culture, will be important measures if the dual goals of supporting carers and maintaining employment in older age groups are to be achieved.

Schemes providing short-term cash support to carers, *e.g.*, during terminal illness, avoid these longer term effects. An example is the new *Compassionate Care Benefit* in Canada, which provides short-term help for carers and enables them to stay in their jobs in the longer term, with a protected return to work (see Annex B: Canada for details). Ireland

also provides the *Carer's Benefit* to enable a carer to be supported during a temporary period of absence from work.

For persons who are outside employment and have other income, such as retired persons having a pension, care-giving does not entail an income loss and therefore there is no insurance argument for compensating them for loss of income. However, to limit the need for costly formal long-term care services, many countries actively seek to mobilise and recognise informal care-givers for their work, particularly by providing direct help for them. This includes support in term of training of informal care-givers, respite care and in some countries payments for all informal carers satisfying basic criteria and disregarding their labour market attachment and other income.

The Australian system introduced choice by enabling those family carers who wish to do so to provide informal care, while receiving a *Carer Payment* to compensate for loss of employment income. This option has been taken up by a small, if growing, number of people, rising from 11 740 recipients caring for those aged 65 and over in June 1998 to 18 097 in June 2002. However, in Sweden the number of people taking a similar option *via* the *Attendance Allowance* has declined to 4 980 in 2001 from 20 000 a decade previously. In this country, the current policy direction is to focus resources for carers on non-financial help through the development of respite care, counselling and personal support for care-givers.

Conclusions

The past ten years have seen growth in new programmes in a number of OECD countries, together with the strengthening of existing arrangements for home-care provision that allow older persons with long-term care needs and their informal carers an increasing choice of options of support. The use of personal budgets that allow the dependent person to purchase the care that best suits their individual needs and schemes that support informal care are growing in a number of countries. However, the programmes reviewed here are of very different extent. Austria and Germany have introduced new programmes giving new rights to many people, whereas some other developments, *e.g.*, in the Netherlands and the United States, have involved widening the scope of what is offered within existing eligibility to include greater consumer choice. Payments for informal carers have also introduced a greater degree of choice for those, mainly middle-aged women, providing care for older people.

Experience with consumer direction, choice and various forms of support for informal care seems overall to be positive, as rated by older persons in need for care and by their main informal care-giver. These findings contrast with the continuing concern in many countries about uneven distribution of quality of care in institutions and continued reports of poor-quality providers of institutional care (see Chapter 4). The flexibility associated with choice can enhance the self-determination and satisfaction of older persons allowing them a certain degree of independent living, even in cases of dependency on long-term care.[7]

Early findings from the *Cash & Counseling* demonstration in the United States also indicate that these gains can be achieved at no additional cost to mainstream services (Dale *et al.*, 2003). However, the extension in consumer direction and satisfaction in some other countries has involved substantial new expenditures, not simply introducing choice into existing schemes. The wider issues around reforms that extend public programmes, as well as efforts to better target existing programmes, are considered in Chapter 5.

Notes

1. From 1 April 2003, 1.5% of the assigned budget does not need to be accounted for, between a minimum of EUR 250 and a maximum of EUR 1 250 per annum.
2. Because the Austrian *Cash Allowance for Care* is also the channel for support to persons with very intensive care needs requiring institutional care, the highest level reaches 131.8% of average private consumption per person. But only 1.2% of older persons receiving support are at this highest level. The lowest payment level is available for persons needing care for more than 50 hours per month.
3. As several of these schemes are only available for low-income carers, however, the amount could alternatively be compared to a lower level of private consumption than for an average person.
4. Carers may receive other transfer income at the same time. In Australia, informal caregivers can receive Carer Payment and Carer Allowance simultaneously if eligible for both. For example, a person aged 50 with low income who provides substantial care to, and lives with, her/his mother or father can receive both Carer Payment and Carer Allowance corresponding to 64% of average private consumption less taxes, but only Carer Payment if living separately corresponding to 54% of average private consumption less taxes. In both cases, other income support payments may be added such as Rent Assistance.
5. Personal budgets for nursing and care were introduced on an experimental basis in two Dutch regions in 1991; from 1995, persons from all over the country who were eligible for long-term care were allowed to apply for budget holder status.
6. The percentages sum to more than a hundred because some budget holders apparently obtained care services from multiple sources. Note that the percentages refer to those with personal budgets in 1999. In that year the majority was receiving care from the traditional non-profit home-care agencies but still not *via* a personal budget.
7. This overall conclusion is broadly shared by Wiener *et al.* (2003) in their recent review of consumer-directed care in the Netherlands, England and Germany.

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Chapter 4

Monitoring and Improving the Quality of Long-term Care

Concerns over severe quality deficits, particularly within nursing homes providing for those with the greatest needs for care, have been important drivers to recent long-term care reforms. This chapter brings together international evidence on these quality deficits and initiatives to identify and reduce them.

Introduction

There is evidence from many OECD countries that the quality of long-term care services for older persons is variable and in many cases does not meet the expectations of the public, the users of services and their families. There have been all too many examples of inadequate care in institutional and community settings, such as inadequate housing (nursing homes), poor social relationships and lack of privacy, inadequate treatment of depression, bedsores and the use of restraints, and this has become a significant public concern. In addition, the incidence of elder abuse (including neglect) has been reported as a growing policy concern in several countries (*e.g.*, House of Commons Health Committee, 2004, for the United Kingdom; Beers and Berkow, 2000, for a comparative review). Problems of quality-of-care for patients have been particularly marked with dementia patients (Moïse *et al.*, 2004).

Concerns about poor quality of services have been among the drivers of reform to improve access to long-term care services and increase spending in several countries (see Chapter 5). Moreover, initiatives to introduce or improve existing regulation of long-term care services for quality assessment and improvement have multiplied in recent years. This chapter first reviews the evidence about the scope of quality deficits, and then looks at the different ways administrations have sought to regulate and monitor quality standards and at initiatives being pursued to improve the situation.* The last section discusses the potential consequences for long-term care providers of substantially improved quality standards, including the cost of services. This is complemented by a brief account of national and international progress with quality measurement that could have important implications for future regulation, policy making, and research.

What do we know about quality deficits in long-term care?

Quality deficits in long-term care are an issue of public concern in many countries. Evidence has emerged from a wide range of sources, *e.g.*, reports in the media and by advocacy groups, the findings of systematic public reviews and monitoring of provider accreditation, and the outcomes from continuing quality control systems.

Evidence on quality deficits also comes from outside the long-term care process, from the interface with acute care, *e.g.*, when patients are transferred to the hospital, and from scrutiny of mortality data concerning long-term care patients. Evidence on severe care deficits for long-term care patients at the end of their life has been found from studies using methods of forensic medicine (Roth, 2001, for Germany). The direct influence of quality of care in nursing homes on mortality was also documented in a recent Canadian study (Bravo *et al.*, 2002).

Defining quality of care in long-term care is a complex task and increasingly more sophisticated models have been discussed and tested recently. A rough classification of

* Sources for this chapter include replies to the questionnaire on long-term care and recent published studies which review the national and international evidence on quality of care (*e.g.*, Institute of Medicine, 2001b; Roth, 2001; Roth, 2002).

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quality in terms of the dimensions of *structure*, *process* and *outcome*, however, can serve as yardstick to look at the variety of quality regulations and quality improvement measures currently taken in countries (Table 4.1). The distinction between these three aspects of quality also helps to analyse broad trends over time.

Table 4.1. **Dimensions and aspects of quality in long-term care**

Quality of structure: examples	
	Quality and safety of buildings (fire hazards, sanitation)
	Amenity of housing environment
	Size of rooms
	Staff ratios; mix of staff qualification
Quality of process: examples	
	Mechanisms to protect resident rights
	Well-functioning transfer and discharge management
	Procedures of resident assessments used for care planning
	Availability of services needed to attain and maintain residents highest practicable level of functioning
	Availability of sufficiently qualified staff around the clock seven days a week
	Well-balanced diet
	Availability of and/or access to ancillary services (*e.g.,* rehabilitation, pharmacy, infection control)
	Requirements for clinical records and process of care documentation
	Maintaining a quality assurance committee
Quality of outcomes: examples	
	Prevalence of pressure sores
	Prevalence of malnutrition (including dehydration); adequacy of tube feeding
	Preventable decline of ADL and IADL functioning
	Residents with poorly managed pain
	Restraints uses (physical and pharmalogical)
	Residents with infections
	Prevalence of anti-psychotic drug use
	Prevalence of tube feeding
	Number of falls; falls prevention
	Prevalence of faecal incontinence
	Social engagement and privacy protection

Quality regulations for long-term care have been made more comprehensive in several countries in recent years. From being minimum requirements for structure and process of care, covering safety of buildings, staffing ratios, etc., they have developed into complex assessment and improvement instructions that include instruments for outcomes measurement, strategies of continuous quality improvement, such as a commitment to continuous staff training, detailed documentation and explicit requirements for protecting patients' rights, privacy and participation.

This "upward trend" of quality standards towards more outcome-oriented measures does not mean that fundamental structural and process measures have become less important. These different dimensions are seen as complementary, and in many cases are governed by different legislation. In Germany, for example, the quest for improved quality standards has recently resulted both in a number of updates of the fundamental regulations

on structure and process of long-term care, and in the introduction of new quality regulations for instruments of assessing and monitoring quality of care, including outcomes.

The state of quality in institutional care

Cases of lapses from quality standards in nursing homes have been reported in many OECD countries. The most frequently reported concerns include the following:

- pressure sores;
- malnutrition, in particular in dementia care;
- inadequate prophylaxis and treatment of incontinency;
- inappropriate use of physical and pharmaceutical restraints;
- deficits with pain management;
- health risks from poor food sanitation;
- neglect and abuse;
- accident hazards;
- a range of problems with lack of privacy and basic patient rights (protocols for sharing rooms, receiving visitors, mechanisms to handle complaints, etc.).

Table 4.2 sets out some evidence on quality deficits in nursing home care. The numbers quoted in this table are only indicative of quality problems. They do not as yet provide quality indicators that could be compared across countries. In spite of the "upward trend" of quality standards, discussed above, in most cases the use of outcome

Table 4.2. **Evidence on quality deficits in nursing home care**

Type of quality deficit	Reported prevalence of deficits	Country; source
Pressure sores, part of which are considered preventable	21% of high-risk patients and 8.5% of low-risk patients in Ontario complex continuing care hospitals/units in 1998-1999	Canada; Teare *et al.* (2000)
	9% of residents with pressure sores in US nursing homes	USA; CMS (2002) Nursing home compare
	10-12% pressure ulcers revealed by post-mortem examinations in the City of Hamburg	Germany; Roth (2002)
Prevelance of chronic pain, part of which is considered as not adequatedly treated	28% of residents in 15 nursing homes in New South Wales, Australia in 1998-1999	Australia; McClean and Higginbotham (2002)
	28.4% of residents in three Sydney aged-care hostels report frequent/constant pain in 2000-2001	Australia; Llewellyn-Jones *et al.* (2003)
	7% of residents in the US nursing homes	USA; CMS (2002) *Nursing home compare*
	39% of Oregon nursing home residents were inadequatedly treated for pain	USA; Wagner *et al.*, (1997) quoted in Institute of Medicine (2001)
Prevalence of tube feeding, part of which is considered inadequate	17.7% of patients in Ontario complex continuing care hospitals/units during 1998-1999	Canada; Canadian Institute of Health Information (2000)
	4% of tube-feeding prevalence in 554 facilities from the state of Massachusetts during October 1998 through September 1999	USA; Massachusetts MDS Repository Data (2001)
Anti-psychotic drug use, part of which is considered inadequate	35.7% of high-risk patients and 9.9% of low-risk patients in Ontario complex continuing care hospitals/units during 1998-1999	Canada; Teare *et al.* (2000)
	39% of high-risk residents and 18% of low-risk patients in 554 facilities from the state of Massachusetts during October 1998 through September 1999	USA; Massachusetts MDS Repository Data (2001)

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measurement for quality monitoring is still in its infancy. And even where national standard instruments have been developed, these tend to differ between countries. In addition, there is a natural bias in reporting: more is known about the scope of quality deficits from countries that have started to tackle these problems with the help of comprehensive reporting systems. In countries where little is known about quality deficits from official sources, the situation may be similar, as has been suggested by epidemiological research based on standardised instruments (but small-scale local samples) across countries (see Carpenter *et al.*, 1999).

Many of the quality problems are interlinked. Problems with pressure sores, for example, can serve as an indicator for quality problems more generally, as the occurrence of pressure sores can act as a "summary indicator" of a number of underlying quality-of-care problems. Malnutrition and dehydration, too little time devoted to individual residents, incontinence, and use of physical restraint all are known to increase the risk of pressure sores, and are quality problems in themselves. Pressure sores have also been found to increase the mortality rate in elderly patients. Moreover, development of pressure sores increases the cost of medical and long-term care (Beers and Berkow, 2000).

There are many factors that affect the outcomes of care and contribute to the problems and concerns listed in Table 4.2. Among these are quality deficits in the structure and process of long-term care. This is reflected in the following list of policy concerns that were nominated as being among the "top three" concerns by policy-makers in replies to the OECD questionnaire on long-term care for this study (Table 4.3).

Table 4.3. **Policy concerns about the quality of nursing home care**

Group of issues mentioned	Countries
Recruiting and retaining an adequately educated and skilled workforce; improved qualification of staff	All twelve countries that replied to this question
Put in place or further develop quality assessment and monitoring system	Austria, Korea, United States
Co-ordination of care services	Canada, Hungary, Germany
Building quality and amenity	Hungary, Japan
Other supply constraints: downward pressure on fees/inadequate fees paid to providers; lack of enough time for staff	New Zealand, United Kingdom, Korea (shortage of government subsidies)
Access to broader range of services, more differentiation	Norway, Austria (number of short-stay units)
Other mentioning of "top concerns" (country specific)	Use of physical restraints (Japan); Number of liability claims; lack of liability insurance for long-term care (United States)

Note: Data are based on replies from national administrations to the following question: "What are the top three concerns in your country in terms of quality of institutional care?"

Source: OECD's questionnaire on long-term care.

Human and physical resources are both important here. The qualifications of care workers often need upgrading, and the resultant adequately educated and skilled workforce has to be retained in the long-term care sector. Both nursing-home and home-care providers report this as one of the most pressing policy concerns in many countries. In other cases, a basic structural quality concern is building quality, which usually includes strategies to move to single- and double-bed rooms in order to provide better amenities and more privacy for nursing home residents (see also Table 4.5 below on differences across countries in the average room size in nursing homes).

Financial constraints facing patients often exert downward pressure on fees, which in turn restricts staff numbers and leads to insufficient staff to care for individual residents (*e.g.*, Korea, New Zealand, and the United Kingdom). Co-ordination of care services, and access to a broad range of different services that are tailored to patients' needs are both important to improve quality of care for individual patients. Progress with quality assessment and monitoring systems is mentioned as an important concern by countries that are at very different stages of developing these systems (*e.g.*, Austria, Korea, and the United States).

The state of quality in home care

The level of satisfaction expressed by people who are cared for at home is relatively high compared with the much higher number of complaints regarding care deficits in institutions. This has been shown by surveys of the views of recipients of home-care services, as well as surveys of dependent older people who are cared for in their own homes by family members and other informal carers. However, objective evidence on the quality of home care is in many countries even more limited than in the case of nursing-home care. Most of the research in this area measures *satisfaction* and *unmet need*, and not quality of care in a strict sense (IOM, 2001b; and Roth, 2001).

Such positive results from surveys of the views of recipients of home-care services have been influential in supporting policies of care allowances and consumer choice in several countries (*e.g.,* Austria, and Germany). There is, however, a case for moving from ad-hoc surveys and research to continuing quality monitoring and to the introduction of survey instruments that have undergone a thorough testing and validation process, given the inherent methodological problems of ad-hoc surveys of consumer satisfactions of older people (Roth, 2002). For example, Austria and Germany have launched initiatives to strengthen quality monitoring of home care, together with policies of extending the range of support services to informal care givers.

Frequently-mentioned quality concerns that currently receive priority attention in countries (Table 4.4) have much overlap with those reported for nursing-home care

Table 4.4. **Policy concerns about the quality of home-care services**

Group of issues mentioned	Countries
Recruiting and retaining an adequately educated and skilled workforce; improved qualification of staff	Majority of countries that replied to this question
Improve skills of care managers	Canada, Japan
Put in place or further develop quality assessment and monitoring system; improved standards framework	Australia, Austria, Korea
Co-ordination of care services; continuum of care	Australia, New Zealand
Lack of information about services	Japan, UK
Prevention of inappropriate residential care admission	Australia
Supply constraints; limited financing	Korea, US
Broader range of services; too little differentiation	Canada, Norway, UK
Adequate care supply for dementia cases	Germany, Japan

Note: Data are based on replies from national administrations to the following question: "What are the top three concerns in your country in terms of quality of home care?"

Source: OECD's questionnaire on long-term care.

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(Table 4.3). This is not surprising in the case of the concern for a sufficient and adequately educated workforce, because both labour markets are direct competitors, and in some cases care providers may even offer both home-care services and nursing-home care. The need for further developing quality standards and monitoring instruments again ranks high, as does the concern for broadening the range of services to support care at home, in particular in support of informal care givers. Supply constraints are both mentioned in general (*e.g.*, Korea and the United States), or for dementia patients in particular (*e.g.*, Germany and Japan).

Quality problems in home care have been documented in a number of surveys of health status and living conditions of dependent people at home and of their informal care givers. Although available surveys report that only a small percentage of persons that are cared for at home receives care that is grossly insufficient or that puts the care recipient at a risk, these surveys have revealed more widespread health risks and a heavy burden on informal carers. These risks can have negative consequences for the quality of care for the dependent person (*e.g.*, Nemeth and Pochobradsky, 2002, for Austria; Schneekloth and Müller, 2000, for Germany).

Frequently reported shortcomings are lack of information available for consumers about the range of services available (*e.g.*, Austria and United Kingdom) and limited access to services that support informal carers (*e.g.,* Badelt *et al.*, 1997, for Austria). Evidence from these surveys indicates that access to a broad range of support services for informal carers, including respite care, training and counselling, is essential to maintaining quality of care at home and to prevent or mitigate adverse effects on the health of informal carers. Wide regional variations in service availability can also limit access to the most appropriate mix of services, leading to less-than-optimal quality of care in some areas (see Chapter 2 on continuum of care).

Efforts to monitor and improve quality in long-term care

Even though quality of long-term care has only recently emerged as a focus for public policy, a number of policy approaches have already been developed, and in some cases implemented, in OECD countries. Broadly speaking, three complementary approaches have been used for better monitoring and ensuring quality of long-term care. They are, firstly, improved monitoring by agencies such as regulators and purchasers; secondly, raising provider and professional commitment to quality improvement; and, thirdly, increasing consumer information and market competition (IOM, 2001a; see Mattke, 2004, for a similar approach to classifying initiatives of quality improvement in acute health care).

In light of the evidence about quality shortfalls, policymakers and field workers in many OECD countries are increasingly concerned that there should be greater accountability of providers. Almost all OECD countries impose a minimum accountability on care providers by setting some external standards. However, the indicators applied in these standards tend to be diverse and to focus too much on aspects of structural and process quality. In this respect, some countries still mainly set minimum requirements for the physical structure while leaving the practice of care up to the providers. A relatively new initiative is the development and introduction of practice guidelines to improve routine care in specific areas, such as use of restraint or pain control.

Some countries have followed a self-regulatory approach, largely relying on service providers. For example, quality assurance is largely delegated to the profession in Norway and Sweden.

Consumer empowerment also constitutes a common feature in developing quality of care for the elderly. Consumer empowerment may involve a number of types of instruments such as complaint hearings, release of quality indicators and benchmarking results to the public.

Government regulation

Standard setting

Many countries attempt to maintain and develop quality of long-term care by setting minimum requirements on providers as precondition of licensing or contracting decisions. These standards frequently regulate structural aspects of the quality of care, such as staffing ratios in institutions and minimum space per resident. Standards on structure of care establish a basic accountability of providers, in particular with respect to crucial safety issues. These standards themselves do not automatically translate into quality of outcome or to the prevention of poor outcomes.

A fairly strong link, however, seems to exist between structural indicators of the scope and quality of the workforce and outcomes. For example, Mor (2003) found that facilities where more than 5% of nurses had been hired on fixed-term contracts had higher rates of problems with outcomes. In light of the evidence about the close correlation between the workforce and quality of care, many countries have introduced or strengthened regulations on the qualifications of staff and staffing levels

Countries differ by whether the responsibility for standard regulation is unified at central level or has been delegated to local governments. Some countries have put in place nation-wide standards of care, *e.g.,* Australia, Germany, Ireland, Japan, New Zealand, the United Kingdom and the United States. In other countries, *e.g.,* Austria, Canada and several Scandinavian countries, standards of care are monitored by regional or local government. In Austria, as social services are the responsibility of the individual Federal Provinces, there is no uniform, binding quality regulation in social services. Instead, quality regulation and quality control by the Provinces has included minimum standards in the framework agreement on long-term care services with the Federal government. In Canada, where health care and social service delivery is the responsibility of provinces and territories, there is no uniform or national binding quality regulation in either home care or institutional care, and there are considerable discrepancies between the provinces and territories. In Switzerland, where no general standard of care has been set, the level of quality assurance is part of individual agreements between providers and health insurers.

Examples of government initiatives to improve the quality of long-term care include the re-accreditation process for care institutions in Australia following reforms in 1997, new and higher standards in Austria from 1994, the quality regulations put in place in Germany from 2002, the *Care Standards Act* of 2000 in the United Kingdom, and most notably, the Nursing Home Reform Act of 1987 in the United States.

The care standards of these countries are complex in that they tend to encompass a wide range of criteria for quality of structure, process, and – often to a lesser extent – of outcome of the services provided. The *Australian Aged Care Act* of 1997, for example, requires an accreditation assessment with a focus on structure and process of care homes

against 44 criteria which cover 1) management systems, staffing and organisational development; 2) health and personal care; 3) resident lifestyle; and 4) physical environment and safe systems. The US Nursing Home Reform Act delineates five major components: 1) resident's rights; 2) quality of life, and quality of care; 3) staffing and services, resident assessment; 4) federal survey procedures; and 5) enforcement procedures. The UK Care Standards Act created a registration and inspection system to enforce new national minimum standards, including 38 new standards for nursing homes that were implemented in April 2002; new standards for home care in the United Kingdom were implemented in April 2003. Germany, Ireland, Japan and New Zealand also apply complex quality assurance mechanisms.

Linking performance monitoring with quality improvement

Care standard-setting itself does not automatically guarantee quality care. Long-term care regulations need therefore to include procedures to monitor actual conditions of residents and to ensure compliance with the standards. Regulators can also provide incentives, financial or non-financial, for specific actions and specify and impose sanctions for non-compliance.

Australia and the United Kingdom have established independent agencies – the Aged Care Standards and Accreditation Agency (ACSAA) in Australia and the Commission for Social Care Inspection (CSCI) in the United Kingdom – to monitor performance of service providers. The responsible US agency, the Centers for Medicare and Medicaid Services (CMS), relies on a survey and certification process administered under contracts by state agencies to monitor and assess compliance by nursing homes with the requirements for participation in government long-term care programmes (IOM, 2001b, p. 143).

There is a noticeable trend away from reliance on an initial inspection, towards combining inspections with more demanding self-assessment and the provision of continuing care documentation by providers, with the aim of making quality assessment more reliable and quality improvement more transparent.

Another aspect of recent reforms has been to strengthen and diversify sanctions aiming at achieving sustained compliance with regulatory requirements of quality of care. For example, the US Nursing Home Reform Act allows the imposition of civil money penalties, denial of payment for new admissions, temporary management, immediate termination, and other remedies or sanctions (IOM, 2001b). In the United Kingdom, CSCI decides on the registration of agencies and the imposition of conditions for registration, variation of any conditions and enforcement of compliance with the Care Standards Act and associated regulations, including proceedings for cancellation of registration, or prosecution.

Impacts of regulatory arrangements on quality of care

The introduction of accreditation of nursing homes tends to initially result in rather substantial numbers of cases where facilities fail to pass accreditation when first assessed, and/or receive accreditation on the condition of substantial improvement within a set time frame. Rates of failure of passing initial assessment of 40% or more have not been uncommon and few institutions seem able to initially report high rankings on all dimensions.

However, the reforms are showing positive results. In Australia, 2 944 homes were accredited, of which 2 755 homes (93.6%) were accredited for at least three years in

June 2003. Building quality and amenity are steadily increasing, as homes are moving to meet the 1999 Certification Assessment Instrument.

The United States has seen substantial improvements since the 1987 Act. State survey results show that care in nursing homes substantially improved during the 1990s. The average number of deficiencies reported per facility by state surveyors declined from 8.8 per facility in 1991 to 6.3 per facility in 2001 (Harrington *et al.*, 2002). Specifically, the reduction of the inappropriate use of physical and chemical restraints is one of the most successful outcomes of the new regulatory framework. However, despite improvements, there remain unacceptable lapses from standards. A recent official US inquiry found one in five nursing homes nationally to have serious deficiencies that may place residents in jeopardy (GAO, 2003b).

Self-regulatory approaches

Although basic standards for long-term care are often defined and enforced primarily through the legislative and administrative process, standards put forward by non-governmental sources are also important. Many professional societies, trade associations and other organisations have set voluntary standards that operate in tandem with regulations through voluntary compliance.

In the Netherlands, all member organisations of the major care service association have to comply with a generic, formal system of internal quality management, initially developed for quality management in industry**.** Although a self-regulatory process, it is prerequisite for membership of nearly all home-care organisations. Compliance of member organisations is checked by an independent agency, and approval results in certification. On a more voluntary level, some associations of private providers have introduced self-regulation to raise the quality of care provided by their members, *e.g.,* in Spain and the United States.

Government agencies providing long-term care may also be largely self-regulating. For example, in Norway and Sweden, the main means of quality control is self-regulation by the municipalities that provide the service.

Current responsibility for ensuring standards of care in Canada is widely distributed among professional and regulatory bodies. The *Canadian Council on Health Services Accreditation* (CCHSA) plays a significant role in assessing quality of long-term care facilities as well as other health-care institutions. It accredits hospitals, long-term care institutions, rehabilitation institutes and primary health care organisations, on a voluntary basis.

Consumer empowerment and market competition

Mechanisms introduced for empowering residents in institutional care have included measures such as setting up residents councils and more effective means of dealing with complaints. For example, Australia established the *Aged Care Complaints Resolution Scheme* in 1997 to deal with complaints about Commonwealth-funded aged care services provided.

Additionally, in Australia the central government provides funds for independent advocacy and information to recipients or potential recipients of care services, their relatives, representatives and carers. In the United States, the best-known advocacy effort is the *Long-Term Care Ombudsman Program*, mandated under the Older Americans Act 1978. Other advocacy efforts involve resident representatives; residents councils; and family councils that participate in a variety of activities in nursing homes, assisted living facilities, and other residential settings (IOM, 2001b).

Regulators may require the publication of measures of the quality of care provided in facilities. For example, the United States introduced the *Nursing Home Quality Initiative* in 2002 to kick-start a process of continuing improvement in the quality of care. After a successful six-state pilot, the regulatory agency CMS published quality-of-care information in November 2002 for nearly 17 000 nursing homes in all 50 states (some of this information is included in Table 4.2 above). The internet is a growing resource in making information and advice available to consumers and strengthening their role in monitoring and reporting on quality (see Box 4.1).

Box 4.1. **The role of the Internet in strengthening the role of the public and of consumers of services**

In a growing number of countries the Internet now plays an important role in allowing consumer groups to gather information on unacceptable quality deficits and to increase the pressure on policy makers to implement strategies to prevent these.

The role of consumers, their families, friends, and relatives is essential in designing and implementing long-term care services. Many OECD countries have begun to incorporate the consumer's view into quality development. In some countries, the results of provider monitoring are released to the public. This initiative should be particularly powerful where patients have control over their choice of provider.

Choice of provider, however, is usually within regional limits. Moreover, the interpretation of assessment reports is a complex task for most consumers. It is difficult to judge whether direct consumer choice or the mere fact of being potentially "named and shamed" via a publicly provided medium, has a stronger influence on provider behaviour.

In a few cases, governments themselves use this channel of communication, *e.g.,* by posting summary reports from inspections for individual providers. For examples, see:

Australia: www.accreditation.aust.com/index.html.

United Kingdom: www.csci.org.uk.

United States: www.medicare.gov (sites: Nursing Home Compare; Home Health Compare).

Regulating and improving the quality of long-term care provided at home

The regulation and regular quality assessment of the home-care market is a relatively new development. Specific policies for quality assessment and improvement have recently been introduced in a number of countries, *e.g.,* Australia, Canada, Germany, Japan and the United Kingdom, and are being considered in others, *e.g.,* Hungary. In general, these focus on setting standards of structure of care provider organisations, and process of care provided. The use of outcome measures in standard setting is much less common, and continuous research efforts are needed to clarify and improve underlying measurement concepts.

External and mandatory control of home-care standards

A number of countries have developed standards of care on a mandatory basis. England introduced regulation of domiciliary care agencies for the first time as part of the Care Standards Act 2000, implemented from January 2003 (Department of Health, 2002).

The Act sets out regulations and national minimum standards to be met by "domiciliary care agencies", judging all three quality dimensions, with a special focus on process. An example of process quality regulation is the requirement that there is a continuity of carers responsible for a client (the change of carers is one of the most frequent complaints of recipients of home care across countries).

In the United States, states have been required to certify to the Federal government that they had methods for assuring quality of home and community-based services. Actual monitoring of quality of home care is very variable across states and across Medicaid benefits. There is generally an emphasis on "input" standards in the form of "provider qualification". Use of outcome standards and corresponding measurement is rare and its adequateness controversial.

Japan has nationally-set standards to be adhered to by service providers; these standards focus on structure and process measures, such as on qualification and training of staff. The prefectural authorities monitor and correct service providers' failure to adhere to the standards, as there could be further deterioration in the quality of care. If a provider fails to adhere to standards, the prefectural authorities can cancel its designation. In the event that some requirements are not met, long-term care fees will be reduced by fixed percentages, for example when care is provided by personnel without the formal qualification level required.

The cost of improving housing standards and quality of accommodation

Setting standards for the quality of buildings, the amenity of the housing environment and staff ratios, is now widely considered a prerequisite for progress with improving quality of care. In order to comply with such standards and to continuously improve quality, capacity increases will be necessary in many cases. Cost pressures are especially expected from the need to improve housing standards. Single-room beds for older persons (at least one double-room for couples) seem likely to become the norm over time for residents in nursing homes.

According to users' surveys, there is no question that this is the preferred living situation for most nursing home residents. However, no country is currently close to such an ideal situation, although there are explicit policies in a growing number of countries to move in this direction, with regulations and investment incentives for new buildings, and/or for limiting the maximum number of people living in one room, and there is evidence that as a result of these changes the situation is improving (*e.g.*, Australia, Norway; Table 4.5).

The building stock for institutional care will not only need to be improved in line with general living standards but also be better equipped to cope with a range of disabilities (*e.g.*, single rooms should have a bathroom attached). Again, this will have to be done in response to an expected higher number of more severe cases and the general tendency observed in several countries where nursing-home care is increasingly been concentrated on more demanding, more "medicalised" patients.

All of these new needs will impose significant resource requirements on providers, in terms of capital investment, staff management and regulatory compliance. Some private providers that are funded from a mix of public and private funds may find it difficult to finance adjustments needed to meet higher standards from new regulations (see Netten *et al.*, 2002, for the United Kingdom). This can pose a dilemma for public policy regulations,

Table 4.5. **Privacy in nursing homes**

	Year	Average number of persons per room	Percentage of all residents living in room that is				
			Single	Double	3-bed	4-bed	5-bed or more
Australia	1997	1.60	24	29	9	29	9
	1999	1.56					
	2000	1.50	61	17	4	14	4
	2003	1.44					
Germany[1]	1999	1.40	45	49	4	1	
	2001	1.40	47	49	3	1	
Japan	2002	2.80	10	13	4	70	3
Korea	2004	2.90					
Netherlands	2000	2.00	22	35	4	33	6
Norway	2000	1.15	75	24	1		
	2002	1.08	80	20	0		
Sweden	2003		97				
United Kingdom	1996	1.40	46	44	6	1	2
	2003	n.a.	84	16			

Note: United Kingdom 2003 refers to private-for-profit institutions only, which, however, account for the majority of nursing home places.

1. Number of beds per room.

Source: Australia: Gray, L. (2001), *Two Year Review of Aged Care Reforms*, Department of Health and Aged Care, Canberra; Germany: Federal Statistical Office (1999, 2001); Japan: Ministry of Health, Labour and Welfare (2004), "Report on Long-term Care Submitted to the Advisory Committee on Social Security", Tokyo; Netherlands: Branchnerapport Care (2000); United Kingdom: Netten, A. *et al.* (1998), *1996 Survey of Care for Homes for Elderly People: Final Report*, PSSRU Discussion Paper 1432/2, University of Kent, Canterbury; and Laing and Buisson Market Survey (2003); Sweden: National Board of Health and Welfare (2004), *Care and Services for Elderly Persons 2003* (in Swedish).

which require improvements in the situation of dependent persons in these institutions. If this results in closures of nursing homes, it could mean fewer places available to match growing demand. Moreover, the need to change places can for frail older persons be detrimental to their health and social outcomes, even in cases where a new place can be found without delay. This can lead to patients or families resisting the closure of sub-standard homes.

Conclusions

The drive to raise quality standards in acute health care has been accompanied in many OECD countries by governments taking a more active role in regulating and inspecting quality of long-term care services. This has two aims: to reduce the risk of receiving poor-quality care (including the risk of harmful care), and to raise average standards of service.

Information on the quality of care and the prevalence of adverse outcomes needs to become much more transparent and be made accessible to the public on a regular basis. Improved measurement combined with transparency is a prerequisite for a functioning market for long-term care services that will support the policy direction of enabling more consumer choice. There is a growing consensus that reporting on quality in long-term care has to be on a more scientific basis and needs to become an integral part of the care process itself.

Although strategies for quality improvement and better quality indicators in long-term care are spreading fast across countries, there is some evidence that *ad hoc* approaches and fragmentation of initiatives may result in sub-optimal results. While at least some authority for providing long-term care services is in many cases devolved to the local level and will likely remain there, there is a strong case for co-operation on quality standards and measurement at the national and international levels. The cost of developing and validating new instruments should not be underestimated. As many of the quality strategies and monitoring instruments are relatively new, more evaluation will be necessary to assess their reliability and monitor their effectiveness in raising standards.

For decisive improvements in quality, countries need to move on from setting standards of quality of infrastructure and process of care to the measurement of quality of outcomes. One of the main challenges will be to back up administrative systems by better information, which ideally should be developed in an interactive way: data and indicators produced from administrative systems should be of a proven reliability and validity, in order to have maximum potential for use in developing better policies and adjustments of infrastructure.

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Chapter 5

Paying for Long-term Care: Current Reforms and Issues for the Future

At the heart of a number of major long-term care reforms over recent years has been the question of how to provide wider and more equitable access to long-term care services, within the constraints of financial sustainability. This chapter considers the various reform paths followed by OECD countries, within the context of different national methods for financing health and social services.

Introduction

Projections set out in Chapter 1 indicate that public expenditure on long-term care in OECD countries could double by 2050 as a proportion of GDP. This raises the issue of the capacity of public systems to meet rising long-term care expenditures, or even, in countries with more generous systems, to sustain existing programmes. However, the issue of sustainability arises in relation to private as well as public expenditures. What may appear to be unsustainable in the future as a public contribution could drain the resources of middle-income families if similar costs had to be borne privately. High long-term care costs borne by individuals are already a major issue driving policy in a number of countries. For the user, the costs of long-term care are potentially very high ("catastrophic" in health insurance terms) unless at least partly covered by a public programme or private insurance.

While policy-makers in all countries are concerned about the sustainability of their system of funding for long-term care, in some this has been seen as a reason to raise extra contributions, while in others it has been seen as a reason to find ways to limit expenditure by increased targeting or raising user payments. Quite different strategies have been followed which widen the differences between OECD countries in how they have treated long-term care within their social protection systems.

Chapter 1 highlighted the large variations between OECD countries in the public coverage of long-term care costs. In summary, of the 19 OECD countries considered in this report, seven – Austria, Germany, Japan, Luxemburg, the Netherlands, Norway and Sweden – provide comprehensive coverage, treating long-term care in broadly the same way as they treat other health-related needs in their social protection system. The share of GDP spent on publicly financed long-term care varies from 0.8% to 2.9% in these countries. The remaining twelve provide a system for long-term care that depends in part or in whole on a means-test of the user's income and/or assets. In these countries, the share of GDP devoted to public spending on long-term care varies from below 0.2% to 1.5%. While these latter countries vary in the generosity of the means-testing, in all cases they treat long-term care differently from the way that other health-related needs are covered.[1]

Of the seven countries in the first group, four have introduced universal funding for long-term care within the past decade. The Netherlands introduced universal funding for long-term care as part of their health insurance system in 1968. It has been modified several times since its introduction, most recently in 2003 in that all home-care users now have the option of a payment in cash to purchase their own care (see Chapter 3).

Neither Norway nor Sweden is considering a structural change to their system for funding long-term care as a universal service. However, there have been considerable modifications in Sweden to target the services on the more sick and disabled older people.

Of the twelve countries in the second group, two – Hungary and Korea – have in recent years seen discussions to introduce long-term care insurance in the future. A third, Ireland, has recently had a report of an independent review recommending the introduction of a

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form of public long-term care insurance (Mercer Limited, 2003), and the government has set up a working group to consider various options.

Three other countries in the second group – Australia, New Zealand and the United Kingdom – have in recent years modified their means-testing formula, but have done so in different directions. Australia made additional types of public support subject to income and asset-testing, while the other two countries have reduced the impact of means-testing.

This chapter considers first the new systems for a public long-term care benefit introduced in four countries – Austria, Germany, Japan and Luxembourg – and the potential lessons from those reforms. It then looks at the different way in which three countries that pay for long-term care from general taxation – Sweden, Australia and the United Kingdom – have attempted to balance greater equity and quality in the system with sustainable financing within a tax ceiling.

New forms of public programmes for long-term care: Austria, Germany, Japan and Luxembourg

Since 1990, these four countries have introduced a universal public scheme to cover a substantial share of the costs of long-term care. The methods adopted differ but in each case a policy decision was made that the costs of long-term care should be brought within the scope of each country's system of social protection. The nature of the schemes differs largely because of differences in the nature of social protection in each of these countries. Summary details of the schemes are set out in Table 5.1 together, for comparison, with that of the long-standing public insurance scheme in the Netherlands, which has been subject to recent significant reforms.

Austria

A tax-funded system of long-term care allowances was introduced in 1993, payable in cash only, with the amounts determined by assessment of recipients on a seven-point scale by the type of care and number of hours of care needed. The allowance replaced and made universal a pre-existing number of allowances for different groups in the population, each with different assessment criteria and benefits. The inequities generated by these different allowances, which had been introduced at different times to meet different needs, were a strong part of the case for reform, as advocacy groups argued that similar needs should receive similar treatment. There was also a strong policy direction to support care of older people at home, both by informal carers and by encouraging growth of more home-based care services.

The new allowances comprise a federal and nine provincial allowances, together covering the whole population and based on the same system of assessment and benefits. While the new allowances were funded from general taxation as part of the same reform package, the level of contributions to health insurance was increased by 0.8% for self-employed persons and farmers and by 0.5% for retired people. This was to relieve the burden of subsidy to the health insurance scheme from general taxation that had arisen in line with the growth of costs of health care for older people.

Germany

A public scheme of long-term care insurance was introduced in Germany in 1995-96. This comprises a mandatory public scheme, currently covering just over 70 million people, and a private insurance scheme, currently covering around 8.5 million people.[2] The public

Table 5.1. **Public long-term care benefits in five countries**

	Austria	Germany	Japan	Luxembourg	Netherlands
Name of the programmes	Long-Term Care Allowance (1 Federal and 9 Provincial allowances, 85% Federal)	Long-Term Care Insurance	Long-Term Care Insurance	Dependency Insurance (Assurance Dépendance)	Exceptional Medical Expenses Insurance (AWBZ)
Date of commencement *a)* Contributions *b)* Benefits *c)* Fully implemented	*a)* 1 July 1993[1] *b)* 1 July 1993 *c)* 1 July 1993	*a)* 1 January 1995 *b)* 1 April 1995 (home care) and 1 July 1996 (institutions) *c)* 1 July 1996	*a)* 1 October 2000 *b)* 1 April 2000 *c)* 1 October 2001	*a)* 1 January 1999 *b)* 1 January 1999 *c)* 1 January 1999	*a)* to *c)* 1968 for nursing homes only 1989: to include home care 2001: to include residential homes 1 April 2003: To include entitlement to a personal budget to spend on care
Funding % *a)* Taxation *b)* Contributions from working-age population *c)* Contributions from older population	*a)* 100% *b)* and *c)* None	*a)* None *b)* and *c)* 100%	*a)* 50% (25% central, 12.5% regions, 12.5% municipality) *b)* 32% *c)* 18% (by deduction from pension)	*a)* 45% general taxation plus revenue from an earmarked tax on electricity bills *b)* and *c)* the rest	*a)* marginal *b)* 88% *c)* 11%
Rate of contribution *a)* Employees *b)* Employers *c)* Self-employed *d)* Retired/older	*a)* to *d)* None	*a)* and *b)* 1.7% *c)* and *d)* 1.7% up to an income ceiling	*a)* to *d)* Contribution from health insurance funds to cover 32% of estimated annual cost of benefits – currently approx. 1% of insured's income *d)* Contributions set by each municipality to cover their costs; these vary are then by income, with social assistance subsidising those on the lowest income	*a)* to *d)* 1% of income	*a), c)* and *d)* 10.25% in 2000 (EUR 2 558 annual maximum) *a), c)* and *d)* 13.25% of taxable income (EUR 4 004 annual maximum) from Jan. 2003 (AWBZ covers all exceptional health expenses not just long-term care)
Assessment of benefits *a)* How *b)* Who	*a)* 7 point scale – level of need and hours of care needed *b)* Medical report to social insurance authorities	*a)* 3 point scale – number of times per day and hours of care needed *b)* "Medical assessment service of sickness funds" (MDK)	*a)* 2 step assessment. Stage 1: on site questionnaire on time needed with ADLs and IADLs to place within a 6 point scale or reject. Stage 2: case conference. *b)* Stage 1: local government officer or care worker Stage 2: health and welfare professionals	*a)* Sliding scale based on No. of hours of care needed with ADLs, above a threshold level *b)* Medical report and social report to multi-disciplinary team for decision, coordinated by government medical staff	*a)* Care need assessment using ICIDH/ICF information *b)* Regional Need Assessment Agencies (RIOs)
Type of benefits *a)* Cash *b)* Services	*a)* Cash	Institutions: *b)* Services from approved providers Home care: Choice of: *a)* Cash *b)* Services from approved providers *c)* Combination of *a)* and *b)*	*b)* Services from approved providers	Home care: Choice of: *a)* Cash *b)* Services from approved providers	Institutions: *b)* Services from approved providers Home care: *a)* Personal care budget (from April 2003 changed to cash payment)
Additional criteria (does not cover all criteria)	Normally resident in Austria	Minimum five years contributions (condition introduced in 2000)	If below 65 the cause of need for care must be one of 15 age-related conditions	Recipient must be likely to need help for minimum of 6 months	–

1. These were contributions to health insurance, not long-term care.

Source: OECD's questionnaire on long-term care and official publications.

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scheme is administered by health insurance funds while the private scheme is administered by private insurers according to federal regulations. The private scheme must provide at least the same benefits as the public scheme. Contributions to the public scheme, from retired as well as working-age people, are set at 1.7% of gross income, up to a maximum contribution, with employers usually paying 50% while the individual pays the other 50%. Contributions to private long-term care insurance are age-related and subject to federal regulation. Where the recipient is receiving care in an institution, the benefit is received as payment for the service part of nursing home costs (*e.g.*, except accommodation), up to a maximum in each of the three care levels.

Two major goals of the reforms were, first, to reduce the burden on local social assistance budgets, by removing as many people as possible from the need to apply for social assistance for long-term care costs and, second, to help maintain as many elderly people as possible in their own home.[3] The first objective is regarded as having been met. In 2001, less than 5% of beneficiaries in their own homes and less than 25% in institutional care were receiving additional help from social assistance budgets (Federal Ministry of Health and Social Security, 2003). There has also been a significant growth in spending on home-care services.

The current programme design poses, however, challenges to its financial sustainability that will need to be addressed in the future as population ageing continues. First, there is a growing gap between the cost of services in the long-term care market and payments per care level, which have been kept fixed since the introduction of the system and not been adjusted for price increases. Second, the annual increases in revenues under the fixed contribution rate have since 1998 been for all but one year substantially lower than the growth of expenditure, in particular due to the spending pressures from care in institutions. The deficit of long-term care insurance was 2% and 4% in 2002 and 2003, respectively. It has continued to grow during 2004. Following a ruling of the Federal Constitutional Court that called for different contribution rates for employees with and without children, the individual contribution rates for the latter have in 2005 been raised from 0.85% to 1.15%.

A government commission on the financial sustainability of the social insurance systems recommended further incentives and support for care at home and increasing contributions paid by pensioners (Federal Ministry of Health and Social Security, 2004). Other proposals have recommended fundamental reforms of the way the current system is financed (see German Council of Economic Experts, 2004). These proposals range from extending mandatory social insurance to the whole population to introducing a funded system with a capital stock as a buffer against the background of ageing populations.

Luxembourg

Luxembourg introduced a new arm to its social insurance system to cover long-term care in 1999. It is funded 45% from general taxation with a 1% individual contribution based on salary or pension (around 35% of funding in 2001). The remainder is funded from a special tax on electricity bills. The new insurance scheme provides both benefits in cash and in kind to cover the cost of care at home or in an institution, with benefits on a sliding scale based on the extent of need for care supplied by a carer with activities of daily living (Inspection Générale de la Sécurité Sociale, 2003).

From 1999 to 2003, the Luxembourg long-term care insurance had an annual budget surplus, due to the combination of fixed payments per care level and moderate growth in the overall number of recipients. Moreover, there has been a significant shift in the balance of care between 2001 and 2004, with a larger share of care recipients now being cared for at home rather than in an institution. This has been one of the goals behind the introduction of the new long-term care system. National projections/scenarios on the longer-term financial sustainability of the new system are currently not available.

Japan

Japan introduced public long-term care insurance in 2000, funded 50% from general taxation (shared between central and sub-national governments), 32% from contributions from employees and 18% from contributions from pensioners. There is no single rate of contribution. Instead, the municipalities, which hold the long-term care insurance funds, levy contributions that are necessary to cover their costs. They are graduated by income, up to a maximum, and social assistance funds subsidise the contributions of those on the lowest incomes. Long-term care insurance is currently restricted to people aged 40 and older. As a consequence, younger age groups with relatively moderate care needs do not contribute to the financial sustainability of the system.

Assessment is by a case conference of health and social professionals according to a six-point scale based on the amount of help required with personal care and household tasks. On-site visit and completion of the assessment is usually delegated to a service provider or municipal official. All benefits are paid according to a national scale and are received as an equivalent amount of services. The user pays 10% of the cost of services.

The new system collects contributions from, or pays benefits to, almost half the population. Given its large scale, the introduction of the scheme was assessed to have gone smoothly. It has also been very well received by the public. As one of the main goals of the scheme, the range of choice of services was enhanced, especially through an increase in home-care services: between April 2000 and October 2002 the number of home-care recipients almost doubled from 970 000 to 1 910 000 (97%) while institutional-care recipients increased by 37% from 520 000 to 710 000.[4]

The new insurance system, together with other service-related long-term care reforms, also had the goal of reducing the level of inappropriate hospitalisation of older people. Previously Japan had large numbers of older people in hospital receiving long-term care. The proportion of older people residing in institutions in Japan was reduced over 1990-2000; this is partly due to reduced institutionalisation in hospital in the period before the new system came into force, as new long-term care services were put in place. The new insurance system helps to pay for the nursing home and home-care costs of those who would have been in hospital, and subsidised by health insurance, in previous years.[5]

There is concern that the ageing population in Japan will put increasing pressure on the current system, as recent projections suggest that average contributions per capita might have to grow by as much as 80 per cent within the next ten years. In order to secure the longer-term financial sustainability of the new long-term care scheme, a number of measures are therefore been considered by the government, such as containing cost of long-term care through more active prevention strategies (Ministry of Health, Labour and Welfare, 2004).

Lessons from the reform process

While there are significant differences in the detail of the reforms introduced in these four countries, and it is still too early to assess their long-term impacts, some common features appear which are noteworthy. First, all of them have been supported by additional contributions.[6] They are not a "free good" but have nonetheless been so far supported by the public paying these contributions.

Second, none of the schemes puts all of the burden onto the working population and employers.[7] All of the schemes require contributions from pensioners as well. In addition, in Austria, Japan and Luxembourg, a substantial share of the cost is spread across all age groups *via* general or earmarked taxation. Contributions from all age groups, including from the older population are important if such schemes are to be sustained in an ageing society.

Third, all of the schemes used the expertise of existing agents for health insurance or social services in their implementation. These were agencies administering the existing rather fragmented dependency allowances, in Austria, the health insurance schemes in Germany, and the municipalities in Japan. All had experience in assessing and delivering benefits to the public and the use of these existing and, to the public, well-known mechanisms appears to have been instrumental in getting these new and extensive schemes up and running.

Finally, it should be noted that introducing a comprehensive public scheme does not have to be at the expense of reducing the coverage of private long-term care insurance. In Germany, the market for *voluntary complementary* long-term care insurance, to meet additional costs not covered by the public scheme, has grown alongside the establishment of the public long-term care system. There are now some half a million such policies. The public scheme has made such insurance affordable by covering the first tranche of the cost.

Reforms to long-term care within the tax envelope: Sweden, Australia, New Zealand and the United Kingdom

Countries that fund both health and social services largely from general taxation will not necessarily wish to adopt a social insurance system for long-term care. This section examines reforms in four countries that fund long-term care from general taxation.

Targeting within the Nordic model: Sweden

Sweden has faced the problem of operating within a very high-cost welfare system in which additional expenditures were ruled out, and reform required getting better outcomes from existing expenditure while not giving up the basic principles of the Swedish system. The approach adopted has been to target services, and therefore public expenditure, more closely on the most sick and disabled, and requiring greater private resources, either financial by buying private services or informal from families, from those with lesser disabilities.

The key reform which initiated a period of considerable change in Swedish long-term care was the Ädel reform of 1992. This involved devolution of responsibility, accompanied by a transfer of funds, for all long-term care and related services to the municipalities, having previously been divided between municipalities and counties. Counties retained responsibility for acute care in hospitals, and, as part of their new responsibilities, the municipalities became financially responsible for older people unnecessarily retained in hospital beyond the clinically necessary time (so-called "bed blockers"), as in principle they should arrange a suitable package of care to allow discharge.

One of the initial aims of the reforms, to reduce "bed blockers", was successfully achieved. In 1990 it was estimated that as many as 15% of hospital beds were occupied by "bed blockers" and this was reduced to around 6% by 1999. During these years the counties also drastically reduced bed capacity, by 30% in short-term care and 55% in geriatric care between 1992 and 1998.[8]

One outcome of this considerable change in hospital use has been a steady and significant transfer of caring responsibility to the municipalities. As this coincided at the beginning with a steep recession in the Swedish economy, municipalities were generally unable to raise new tax expenditure to compensate. In addition, between 1990 and 1999 central government introduced various controls to cap local government taxation. The net result has been a considerable increase in targeting, and a qualitative change in the nature of services supplied.

As a result, one of the aims of the reforms, namely that of creating more "social" nursing homes, has not been met in face of the over-riding need to "re-medicalise" nursing homes to cater for the higher nursing and medical needs of residents (Johansson, 2000, p. 13).

The impact on home care has been even more marked. There was a significant shrinkage of the proportion of the older population supplied with home care, from between 13-14% in 1990 to around 9% in 1995,[9] a level sustained thereafter. However, the volume of help supplied to this smaller group was higher. For example, in 1988, 16% of home-help recipients received care during the nights and weekends; by 1997 this had increased to 28% (Johansson, 2000). Charges to recipients were increased but then capped by central government in 2002, together with charges in care homes.

However, recent projections of the future cost of care of older people suggest that the pattern of care which has emerged following the Ädel reforms may be more sustainable over the longer term than was previously thought (Lagergren, 2002). A recalculation to take account of recent trends in improved health among older people results in a projection of a 20-25% increase in spending in real terms over 2000-30, significantly lower than older projections relying on a simple demographic multiplier. Current policies rest on this latest projection. The main issue for the future, rather than how to curb the growth in cost of services, is seen as that of maintaining – or increasing – the level of employment in the working-age group to secure the tax base for services and benefits.

Grappling with income and asset testing for long-term care: Australia, New Zealand and the United Kingdom

A major reform of long-term care was implemented in Australia in 1997. As the financing of institutional long-term care is primarily a federal (Commonwealth) government responsibility, the reform process was highly centralised, with the federal government consulting with community representatives and then implementing its proposals.

A major issue for the government was the high projected growth rate of the over-80 population, leading to concerns about sustainability of a pre-1997 system that was primarily government-funded with a limited user contribution. There was also concern that the separate scales of subsidy for nursing homes and for hostels (residential homes with some care provided) led to inequities in treatment. Hostels in many cases provided significant care, especially for older people suffering from dementia, but had a subsidy cap that did not recognise this. This could necessitate relocation to a different facility even though the hostel would in principle be willing to increase the level of care provided.

To address these concerns, the reform unified nursing homes and hostels under one assessment and subsidy system and introduced income-tested fees to reduce government subsidy. From 1997, all facilities were unified into one system that could offer the full continuum of care, subsidised through a single funding scale. This scale, the Resident Classification Scale, was designed to cover the full spectrum of care needs in any location, and to make more specific recognition of the costs of caring for those with dementia. The reforms also unified the preceding different systems for paying for care and accommodation in institutions. Under the reforms, users now had three possible components of cost to meet: a uniform basic contribution that was designed to be affordable to those receiving the public old-age pension, income-tested fees for care, and an asset-tested accommodation payment.[10] Federal subsidies meet costs not met by users under these rules.

The outcome of the reforms was subject to an evaluation two years later. The overall impact of the reforms was found to have enabled a greater focus on providing a continuum of care, especially in hostels, and on the needs of those with dementia (Gray, 2001). They also increased the average level of user payments through increased income and asset-testing, thereby generating finance to support the drive to raise standards in institutional care homes.

The UK Government was also concerned in the late 1990s about the longer-term sustainability of financing of long-term care. However, there was no official view that current government subsidy of institutional care was over-generous, unlike the Australian case, where institutional long-term care subsidies had been available to most of the population. On the contrary, there was considerable concern on the part of advocacy groups and the older public about the need for service users to spend down their savings to a social assistance means-test level before receiving any government subsidy with nursing and residential home costs. Charges for home care were set by most local governments according to different local formulas, leading to concerns about inequities. In 1997, the recently elected Labour government set up a Royal Commission to consider options and recommend a sustainable system of financing for the future.

The Commission argued in its report (1999) that long-term care is a risk that is best covered by some kind of risk-pooling. Having considered and rejected other options for risk-pooling – such as private long-term care insurance and a social insurance scheme – they recommended that nursing and personal-care costs, both for institutional and home-based services, should be covered by general taxation, in the same way as the National Health Service.

The UK Government responded to these recommendations as part of a wider programme of investment and reform in health services, the NHS Plan. It took a different view of priorities in health and social care for older people to that of the Commission. It accepted several proposals for ameliorating the means-testing mechanism and to correct the anomaly that nursing care in nursing homes was currently means-tested rather than provided free of charge, as in the health service. However, the government argued that to make all personal care free of charge would involve committing large sums without seeing any increase in services available to older people.[11] Reforms reducing the impact of means-testing for institutional care, without removing it altogether, were introduced in 2001/02. New guidance to local governments was issued to encourage a more consistent approach to charging for home care.

The New Zealand Government that was elected in 2000 was pledged to introduce a number of reforms to health and long-term care that were designed to make the system more effective and less costly to the users, the quality and cost of care having been a growing public issue through the 1990s. As noted in Chapter 2, separate streams of funding for health and long-term care were brought together under the management of District Health Boards (DHBs) that are funded by central government from taxation and which have assumed responsibility for all of these services (acute health in 2000 and long-term care in 2003).

Most institutional long-term care in New Zealand is provided in licensed private care homes, and around two-thirds of the residents are eligible for state subsidies through the Residential Care Subsidy scheme. However, some long-term care is still provided in public hospitals, which were in the past the major supplier. The more generous terms available to users of the shrinking number of public sector beds were a major driver of public criticism of means-testing.

Access to Residential Care Subsidies is income and asset-tested, these tests being administered on behalf of DHBs by the Ministry of Social Development. The subsidy formula is designed to keep private cost-sharing below a maximum payment per week. In order to qualify for the subsidy, the person must have assets below a certain level, leading some users to "spend down" their assets, including housing, before qualifying for help. The impact on housing assets was a major public concern.

To meet their election commitment, the New Zealand Government has announced that asset tests for institutional care will be phased out in stages from 2005, to leave a system of income tests that will on balance be more generous to the user than the current system. While making a commitment to higher public costs for long-term care in future years, it is noteworthy that New Zealand has taken other measures to reduce the public finance costs of ageing, most notably raising the age of receipt of state pension from 60 to 65.

Conclusions

When confronted with a rising demand for long-term care, some OECD countries have been prepared to raise additional taxes or social insurance contributions specifically to finance a new benefit for long-term care. This has been justified on two main grounds: *i)* it represents the most efficient way of insuring against this risk; and *ii)* it yields immediate benefits to the public in relieving them of high personal costs or the need to apply for social assistance when savings have been depleted.

It has helped that the governments who have implemented these benefits have been able to use good-quality information to predict with some accuracy the expected scope and cost of the new benefit, avoiding immediate financial problems. While this has solved the shorter-term problems by generating additional finance, these countries now have a significant new commitment to maintain in economic bad times as well as good. A lot may hinge on how far the health of the older population improves in the future, such that the size and needs of the target population are contained. It is far from certain that long-term financial sustainability of their systems is assured.

Countries with universal long-term care coverage consequently share the concern about the financial sustainability of their systems in the future as populations age. In social insurance countries, a number of options for further reform are currently being discussed, such as improving prevention and rehabilitation strategies and broadening the contribution base, *e.g.* by seeking substantial additional contributions from pensioners in particular.

Those countries trying to live within a tax envelope have faced difficult choices, such as reducing the scope of services while targeting services on the more sick and disabled people (Sweden). Other countries with tax-funded systems have unified their system of subsidies and care assessment across settings of care (Australia). Means-testing has been tightened in Sweden (where in the past benefits had been offered to most of the population) and increased for residential care subsidies in Australia, but has been relaxed in New Zealand and the United Kingdom.

Private long-term care insurance as primary cover has played a very limited role in most OECD countries (see Colombo and Tapay, 2004). However, private insurance might play in the future a stronger role in the market for voluntary complementary long-term care insurance to meet additional costs not covered by public programmes. This type of complementary insurance has become more affordable when the public system covers the first tranche of the cost.

Notes

1. This description fits the system for health care for older people (Medicare) in the United States, not the system for those below retirement age.
2. Mainly higher income groups and civil servants.
3. For a full account of the background to the reforms, see OECD (1996a), Chapter 18. See also Evans and Wiener (2000).
4. Japanese reply to OECD's questionnaire on long-term care.
5. For a full treatment of the Japanese system prior to the introduction of the new insurance system, see OECD (1996, Chap. 10). On the impact of the reforms on that system, see Matsuda (2002).
6. Although these were indirect in Austria, higher health insurance contributions to cover acute health care costs of the elderly were a vital part of the package, enabling the launch of a tax-funded scheme.
7. There are limits to how much contributions can be raised from employees and employers, especially in countries where they are already high and make up a big proportion of labour costs. If total labour costs are too high, this has implications for the level of employment, with resulting erosion of the contribution base. The same caveat applies to some forms of general taxation.
8. Average length of stay in hospital also fell, very dramatically in the case of stroke victims from 56 days in 1989 to 13 days in 1999.
9. Response to OECD's questionnaire on long-term care (see Table 2.3 in Chapter 2).
10. In Australia, the assets test excludes a significant part of the value of the family home, applying to long-term care the same rule as for pensions.
11. In Scotland, however, following devolution of responsibility for health and social care to the Scottish Parliament, the Commission's central proposal to provide personal care free of charge has been accepted and implemented.

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ANNEX A

Demographic Trends and Changes in Living Arrangements of Older Persons

Introduction

The rising number of very old people in OECD countries has caused policy concerns about the sustainability of future costs of care for this age group, and consideration of different policy options for providing and paying for long-term care. However, future demand for long-term care will not be driven only by growth in numbers in relevant age groups. A number of other factors will influence future demand for care services, and some of these are in principle able to be influenced by social and health policies in ways that may reduce future demand.

An important factor that will influence the demand for care services is the level of health and disability of future generations of elderly people. If the elderly in the future are more able to provide for themselves and in less need of services, demand for services will be less than demographic projections would suggest. Perhaps as important is the supply of informal care in the future. Currently, informal care provides over half of all long-term care in all OECD countries. Unless informal care can expand to keep up with the need for care of elderly people, there is likely to be a higher demand for care services.

The future level of informal care will itself be a response to a number of factors, which will include the living arrangements of elderly people, the longevity of elderly husbands and wives, and trends in the labour market participation of those groups in the labour force that currently shoulder the bulk of informal care, especially women aged over 45.

This annex sets out current trends in each of the areas sketched above in reviewing latest information about:

- Demography, including population projections of numbers of older people, trends in life expectancy and trends in dependency.
- Changes in living arrangements of older persons.
- Trends in informal care giving and in the working patterns of older workers who supply much of the informal care provided in a home-based setting.

Demographic trends

Decisions today on how to organise provision and financing of long-term care for older persons have to be taken against the background of population ageing in OECD countries. Current population projections assume that, firstly, gains in life expectancy observed in the

past will continue in the future, secondly that patterns of declining fertility will not revert rapidly, and thirdly, that future international migration will only have a limited contribution to changing current population trends.

Under these assumptions, the numbers and shares in the population of older persons will increase rapidly over the next 20 years, when the post-war baby-boom generation will reach the age of retirement in many OECD countries. By the year 2040 one person in four may be 65 years or older for OECD countries on average. For Italy, Switzerland and Japan, this number could come close to one in three if current demographic trends prevail. As the populations of OECD countries age, the oldest cohort of the population grows the fastest. The increase in the number of those aged 80 and above contributed over the past 40 years around a third to the total increase of the share of older persons. It is this group of the population which has the most pronounced care needs. Table A.1 brings together population projections which suggest that the share of the oldest-old in the population will double over the next 30 to 40 years.

In 1960, only one out of seven older persons (65 and over) belonged to the oldest age group (80 and over) across OECD countries on average. Today, this is the case for more than one in five, and this share is expected to increase to around one third in some OECD countries by the year 2040 (Table A.2). The demand for long-term care is therefore likely to grow in all OECD countries in future decades. This is a major concern for policy-makers in OECD countries. It implies that any decisions made about extending the supply of services or improving the financial terms to users could lead to significant additional costs in future decades.

However, there are large differences across countries. Several countries (*e.g.*, Sweden and Norway) already have numbers of oldest-old persons among the elderly that come close to the estimated average across all countries by the year 2040. Several countries that today have relatively "young" populations (such as Mexico, Turkey and Korea) are likely to experience the fastest ageing among OECD countries in the decades to come.

Demographic projections of ageing populations crucially depend on the reliability of forecasts of future trends in life expectancy, in particular of the remaining life expectancy at higher ages, as most of the additional years added to life in the past few decades of the 20th century were at higher ages (Cutler and Maera, 2001). Increases in life expectancy at higher age groups are a major driver behind growing dependency ratios in the population, and long-term gains in life expectancy in the past (Table A.3) have been consistently underestimated by demographers and actuaries (Wilmoth, 1998). Demographers are divided in their opinions as to the extent to which life expectancy will be further prolonged in the future (Tuljapurkar *et al.*, 2000). The factors driving mortality decline, in particular at higher ages, are currently poorly understood. Consequently, there is an ongoing scientific debate about whether past trends will prevail and can be extrapolated into the future.

From a fiscal policy perspective, and for the question of financial sustainability of long-term care services, trends in demographic dependency ratios are crucial. The ratio of older persons to the number of those in working age is projected to roughly double over the next 40 years under the assumption of current demographic trends (Table A.4). This raises difficult questions about the future financial sustainability of a range of publicly funded old-age benefits: pensions, health care and long-term care benefits.

The fiscal outcome of this major demographic change will crucially depend on how many persons of working age will be in gainful employment. Perhaps most importantly, this calls for a reversal of past trends towards earlier retirement. In addition, there will be

Table A.1. **Share of older persons in the population, 1960 to 2040**

	65 and over					80 and over				
	1960	2000	2040	Change in % points		1960	2000	2040	Change in % points	
				1960-2000	2000-2040				1960-2000	2000-2040
Australia	8.5	12.4	22.5	3.9	10.1	1.2	2.9	7.3	1.7	4.4
Austria	12.2	15.5	29.6	3.3	14.1	1.8	3.5	8.2	1.7	4.7
Belgium	12	16.8	27.4	4.8	10.6	1.8	3.6	8.6	1.8	5.0
Canada	7.5	12.5	24.6	5	12.1	1.2	3.0	8.1	1.8	5.1
Czech Republic	8.7	13.8	28.8	5.1	15.0	1.2	2.4	8.5	1.2	6.1
Denmark	10.6	14.8	24.1	4.2	9.3	1.6	4.0	6.9	2.4	2.9
Finland	7.3	14.9	26.2	7.6	11.3	0.9	3.4	9.0	2.5	5.6
France	11.6	16.1	26.6	4.5	10.5	2.0	3.7	9.1	1.7	5.4
Germany	–	16.4	29.7	–	13.3	–	3.7	8.7	–	5.0
Greece	8.1	17.3	28.2	9.2	10.9	1.3	3.5	7.9	2.2	4.4
Hungary	9.0	15.1	25.7	6.1	10.6	1.1	2.6	7.1	1.5	4.5
Iceland	8.0	11.7	22.6	3.7	10.9	1.1	2.8	7.1	1.7	4.3
Ireland	11.1	11.2	20.5	0.1	9.3	1.9	2.6	5.5	0.7	2.9
Italy	9.3	18.1	33.7	8.8	15.6	1.4	4.0	10.0	2.6	6.0
Japan	5.7	17.4	35.3	11.7	17.9	0.7	3.8	14.1	3.1	10.3
Korea	2.9	7.2	27.8	4.3	20.6	0.2	1.0	7.1	0.8	6.1
Luxembourg	10.8	14.2	24.0	3.4	9.8	1.6	3.0	7.4	1.4	4.4
Mexico	4.2	4.6	15.4	0.4	10.8	0.5	0.6	3.7	0.1	3.1
Netherlands	9.0	13.6	25.5	4.6	11.9	1.4	3.2	7.6	1.8	4.4
New Zealand	8.6	11.7	22.8	3.1	11.1	1.5	2.8	7.0	1.3	4.2
Norway	11.0	15.2	26.3	4.2	11.1	2.0	4.3	8.6	2.3	4.3
Poland	6.0	12.2	24.1	6.2	11.9	0.7	2.0	7.5	1.3	5.5
Portugal	7.9	16.3	24.0	8.4	7.7	1.1	3.4	6.2	2.3	2.8
Slovak Republic	6.9	11.4	23.2	4.5	11.8	1.0	1.9	6.3	0.9	4.4
Spain	8.2	16.9	30.7	8.7	13.8	1.1	3.8	8.5	2.7	4.7
Sweden	11.7	17.3	25.2	5.6	7.9	1.9	5.0	7.9	3.1	2.9
Switzerland	10.2	15.3	33.1	5.1	17.8	1.5	4.0	11.1	2.5	7.1
Turkey	3.5	5.7	14.3	2.2	8.6	0.3	0.6	2.6	0.3	2.0
United Kingdom	11.7	15.9	25.4	4.2	9.5	1.9	4.0	7.3	2.1	3.3
United States	9.2	12.4	20.4	3.2	8.0	1.4	3.3	6.9	1.9	3.6
OECD average	8.7	13.8	25.6	5.0	11.8	1.3	3.1	7.7	1.8	4.6

Note: Germany 1960 (before reunification) not comparable with 2000 data.

Source: *OECD Health Data 2004* for 1960 and 2000; 2040 projections: Eurostat (15 EU countries); national sources (Canada and the United States); United Nations (2002).

fewer adult children to care for the baby-boom cohorts when they begin to require long-term care in 20 to 30 years time.

One broad indicator that is used to show the trend in potential for societies to provide care for older people is the "old-age dependency ratio". This is normally expressed as the number of people aged 20-64 as a proportion of those aged 65 and over. Expressed in this way, the ageing of OECD societies means that the ratio will become significantly worse in future decades, *e.g.*, shrinking to about half the 1960 level by 2030 in the United States.

However, while this may be the appropriate indicator to consider the trend in social protection schemes that are financed by the working population and received by older people, such as pensions and health care in many countries, it is not obvious that this is the best way to look at the potential for care. Knickman and Snell (2002) show that

Table A.2. **Share of very old persons (80+) among the elderly, 1960 to 2040**

	1960	2000	2040	Change in % points	
				1960-2000	2000-2040
Australia	14.3	23.6	31.8	9.3	8.2
Austria	14.4	22.8	28.1	8.4	5.2
Belgium	15.4	21.3	31.9	5.8	10.6
Canada	15.8	23.6	32.9	7.8	9.3
Czech Republic	14.0	17.1	30.4	3.1	13.3
Denmark	15.3	26.7	28.9	11.4	2.2
Finland	12.7	22.5	35.1	9.8	12.6
France	17.2	23.3	34.6	6.1	11.3
Germany	–	22.3	29.9	–	7.6
Greece	16.0	20.5	30.1	4.6	9.6
Hungary	12.3	17.5	28.7	5.2	11.3
Iceland	14.3	24.2	31.6	10.0	7.3
Ireland	17.5	23.0	26.7	5.5	3.7
Italy	14.6	22.2	30.6	7.6	8.4
Japan	12.6	22.0	41.1	9.5	19.1
Korea	8.1	14.2	26.1	6.1	11.9
Luxembourg	14.7	21.0	26.9	6.3	5.9
Mexico	12.0	14.0	23.5	2.0	9.6
Netherlands	15.2	23.5	30.0	8.3	6.5
New Zealand	17.1	23.8	30.5	6.8	6.7
Norway	18.0	28.3	32.7	10.4	4.4
Poland	12.2	16.2	31.9	4.0	15.7
Portugal	14.4	20.6	25.8	6.2	5.2
Spain	14.5	16.5	28.3	2.0	11.8
Slovak Rep.	14.0	22.3	27.6	8.3	5.3
Sweden	15.9	29.0	31.5	13.1	2.5
Switzerland	15.0	26.0	34.9	11.0	8.9
Turkey	8.5	11.3	18.2	2.8	7.0
United Kingdom	16.4	25.4	29.1	9.0	3.7
United States	15.2	26.4	33.3	11.2	6.9
OECD average	14.4	21.7	30.1	7.3	8.4

Note: Germany 1960 (before reunification) not comparable with 2000 data.

Source: OECD Health Data 2004 for 1960 and 2000; 2040 projections: Eurostat (15 EU countries); National sources (Canada and the United States); United Nations (2002).

reconceptualising the dependency ratio has a marked effect on the potential for care in the United States in future decades. They argue that reductions in the number of children with care needs will offset some of the increase in older people needing care. Moreover, relatively few people in the 65-74 age group require long-term care and an increasing share of persons in that age group contribute to providing care and supervision to both young people and the very old. This improves the ratio of potential carers to those needing care.

Disability in older age

The share of older persons with functional limitations increases exponentially with age and is highly concentrated in the oldest age groups. Since they have longer life expectancy, women are more likely to be in need of long-term care than men (Figure A.1). There is some evidence that care needs are becoming increasingly concentrated in the

Table A.3. **Life expectancy at age 65 and 80, 1960 to 2000**

	Life expectancy at age 65				Life expectancy at age 80			
	Male		Female		Male		Female	
	1960	2000	1960	2000	1960	2000	1960	2000
Australia	12.5	16.9	15.6	20.4	5.6	7.6	6.6	9.4
Austria	12.0	16.0	14.7	19.4	5.1	7.0	5.9	8.3
Belgium	12.4	15.5	14.8	19.5	5.3	6.7	6.1	8.4
Canada	13.6	16.9	16.1	20.5	6.2	7.8	7.0	9.7
Czech Republic	12.5	13.7	14.5	17.1	5.6	6.1	5.7	7.1
Denmark	13.7	15.2	15.3	18.3	n.a.	6.8	n.a.	8.8
Finland	11.5	15.5	13.7	19.3	5.0	6.6	5.5	8.1
France	12.5	16.7	15.6	21.2	5.1	7.6	6.3	9.5
Germany	12.4	15.7	14.6	19.4	5.2	7.0	5.9	8.5
Greece	13.4	16.3	14.6	18.7	5.7	7.1	6.3	7.5
Hungary	12.3	12.7	13.8	16.4	5.0	6.0	5.5	7.0
Iceland	n.a.	18.1	n.a.	19.6	6.2	8.4	7.1	8.8
Ireland	12.6	14.6	14.4	17.8	n.a.	6.1	n.a.	7.6
Italy	13.4	16.5	15.3	20.4	5.7	7.3	6.4	9.0
Japan	11.6	17.5	14.1	22.4	4.9	8.0	5.9	10.6
Korea	n.a.	14.1	n.a.	18.0	n.a.	6.2	n.a.	7.7
Luxembourg	12.5	15.5	14.5	19.7	5.0	6.5	5.4	8.7
Mexico	14.2	16.8	14.6	18.3	7.1	8.7	7.1	9.1
Netherlands	13.9	15.3	15.3	19.2	5.7	6.4	6.2	8.3
New Zealand	13.0	16.5	15.6	19.8	5.5	7.4	6.4	9.2
Norway	14.5	16.0	16.0	19.7	6.2	6.7	6.7	8.6
Poland	12.7	13.6	14.9	17.3	5.6	6.5	6.2	7.4
Portugal	13.0	15.3	15.3	18.7	n.a.	6.4	n.a.	7.7
Slovak Republic	13.2	12.9	14.6	16.5	n.a.	6.1	n.a.	6.9
Spain	13.1	16.5	15.3	20.4	5.7	7.3	6.5	8.8
Sweden	n.a.	16.7	n.a.	20.0	5.7	7.1	6.2	8.8
Switzerland	n.a.	16.9	n.a.	20.7	5.5	7.4	6.1	9.1
Turkey	11.2	12.6	12.1	14.2	4.7	5.3	5.0	5.8
United Kingdom	11.9	15.7	15.1	18.9	5.2	6.9	6.3	8.6
United States	12.8	16.3	15.8	19.2	6.0	7.6	6.8	9.1

n.a.: not available.

Note: Canada, Italy: 1960 refers to 1961; Greece, Korea: 2000 refers to 1999; United Kingdom: 1960 refers to 1961 for life expectancy at age 80.

Source: OECD Health Data 2004.

oldest age groups, but comparisons across time are fraught with problems. Surveys of the prevalence of disability among older persons are often available for only few points in time and their comparability may be limited. Where take-up rates of services, such as numbers of recipients of long-term care in various settings, are derived from administrative data of public programmes, changes over time partially reflect the way care assessment may have changed.

Until the late 1980s, there was little longitudinal data that would enable direct measurement of the trend in the level of disability among the elderly over time. There was ample data indicating a general improvement in the health and well-being of the population in OECD countries, leading to greater average lifespan. However, there was debate about the potential impact of increases in lifespan in old age, beginning to be seen as a significant trend in OECD countries around 1980.

Table A.4. **Old age-dependency ratio, 1960 to 2040**

Ratio of persons 65+ to the population 20-64

	1960	2000	2040	Change in % points	
				1960-2000	2000-2040
Australia	15.8	20.7	43.8	4.9	23.0
Austria	21.1	25.1	59.0	4.0	33.9
Belgium	20.4	28.2	51.2	7.7	23.0
Canada	14.7	20.3	43.6	5.6	23.2
Czech Republic	15.2	21.9	47.8	6.8	25.9
Denmark	19.0	24.1	44.4	5.2	20.3
Finland	13.4	24.6	49.8	11.2	25.1
France	20.8	27.5	50.0	6.7	22.5
Germany	–	26.4	54.5	–	28.1
Greece	14.0	28.3	57.9	14.3	29.6
Hungary	15.5	24.5	38.4	8.9	13.9
Iceland	16.1	20.4	41.0	4.3	20.6
Ireland	22.4	19.2	37.7	–3.2	18.5
Italy	15.9	29.1	63.9	13.2	34.8
Japan	10.6	27.9	59.9	17.4	31.9
Korea	6.4	11.4	43.5	4.9	32.1
Luxembourg	17.6	23.0	36.9	5.4	13.9
Mexico	11.3	9.0	26.0	–2.4	17.1
Netherlands	16.9	21.9	48.1	5.0	26.1
New Zealand	17.0	20.1	48.2	3.1	28.1
Norway	19.8	25.7	42.9	6.0	17.2
Poland	11.1	20.3	41.1	9.2	20.8
Portugal	14.5	26.7	46.3	12.2	19.6
Slovak Republic	12.8	18.8	39.4	6.0	20.6
Spain	14.5	27.2	55.7	12.7	28.5
Sweden	20.2	29.5	46.7	9.3	17.2
Switzerland	17.6	24.9	63.9	7.3	39.0
Turkey	7.5	10.7	23.9	3.1	13.2
United Kingdom	20.1	26.9	46.3	6.8	19.4
United States	17.6	21.1	37.9	3.4	16.8
OECD average	15.9	22.9	46.3	6.9	23.5

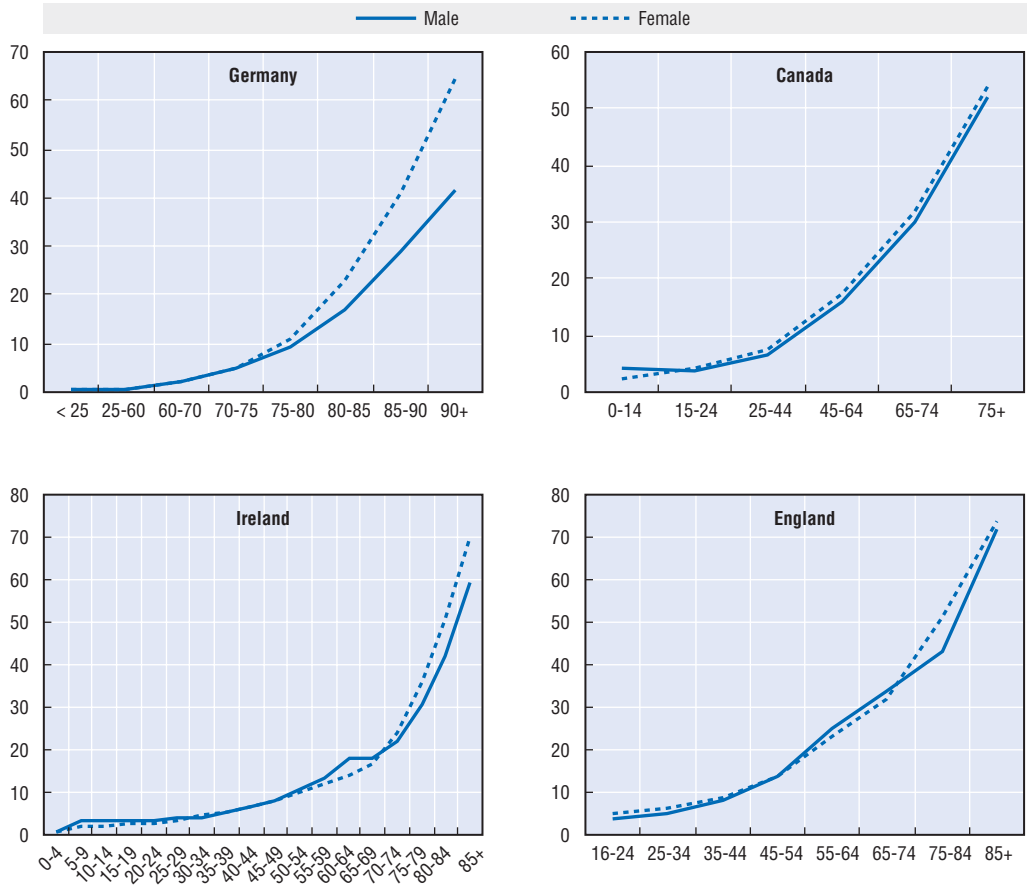
Note: Germany 1960 (before reunification) not comparable with 2000 data.

Source: *OECD Health Data 2004* (for 1960 and 2000); 2040 projections: national data for Norway, Canada and the United States, United Nations (2002) for Greece, Iceland, Luxembourg, Mexico, Slovak Republic, Switzerland, Turkey.

Additional years of life in very old age could in principle lead to any of three outcomes:

- Elderly people may continue to become sick and disabled at the same ages as previously, leading to additional years of disability at the end of life: extended lifespan is associated with extended morbidity.
- The extension of lifespan has an upper limit. As poor health and disability tend to appear at later ages on average, this would lead to a "compression of morbidity". First propounded by Fries (1980), this thesis has been the subject of lively debate ever since.
- The third possibility is that both average lifespan and age of onset of poor health or disability would continue to extend, leading to deferral of disability. Whether the average length of years of disability would grow, decline or stay the same would depend on the relative rate of extension of both. This led to a further change in the way disability in old

Figure A.1. **Prevalence of disability by age and gender**



Note: Definitions of disability differ across countries; disability is defined as any of a number of functional restrictions from a range of activities (broad definition of disability).

Source: Germany: Micro census, 1999; Canada: Statistics Canada, Participation and Activity Limitations Survey, 2001; Ireland: Central Statistical Office, Population and Vital Statistics, 2002; England: Health Survey of England, 2001.

age was perceived: perhaps it was best seen as "end-of-life" disability, rather than inevitably associated with passing a particular age, in which case its onset might be deferred at the same rate as the rate of extension of lifespan.

The emerging trends in international data up to the mid-1990s are described in Waidmann and Manton (1998), Jacobzone *et al.* (1999) and Lagergren and Batljan (2000). These reviews suggest that the third of these possible scenarios best coincides with the observable trends in the data. With some exceptions, there was little support for the "extended morbidity" thesis. Finally, there was evidence from a review of a number of countries – Canada, France, Japan, the Netherlands, Sweden, the United Kingdom and the United States – of a reduction in prevalence of disability rates in old age.

This reduction was found mainly among the age groups 65 to 80 years, and was more striking for males than for females (males having poorer health at similar ages and shorter lifespan in old age to begin with). This decline was partly offset by an increase in disability

in the institutionalised population. However, trends were far from homogenous across countries, and reductions in disability among older women were seen in some countries.

More recent data have continued to indicate a trend to lower levels of disability in old age. In particular, the US National Long-Term Care Survey (NLTCS) has added a 1999 wave to previous waves in 1982, 1989 and 1994. As reported by Manton and Gu (2001), the trend towards lower prevalence of disability in the United States is not only continuing but is growing. The average drop in disability prevalence has been higher between each wave of the NLTCS and was over 0.56% per year during 1994-99. In addition, it could now be concluded that the older black population, which had not shown any declines in disability in the earliest waves of the NLTCS, was now benefiting from this trend as well. To counter a response that this may be a single exceptional result for one generation, Manton and Gu point to historical work by Fogel and Costa (1997) using records of medical assessments of US army veterans from 1912 to the 1990s, showing a long-term trend of a similar magnitude.

Some, *e.g.*, Cutler (2001), have seen this as "clear, overwhelming evidence that the average health of the elderly population is improving". Others, however, such as Freedman *et al.* (2002), have urged caution, as comparison of different sources shows little if any agreement as to which ADL or IADL functions have shown improvements, and there remains little if any sign of a decline in the underlying conditions. In addition, to the extent that measured reductions are in IADL functions, measured improvement could be environmental, arising from improved housing conditions and use of assistive technology, as much as improvement in bodily function. Nonetheless, even if such environmental improvements do explain part of the trends, they do mean that the need for care services has declined.

Recent evidence from other countries mostly supports the overall conclusions from Jacobzone *et al.* (1999) and Manton and Gu (2001) and provides support for the "deferral" thesis. Most of the available evidence from Canada, France and Sweden suggests that prevalence of disability among elderly people has declined over time. In some other countries, *e.g.*, Finland, Italy, the Netherlands, Switzerland and the United Kingdom, the data does not yet lend itself to consensus as to whether disability has declined, but there is no evidence of an increase. In one of these countries, the United Kingdom, Jarvis and Tinker (1999) have re-analysed the main longitudinal data set and concluded that the health status of older people in the United Kingdom is improving, but lagging behind the improvements seen in the United States by several years.

The overview in Table A.5 brings together results from national information systems and studies on disability-free life expectancy. Disability-free life expectancy is measured as the number of years without major functional limitations with activities of daily living. Available evidence seems to support the hypotheses of a growing number of years of disability-free life expectancy for several countries covered in this publication (Table A.5), as this indicator moves roughly in parallel with growing life expectancy. This is an important finding for long-term care policy and planning. Future projections of care needs depend very much upon which scenario for disability trends is taken as starting point for projections: the scenario of constant dependency ratios per age group (which would result in a growing number and share of years lived with dependencies) or a scenario of growing disability-free life expectancy.

However, the trend is not clear for many countries. And in one country, Australia, there has been a measured increase is disability rates among the elderly, although at least half of this is attributed to changes in the measurement instrument (AIHW, 2003). Also, because

Table A.5. **Disability-free life expectancy at age 65, selected countries**

	Year	Male			Female		
		DFLE	LE	DFLE/LE in %	DFLE	LE	DFLE/LE in %
Australia	1981	7.9	13.9	57	10	18.1	55
	1988	6.7	14.8	45	8.6	18.7	46
	1993	6.5	15.7	41	9.1	19.5	47
	1998	6.6	16.3	40	9	20	45
Canada	1986	10.6	15	71	11.7	19.3	61
	1991	11	15.8	70	12.1	19.9	61
	1996	10.9	16.1	68	12.4	20	62
Germany[1]	1986	10.6	13.5	79	13	17	76
	1989	11.2	14	80	13.6	17.6	77
	1992	12	14.5	83	14.6	18.1	81
	1995	12.2	14.7	83	14.9	18.5	81
Japan	1975	12.3	13.7	90	14.7	16.6	89
	1980	13.2	14.6	90	15.8	17.7	89
	1985	14.1	15.5	91	17.1	18.9	90
	1990	14.9	16.2	92	17.3	20	87
Korea	1998	8.5	13.9	61	8.4	17.7	47
Netherlands	1990	10.1	14.4	70	9.5	18.9	50
	1992	9.8	14.7	67	9.6	19.1	50
	1994	10.4	14.8	70	9.4	19	49
	1996	11.1	14.8	75	9.7	19	51
	1998	11.9	15.1	79	12.3	19.2	64
	2000	12.1	15.3	79	12.8	19.2	67
New Zealand	1996	7.5	15.5	48	9.2	19	48
Spain	1999	11.4	16.1	71	12.4	20.1	62
Switzerland	1981	11.5	14.6	79	12.2	18.3	67
	1988	12.2	15.3	80	14.8	19.4	76
	1992	12.4	15.7	79	15.1	19.9	76
United Kingdom	1981	7.6	13	58	8.5	16.9	50
	1985	7.5	13.3	56	8.8	17.3	51
	1990	8	14	57	9.2	17.9	51
	1995	8.3	14.6	57	9.5	18.2	52
	1999	8.8	15.3	58	9.8	18.5	53
United States	1970	6.6	13.1	50	9.1	17	54
	1980	6.8	14.1	48	9.3	18.3	51
	1990	7.4	15.1	49	9.8	18.9	52

Note: LE: Life expectancy; DFLE: Disability-free life expectancy.
Disability-free life expectancy is defined as the average number of years an individual is expected to live free of disability if current patterns of mortality and disability continue to apply. Disability definitions and measurements are only partly harmonised across countries.
1. Western Germany only.

Source: OECD Health Data 2004.

national disability scales used for this indicator and estimation methods can vary substantially across countries, the numbers in Table A.5 should mainly be analysed with respect of trends over time, but are less suitable for inter-country comparisons.

Work to explain changes over time and across countries is still a relatively recent activity. Potential factors that might influence disability rates among older persons are therefore currently not well understood. Available evidence shows that there is a strong socio-economic gradient of disability in older age (Kjøller and Rasmussen, 2002). Improvements in education, health-related behaviour, general improvement in socioeconomic status, and improvements in the treatment of chronic disease have been associated as factors driving disability rates in older age (Cutler, 2001).

The role of informal care giving and trends in labour market participation

In each of the nineteen countries studied, informal care-giving is an indispensable component of care for older persons with long-term care needs. Surveys on the living situation of older persons and available time-use studies consistently show that the majority of care is provided informally, usually in a range of 80% plus of hours of care provided (see, *e.g.*, Lamura; 2003; Sundström *et al.*, 2002; and Zukewich, 2003). However, most of this time is spent on lower-level care, such as help with instrumental activities of daily living (Romoren, 2003). But informal carers also provide for many older persons with the highest care needs, such as dementia patients, for whom informal care is often the most important source of support (Moïse *et al.*, 2004).

The bulk of informal care is provided by women, although with marked differences across countries (Table A.6). Men are more likely to take over the role of care-giver for their spouses than in other family roles. Because more elderly people are living as couples and for a longer time, this has led to some increase in the participation of men in informal care giving over time (Sundström *et al.*, 2002). There are, however, gender differences in the care levels provided, which are not shown in Table A.6. Women are predominant among informal care givers with the heaviest commitments. They are more likely to be the main carer rather than an additional carer. The more demanding personal care services become, the more likely it is that women provide them. The share of domestic help rather than personal care is correspondingly higher for male carers.

Across countries, there seems to be a peak in care giving by those aged 45-65 (Table A.7). This is the age group which frequently has multiple care responsibilities for elderly parents or for a spouse or partner with age-related health problems. In addition, fiscal and labour market policies for ageing populations have been targeting this age group to encourage higher labour market participation, such as by reversing trends towards early retirement. It will be important to ensure that caring responsibilities can be combined with employment in this age group.

Although concerns have been expressed about declining care potential from children, in at least one of the countries in this study, the United Kingdom, research has shown that the proportion of older people with at least one surviving child will be at a historic high level for the cohort reaching late old age over the next two decades (Comas-Herrera and Wittenberg, 2003). This suggests that, other factors remaining equal, the supply of informal care by children relative to demand is likely at least to be sustained over the coming two decades. The prospect for later in the century is less optimistic (Figure A.2).

Living arrangements of older persons

Older persons with care needs who live together with their family or partner are more likely to receive informal help than those living alone (*e.g.*, Sundström, 1994). Given in

Table A.6. **Relationship between care recipient and informal care giver**

Country (source)	Year	Relationship	Total	Male	Female
Australia (ABS Survey of disability, ageing and carers, 1998)	1998	Partner	43	19	24
		Parent	22	3	19
		Child	24	6	19
		Other	11	2	9
		Total	100	30	71
Austria (Microcensus 2002)	2002	Partner	18	7	11
		Child	38	14	24
		Other	43	12	32
		Total	100	34	66
Canada (Survey on informal caregivers to adults in British Columbia)	1995	Partner	20	7	13
		Child	35	9	26
		Others	45	11	34
		Total	100	27	73
Germany (Schneekloth and Müller, 2000)	1998	Partner	32	12	20
		Parent	13	2	11
		Child	28	5	23
		Other	27	1	26
		Total	100	20	80
Ireland (Survey of older persons, 1993)	1993	Partner	22	5	17
		Parent			
		Child	48	13	35
		Other			
		Total			
Japan (Comprehensive survey of living conditions, 2001)	2001	Partner	36	12	25
		Parent	1	0	1
		Child	60	11	48
		Other	3	1	3
		Total	100	24	76
Korea (Survey on long-term care needs of the elderly, 2001)	2001	Partner	32		
		Child	55	7	49
		Other	13		
		Total	100		
Spain (Survey on impairment, disabilities, and handicaps)	1999	Partner	23		
		Child	38	6	32
		Other	39		
		Total	100		
Sweden (Survey of aged care, 2000)	2000	Child	46	13	33
		Other	53		
		Total	100		
United Kingdom (General household survey, 2000)	2000	Partner	15		
		Parent	7		
		Child	43		
		Other	35		
		Total[1]	100		
United States (National long-term care survey, 1994)	1994	Partner	23	10	13
		Child	41	15	27
		Other[2]	35	11	24
		Total	100	36	64

Note: Definition of carers and care recipients may differ between countries. The number of informal carers is usually higher than the number or carers receiving support under public long-term care programmes (*e.g.* as cash allowances).

1. National data on the shares of care-recipients in the different categories, which include persons receiving care from more than one care-giver, have been recalculated to add up to 100.
2. Missing values are included in the category "Other".

Table A.7. **Age distribution of care givers**

Percentage

	Year	44 and less	45-64	65 and over
Australia	1998	47	36	17
Austria	2002	27	48	25
Canada[1]	1995	35	42	23
Germany[2]	1998	15	53	33
Ireland	2002	46	43	11
Japan[3]	2001	4	42	54
Korea	2001	30	39	31
United Kingdom[4]	2000	35	45	20
United States[5]	1994	12	37	51

1. British Columbia only.
2. Germany: main caregivers only, age groups refer to –39, 40-64, 65+.
3. Japan: age groups refer to –30, 40-59, 60+.
4. United Kingdom: age groups refer to 16-44, 45-64, 65+.
5. Primary active caregivers only.

Source: See Table A.6.

particular the importance of partners in providing care, the growth in the number of older people living alone will itself increase the demand for formal care services in the future. Living alone has become a much more frequent experience for elderly people in the OECD area. During the decade 1990-2000, the proportion of elderly people living alone grew in most OECD countries, other than New Zealand, the United Kingdom and the United States. Northern European countries, including the Netherlands, Norway and Sweden, which started with a high proportion of one-person elderly households showed the highest rates of living alone in 2000. Mexico, Japan, Korea and Spain had the lowest rates (Figure A.3).

Living alone becomes more frequent as people age, mainly due to the death of one spouse. For example, around half of all persons aged 75 and over live alone in Canada, around 42% in New Zealand and Sweden, and 44% in the United Kingdom. Women aged 75 and above are at the highest risk of living alone. It is estimated that almost 60% of elderly women aged 75 and over in Canada, Sweden and the United Kingdom live alone.

Several studies forecast a change in the trend towards living alone. A modelling exercise for the United Kingdom, for example, suggested that, between 1996 and 2031, the numbers of dependent elderly people living with others will increase faster than the numbers living alone, largely due to higher marriage rates and male longevity. In turn, the proportion of dependent elderly people living alone is projected to fall slightly, from 43% in 1996 to 38% in 2031 (Pickard *et al.*, 2000). Wolf (1995) projected that the percentage of older women living alone in eight countries would decrease sharply around by 2010 and then would climb again.

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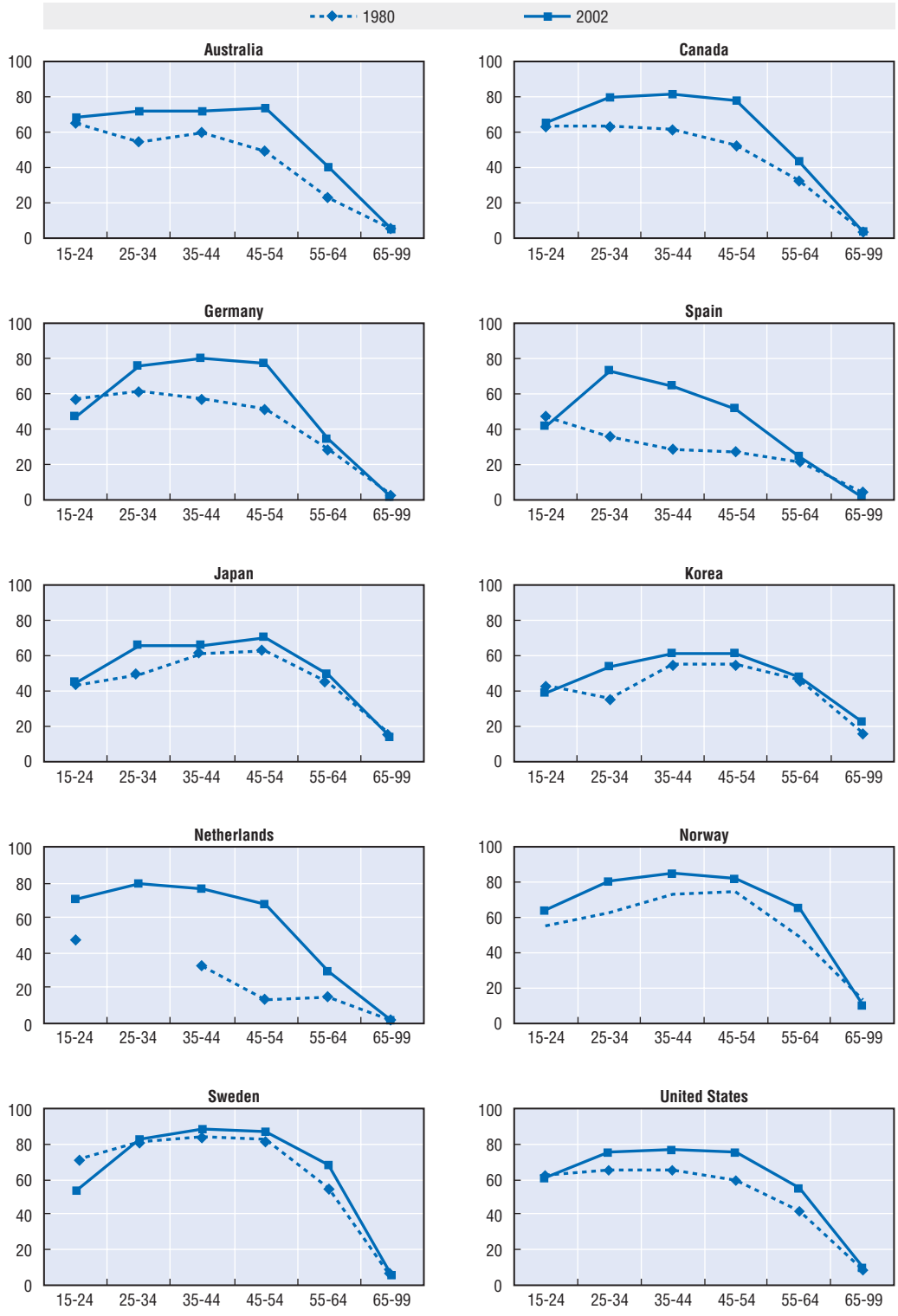
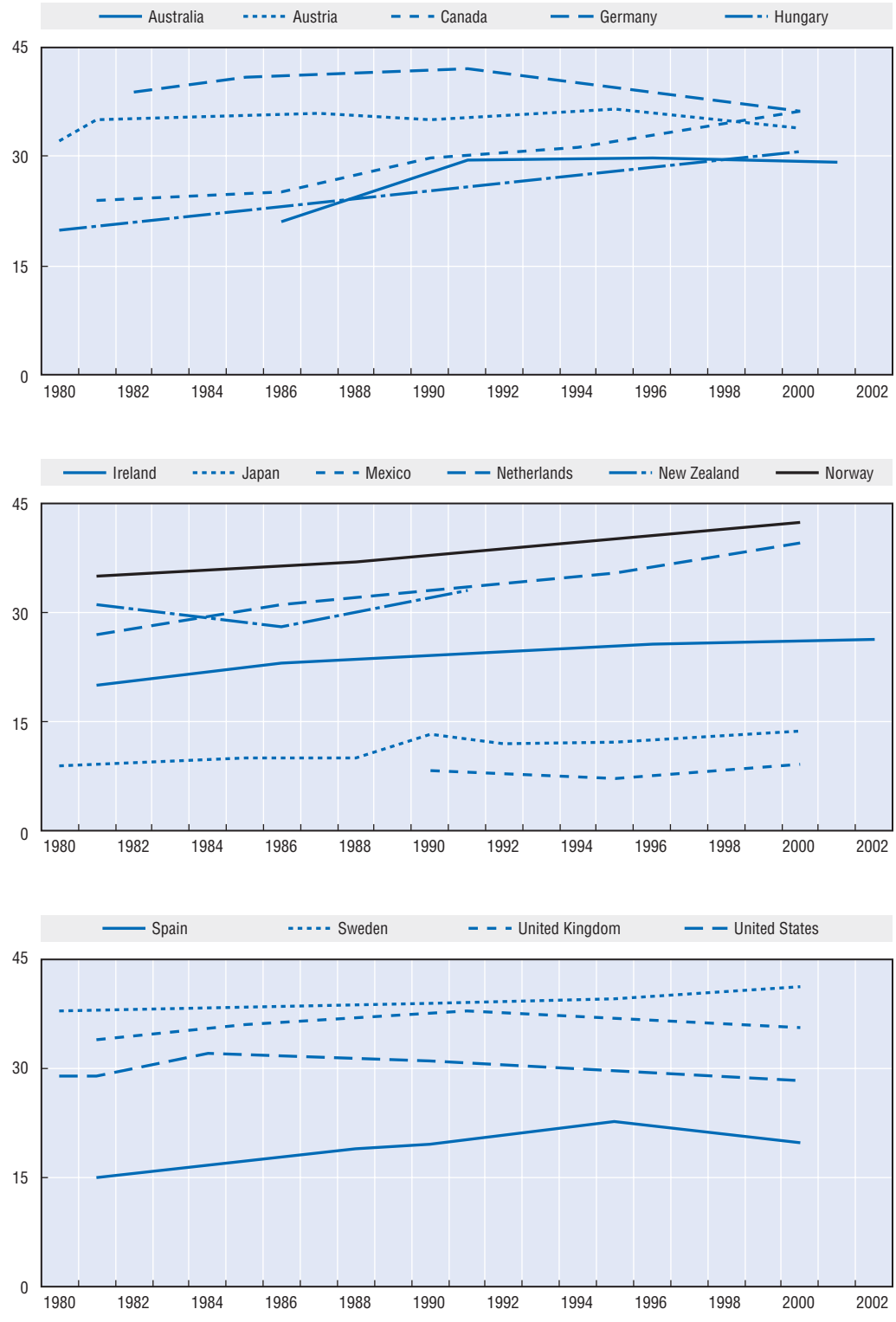
Figure A.2. **Female labour force participation by age groups, 1980 and 2002**
Percentage



Source: OECD Labour Force Statistics.

Figure A.3. **Trends of older persons living alone, 1990 to 2000**

Percentage



Source: National Population Census.

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ANNEX B

Profiles of Long-Term Care Systems in 19 Countries[1]

Australia

Australia has a federal structure in which the Australian (central) Government deals with national concerns such as foreign policy, social security and major forms of taxation, and State/Territory governments cover areas such as education, public housing and hospitals. The provision of long-term care ("aged care") involves both tiers of government, with care being provided by a range of public and private (profit and non-profit) providers.

Client assessment and eligibility

The Australian Government provides funding for *Aged Care Assessment Teams* (ACATs) who provide expert assessment and advice regarding the long-term care needs of older people and assess eligibility for appropriate services. ACATs assess the person's medical, physical, social and psychological needs. ACATs also provide information and advice about care choices. Clients need to be assessed as eligible by an ACAT before they can receive an Australian Government subsidy for institutional long-term care and some forms of home and community care.

Institutional long-term care

Institutional long-term care is provided to those people who are no longer able to maintain themselves or be maintained by others in their own homes. There are two main types of institutional care for older people, high-level care and low-level care. High-level care usually involves 24 hour care. Nursing care is combined with accommodation, support services (cleaning, laundry, meals), personal care services (help with dressing, eating, toileting, bathing and moving around) and allied health services (physiotherapy, occupational therapy and podiatry). Low-level care focuses on personal care services, but also provides accommodation, support services and some allied health services.

Through a needs-based planning framework, the Australian Government seeks to achieve and maintain a national provision level of institutional places and *Community Aged Care Packages* (CACPs). By June 2007 the provision ratio will be 108 places per 1 000 of the population aged 70 years and over. As of June 2003, 5.3% of people aged 65 and over were permanent residents.

While the Australian Government is responsible for providing the majority of the funding for institutional care, residents make a financial contribution, with the Australian Government regulating the maximum charges, with the aim of ensuring that care is affordable for all who need it. Daily care fees contribute to daily-living costs and include a

basic daily care fee for all residents, based on the pension, plus an additional income-tested amount for residents who have private income over a certain amount. Residents may also be asked to pay an accommodation payment as a contribution to the cost of their accommodation. These payments can only be charged under certain conditions, with protection for residents who cannot afford these payments.

The Australian Government has instituted a quality framework based on accreditation and certification programmes. The accreditation programme covers matters ranging from health and personal care through to the physical environment and safety, and then how that care is delivered. Care homes for older people must be accredited in order to receive Australian Government funding.

Home and community care

Whenever possible, people are assisted to stay in their own homes through three main programmes: the *Home and Community Care Programme*, *Community Aged Care Packages*, and *Extended Aged Care at Home Packages*. The *Home and Community Care* (HACC) Programme is a joint Australian Government and State/Territory government funded programme for frail older people, people with disabilities and their carers. State/Territory governments are responsible for the day-to-day management of the programme. HACC services include community nursing, domestic assistance, personal care, meals, home modification and maintenance, transport, and community-based respite care. An ACAT assessment is not required for a person to access the HACC programme. Services have to meet HACC *National Service Standards*. These standards provide agencies with a common reference point for internal quality control and outline expected outcomes for consumers.

Community Aged Care Packages (CACPs) were introduced to provide a home-based alternative for frail older people whose dependency and complex care needs would qualify them for entry to institutional care. CACPs are individually tailored packages of care services for people assessed by an ACAT as requiring a range of care services in their own homes.

Extended Aged Care at Home (EACH) packages provide high-level care to people living at home who need more assistance than a CACP can provide. 450 EACH packages were available as of June 2003. Similarly to institutional care, the Australian Government and State/Territory governments together provide most of the funding for these programmes. Users are charged different fees for services depending on the type of service and the client's capacity to pay.

Support for informal carers

The Australian Government funds a number of services in recognition of the significant contribution individual carers make to the lives of older Australians and people with disabilities, including many who would not otherwise be able to remain at home. Support includes:

- The *Carer Payment* is an income-support payment for people whose caring responsibilities prevent them from undertaking substantial workforce participation.
- The *Carer Allowance* is an income supplement for people who provide daily care and attention at home for an adult or child with a disability or severe medical condition.
- The *National Respite for Carers Programme* provides funding for short term or emergency respite in the community. The programme provides information, counselling and support for carers, as well as assistance to help them take a break from caring.

- *Residential respite* provides short-term stays in care homes for people who are in temporary need of institutional care. Residential respite may be used on a planned or emergency basis to help with carer stress, illness, holidays or the like.

Austria

The social welfare sector in Austria comprises three sectors: social insurance, social assistance and "other support". Social insurance provides sickness, pension and accident insurance to defined population groups in return for mandatory contributions. Social assistance provides a need-based safety-net for individual cases and is financed by the provinces from taxation. "Other support" is provided as a coverage for special groups for which the State has to take direct responsibility, *e.g.*, war victims, and for which benefits are provided from general taxation.

Long-term care allowances

Prior to 1993, a variety of allowances to cover need for long-term care had developed under all three welfare sectors, leading to concerns about inconsistencies in treatment of different groups and gaps in coverage. In response, in 1993, Austria introduced a universal cash-payment programme at federal and provincial level to provide financial help with both institutional long-term care and home care. This system of care allowance (*Pflegegeld*) replaced and unified the existing programmes.

The system of care allowance comprises the *Federal Long-Term Care Allowance* and the nine corresponding *Provincial Long-Term Care Allowance* programmes. Together, they cover all persons in need of care, irrespective of age.

The eligibility criterion for these allowances is the degree of need for care, regardless of income and assets the beneficiaries may have. However, income and asset tests are still applied in cases of intensive care needs where the care allowance does not cover all expenditure, and private households do not have the income or assets to supplement the care allowance out of their own pocket. In this case, social assistance can provide funding in addition to the care allowance. Moreover, long-term care facilities may receive direct transfers from government budgets, providing another source of funding.

Federal Long-Term Care Allowance and *Provincial Long-Term Care Allowance* are financed by general taxation. This is also the case for social assistance benefits and direct government subsidies for providers of care.

Long-term care providers

Institutional care is predominantly provided by provinces and municipalities, or by religious and other non-profit organisations. Home-care services are provided by non-profit organisations. In 2000, 3.6% of older people in Austria received long-term care in an institutional setting. An estimated 15% received long-term care allowances for support of care given at home.

Informal care traditionally plays a major role in Austria as provider of long-term care. Around 80% of persons requiring care are cared for by family members. The formal home care sector is still in a phase of expansion and there are marked regional differences in the availability of services, in particular of services in support of informal care giving (such as counselling and respite care).

Canada

Within the Canadian federal system of government, health care, including long-term care, is assigned to the provinces and territories. A set of national principles is set out in the *Canada Health Act 1984*. This sets out two major categories of service, *Insured Health Services* (IHS) and (uninsured) so-called *Extended Health Care Services* (EHCS). IHS include hospital care and services provided by physicians and are covered by the five principles set out in the Act, namely, universal coverage, comprehensive service coverage, reasonable access without financial barriers, portability of coverage and public administration of insurance plans. EHCS include nursing homes, long-term residential care, home care and ambulatory health care services. As uninsured services they are not covered by these five principles. Other services such as home help and adult day care are not covered by the *Canada Health Act*.

Long-term care programmes

As long-term care has evolved separately in each province and territory, the services supplied and the terms under which they are supplied vary between jurisdictions. However, the following can be considered core services as they are supplied in all jurisdictions: long-term care institutions, palliative care, respite care, home-care nursing, rehabilitation services such as physiotherapy and occupational therapy, domestic help and personal care services. Other commonly provided services include meal programmes, day-care, group homes, equipment and supplies and quick response teams.

Institutional long-term care

While terminology differs between jurisdictions, there is a distinction in all provinces and territories between nursing homes providing long-term nursing care and residential care homes that provide support and social care. The financial terms for those entering either type of home vary considerably between provinces. In general, eastern seaboard provinces require the user to pay all or most of the cost if they can afford to do so, while other provinces provide a varying degree of subsidy to all users.

All provinces have some form of assessment of need for care, but the type of assessment of needs before entry varies between provinces and is related to the degree to which the province will have to subsidise the resident. For example, in Nova Scotia, where residents are expected to pay the full charge if they can, a resident able to pay for 18 months of care may enter a home directly. If public subsidy turns out to be required after that time they must be assessed and classified as to level of care. In British Columbia, where most care costs (but not other costs of living) are covered by the province, there is a requirement for case manager assessment before becoming eligible.

Home care

Home care and rehabilitation services are generally provided according to need and free of charge in all provinces and territories. Other home-care services such as homemaker services and personal care generally carry a fee or an income and asset related charge. Adult day care or meals usually carry a set charge. There are generally some limits set to the amount of home care that a client can receive, although British Columbia recently abolished upper limits. Most of the other jurisdictions have a ruling that the cost of home care provided should not exceed the cost of a residential facility. There may be limits set lower than this for some services. User charges for home care services vary

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between jurisdictions but generally relate to a proportion of the cost together with the user's monthly income.

Support for carers

About 80% of care to older Canadians is provided by family and friends. Informal carers often have a heavy care burden and have other costs such as increased out-of-pocket expenses and limitations on employment and personal time. To address these issues, Health Canada contributed to the creation of the *Canadian Caregiver Coalition* in 2000, to drive forward research and policy development on issues such as the role of the family carer in the home care sector, the role of men as carers, out-of-pocket expenses, respite care and employment implications. Although provinces and territories have a range of initiatives designed to address family/informal care-giving issues, there is a growing demand for services that exceeds current resources.

Canada introduced a new cash benefit to provide short-term support for carers in 2004. The *Budget Bill 2003* included provision of a new Employment Insurance (EI) benefit called the *Compassionate Care Benefit* (CCB). As of January 2004, CCB has been available to EI-eligible workers who are absent from work to provide care to a close family member (child, parent or spouse) who has a serious medical condition with a significant risk of death within six months. The applicant must have a medical certificate to show the significant risk of death and that care is needed by a family member. The benefit lasts for six weeks but can be taken within a 26-week "window" specified in the medical certificate. Within this "window" the benefit can be received whenever the eligible person decides, and can also be shared among family members meeting the eligibility conditions.

Federal, provincial and territorial governments also provide indirect financial assistance to care-givers via tax relief. The federal *Caregiver Tax Credit* is a non-refundable tax credit designed to reduce the income tax owed by individuals who reside with, and provide in-home care to, dependent relatives. Other federal tax credits from which some family caregivers benefit include the *Infirm Dependent Tax Credit*, the *Disability Tax Credit*, the *Eligible Dependent Tax Credit* and the *Medical Expense Tax Credit*. Some provincial tax systems also provide assistance to individuals caring for relatives disabilities or infirmities, *e.g.*, the *Caregiver Tax Credit* in Ontario.

Germany

Germany has a social insurance system covering, among other needs, old age and disability pensions, acute health care and, since 1995, long-term care. Around 90% of the population are covered under social health and long-term care insurance. People primarily covered under private insurance (mainly higher income earners and civil servants) are obliged to purchase equivalent private long-term care insurance. For the small proportion of the population not covered by either social or private health insurance, there exists since 2001 the right to join long-term care insurance, with a choice between social and private insurance. The terms of social insurance are regulated by the Federal government. Social assistance from the States (*Länder*) provides a means-tested safety net for those whose needs exceed the level of social insurance benefits or who are uncovered for some reason.

Long-term care insurance

Social long-term care insurance is a separate "pillar" of social insurance, which is financed and regulated independently from health insurance, but managed by existing sickness funds. Both social and private long-term care insurance is governed by analogous governmental regulation. Private households are required to cover cost of accommodation of institutional care, and social assistance contributes to the funding of long-term care (both home and institutions) for persons with an income insufficient to cover the out-of-pocket expenditure associated with long-term care.

Benefits under long-term care insurance are granted after medical assessment. Beneficiaries are classed under one of three levels of care need, and are entitled to cash and/or in-kind benefits up to the ceiling for each care level. Beneficiaries have a free choice between benefits in kind and benefits in cash or a combination of the two. The total amount awarded of benefits in kind is substantially higher for each care level than the corresponding benefit in cash (or a combination of in kind and cash benefits).

Social long-term care insurance is funded by insurance contributions which are collected on top of the health insurance premium. Contrary to other social insurance branches, the contribution rate of 1.7% of gross earnings is currently fixed by law, providing a cap on the overall funds available, which accordingly depends on the business cycle and on the growth of the revenue base relative to the economy. The annual increases in revenues under the fixed contribution rate have since 1998 been for all but one year substantially lower than the growth of expenditure, in particular due to the spending pressures from care in institutions. The deficit of long-term care insurance was 2% and 4% in 2002 and 2003, respectively. Social assistance is funded by general taxation.

The new long-term care system appears to have raised the awareness of households of the risk of dependency in old age, as shown by the currently small (1% of the population) but growing market of voluntary private complementary long-term care insurance, to cover the costs falling to private households, such as for accommodation in nursing homes.

Institutional long-term care benefits

The number of places in nursing homes (and similar institutions) has substantially increased since 1995 and there are currently no significant waiting times or shortages reported of places in institutional care. In 2002, around 635 000 dependent persons received institutional care benefits from either the social long-term care insurance (around 600 000) or private long-term care insurance (around 35 000).

Home care benefits

The number of home-care providers has increased since 1995 from around 4 000 to around 10 600 and the current infrastructure is now seen by the administration as sufficient in quantitative terms. In 2002, a total of 1.37 million people received home care benefits from either the social long-term care insurance (1.29 million) or private long-term care insurance (79 000).

Informal care continues to play its traditional strong role in Germany, and this is reflected in the benefit system allowing a recipient to draw a cash allowance which can be used to reward informal carers.

Non-profit organisations are the major providers of long-term care services at home. The introduction of long-term care insurance has resulted in strong growth of providers of

home-care services, which by law have to be mainly private providers (either non-for-profit or for-profit). This is based on the view that a system of private providers will create an environment of competition, leading to better outcomes in terms of cost and quality of care than a system dominated by public providers.

Hungary

Social services for the elderly and the disabled have a relatively well developed institutional network in Hungary. However, they do not meet growing needs either in terms of number of places or quality of the services. Development of special institutions for long-term care within the health sector (home care, nursing homes and hospices) started only in the 1990s and still needs considerable extension. The 2002 election programme of the government suggested considering the introduction of public long-term care insurance.

Provision of long-term care services

Health care system

The health insurance system offers no special services for the elderly as such, although long-term care in hospitals, services in nursing homes and home-care services are provided and received mainly by older persons. Moreover, drugs for the treatment of certain geriatric conditions are subsidised at high rates, reducing the user charge to a comparatively low amount or to zero in the case of low-income recipients.

In rural areas particularly, General Practitioners (GPs) and primary care nurses tend to spend considerable time visiting patients (many of them elderly) at home, with a significant part of these visits serving a social and mental health function. In addition, there are a growing number of specialised home-nursing care organisations, which provide post-operative and pre-operative care as well as limited ongoing treatments. Both GPs and home care organisations are mainly private providers, but their services are financed by compulsory health insurance.

Social services

Personal social services include services for the elderly, and for mentally and physically disabled persons. Services provided in their own homes or on a daily basis include meal-delivery, home help, day-care facilities, clubs for elderly people and day care for the disabled. Residential care includes the following types of facilities: homes for the elderly: homes for psychiatric patients, disabled children, disabled adults, and for alcohol and drug addicts. These residential facilities can be permanent care homes or temporary care homes.

Coverage of long-term care programmes

Elderly person are entitled to health care under the mandatory health insurance system. Eligibility for a particular health service is based on needs assessment by a doctor. Eligibility for social services is defined by the *Social Care Act* of 1993 and related decrees of local governments, which regulate eligibility and user fees. The applications by elderly persons are sent to the particular institution the person wants to stay in, and the needs assessment is done by the institution. In 2000, 50 in each thousand older people (above the age of 60) were delivered meals, 20 received home help and 20 attended day-care centres for the elderly.

For residential care institutions providing permanent care, in 2001, there were 6.5 places per thousand inhabitants (including institutions both for the elderly and the disabled), and one place per thousand inhabitants in institutions providing temporary care.

Funding of long-term care programmes

Health care services are mainly financed by mandatory health insurance and services of "basic quality" are free of charge. However, for services of "higher quality" and services provided for patients from outside the official catchments area of the hospital, the hospital can require fees (in addition to the payment by the health insurance) from the patients. These fees are set by the institutions. Services can also be provided and financed totally in the private sector.

Local governments are responsible for social care. Social care is co-financed by central government and local governments. For social services, user payment is required and it is set by the institution within the range defined by the local governments in their decrees on social care. However, fees for social services cannot exceed a certain proportion of the income of the client.

The organisation of service provision

Hospitals are run by local governments. There are a growing number of private nursing homes. GPs and home care organisations are mainly private providers, but their services are financed by compulsory health insurance.

Social services are provided by local governments: local governments in cities with more than 10 000 inhabitants operate so called social service centres that integrate the different kind of social services provided by the city government. The role of the private sector in service provision (subsidised by public expenditure) is growing. In 2001 there were 886 residential care homes for permanent care (with 66 029 places, 6.5 per thousand) and 344 residential care homes for temporary care (with 1.0 places per thousand). 78% of these places were provided by local governments.

Ireland

The Irish Government's policy is to maintain elderly people in independence at home when they wish, and to provide high quality care in hospital and care homes when they can no longer be maintained at home. The public health system provides both residential and community services, but an independent review of long-term care funding in 2003 argued that current funding arrangements favour residential care and proposed a new social insurance scheme for long-term care, to be supplemented by voluntary insurance (Mercer Limited, 2003). Long-term care is currently financed principally from general taxation and private out-of-pocket payments. The government has set up a Working Group comprising of all stakeholders to consider the recommendations of the Mercer report and of a separate review of nursing-home subventions (O'Shea, 2003). At the end of 2004, the work of the Working Group was ongoing and no decision had been taken on a fundamental redesign of the Irish long-term care system.

Long-term care programmes

All public long-term care programmes in Ireland are funded by general taxation and services are granted based on medical need which is assessed by the Health Board.

Institutional long-term care

As of 2000, there were 24 052 non-acute care beds for older people in long-stay facilities, equivalent to 56.2 beds per 1 000 elderly people (65+). Of these, 11 415 beds were directly provided by Health Boards. Health Boards also contracted 1 281 beds out to private nursing homes. Health Boards fund other private facilities through the *Nursing Home Subvention Scheme* (6 196 beds). Overall, about 80% of total non-acute care beds are funded by Health Boards, the rest being privately funded.

Long-term care in public institutions

In order to receive long-term care in public institutions, including contracted-out private institutions, needs assessment is required, covering, among other issues, housing, social situation, family support and health. Those admitted as residents have to contribute up to a maximum of 80% of the non-contributory *Old-Age Pension*. However, the terms of means-testing are usually more stringent for those applying to enter a private nursing home than those applying for a bed in a public institution.

Public support for long-term care in private nursing homes

Private nursing homes are regulated under the terms of the *Nursing Homes Act* and other related regulations and subject to inspection by Health Boards. A subvention may be paid to a person in need of nursing-home care towards the cost of a private nursing home. A medical assessment is required, in which the applicant is categorised according to level of dependency, as medium, high or maximum. In addition, the applicant must pass a means-test.

Subventions are provided to assist persons in meeting the cost of nursing-home care, but are not intended to meet the full costs involved. The maximum rates of subvention payable depend on the level of dependency: EUR 114.30 for medium dependency, EUR 152.40 for high dependency and EUR 190.50 for maximum dependency (at 1 April 2001). The residents have to pay the balance.

The means-test for the subvention always takes account of the applicant's income, and may also take assets into account. Health Boards have considerable discretion in relation to how assets are treated for the purposes of assessing means. Since its creation, the cost of the scheme has been continuously growing. The government established a review of the subvention scheme to consider future options. The report (O'Shea, 2003) called for more consistency in the regulation of public *versus* private institutions, greater support for home-based care and a more stringent comprehensive assessment to be developed and applied to have greater control on access to institutional care.

Home care

The home-care services available to elderly people in the community include community nursing, home helps, respite services, day-care centres and meals services together with paramedical services such as physiotherapy, occupational therapy, chiropody and speech therapy. Public Health Nurses assess and arrange appropriate home care.

Cash benefits for informal care

Carer's Allowance is a payment for carers with low income who live with and look after people who need full-time care and attention. *Carer's Benefit* is a payment made to insured

persons who leave the workforce temporarily to care for a person in need of full-time care and attention. In order to receive these benefits, the care recipient must be so disabled as to require full-time care and attention but not normally living in a hospital, home or other institution.

Japan

Japan has a social insurance system to cover major risks including old age, disability and health care. Since 2000 there has been a new branch of social insurance to cover the risk of needing long-term care.

Long-term care insurance

Long-Term Care Insurance (LTCI) is a mandatory social insurance operated by municipalities under central government legislation. All residents in Japan aged 40 years and older are insured, either as so-called 1st category insured person (aged 65 and over), or as a 2nd category insured person (aged between 40 and 64).

Eligibility criteria and service utilisation

Insured people who are in need of care are assessed on application and classified into one of the six care levels according to their need for care. Decision on the care level of each beneficiary is agreed by a municipal long-term care council, but collection of relevant data on individual cases is usually delegated to service providers. Both institutional and home cares are funded by LTCI. A fee schedule is set nationally according to the level of care need. For home care services, each care level has a budget ceiling, ranging from JPY 61 500 to JPY 358 300 per month (around EUR 470 to EUR 2 750 per month)**.** Beneficiaries have access to care services up to the ceiling of their care level. Those in the lowest care level are not eligible for subsidised institutional care.

Second category insured persons are also eligible for the services funded by LTCI, but only when their disability is the result of ageing-related diseases such as stroke and Parkinson's disease. 2nd category insured persons in need of long-term care whose need is not the result of ageing-related diseases are covered by other social service programmes or health insurance.

The role of "care manager" has been newly created with the introduction of LTCI. After determination of care level and before use of care services, a care plan has to be drawn up with the help of a care manager, reflecting the need of the recipient. The care plan is revised on a monthly basis or when there is a change in living arrangement or mental and physical condition of the recipient. As of March 2003, 73.4% of all long-term care recipients aged 65 and over were receiving home care services, while 26.6% were receiving care in institutions.

Financing

Beneficiaries pay 10% of the cost of services. The rest of the cost is borne by the insurers, *i.e.*, the municipalities. The insurers' revenue in total is derived from several sources: contributions from 1st category insured persons (18%) and 2nd category insured persons (32%), an ear-marked subsidy from the central government (25%) and the prefectural government (12.5%), and the municipality's own general budget (12.5%). However, government subsidy varies according to the number of the elderly people in the municipality. The rate of contribution for 1st category insured persons is determined by

each municipality. The national average for 2003 is about JPY 3 200 per month (EUR 25). Contributions by the 2nd category insured persons are included in contributions for public health insurance.

Allowance for families caring for elderly

This is a cash benefit funded by the municipalities with a subsidy from the central government. The amount of benefit and the eligibility criteria are determined by each municipality, and not all municipalities have chosen to introduce this scheme. Those eligible are families caring for an elderly person with the severest need of care (4th or 5th degree of care level) for one year without using any public services funded by LTCI. There is no available estimate of numbers of families receiving the allowance, but it is known that these are fairly small.

Korea

Korea does not currently have a comprehensive long-term care system. The great majority of older persons who need help with activities of daily living are currently cared for informally in families, with only a small number of persons receiving formal long-term care services. There is evidence of some older people remaining in hospital for an extended period of time due to the general lack of long-term care services.

However, the government has in 2004 announced that a system of long-term care insurance will be introduced from 2007 onwards. The Ministry of Health and Welfare has central policy responsibility for long-term care and is drawing up plans for phased implementation of long-term-care insurance from 2007. However, local governments will have the main responsibility for implementation and also shared budgetary responsibility.

Long-term care programmes

The current long-term care services for the elderly are classified into two types under the *Older Persons Welfare Act*: institutional care and home care. Institutional care comes in two forms; so-called general nursing-home care, and special nursing-home care. Service to support older persons with care needs at home comprises mainly home help services, day care, and other short stay services.

Institutional long-term care

Two types of institutional care are provided; general and special nursing-home care. General nursing homes provide care for the disabled elderly with minor or no chronic diseases while special nursing homes for the elderly provide for those with severe chronic conditions such as stroke or dementia. Uniform standards on degree of disability for entry to care have been developed. In addition, geriatric hospitals provide services for elderly with acute health care needs.

These forms of institutional care are provided only for those aged 65 and over. Moreover, care services from publicly financed institutions are limited to relatively poor elderly people. Only older persons who receive social assistance benefits are entitled to care in nursing homes free of charge, while older persons with an income that is on the margins of social assistance levels are entitled to receive care in nursing homes which is partially subsidised by the government (OECD, 2003c). Those with higher incomes have to meet the total cost.

Most institutions are non-profit organisations. As of 2002, 162 institutional care facilities covered around 12 000 frail older persons, equivalent to 0.3% of the population aged 65 and over.

Home care

There is a growing supply of home care services including home help, day-care and short-stay services. Home help covers domestic support and personal care services. Day-care centres provide rehabilitative care services for recovering ADLs, wheels-on-meals, bathing and recreation services. Older persons can stay at short-stay facilities for 45 days at a time and a maximum of 90 days a year.

As with institutional care, public coverage for home care is income tested. Only recipients of social assistance benefits are eligible for home care services free of charge. The elderly with marginal income have to contribute to the cost while upper and middle income elderly have to pay the whole costs. There were 322 home care organisations in 2001, all of which were non-profit organisations. In total 16 663 older persons used these services, equivalent to 0.4% of those aged over 65.

Luxembourg

Luxembourg has a social insurance system covering old age and acute health care, and in 1998 introduced a new arm of social insurance to cover long-term care.

Long-term care insurance

In June 1998, Luxembourg introduced a universal long-term care insurance programme (*assurance dépendance*) as part of its health care insurance. The coverage is identical with the coverage of the population under the health insurance system. There is consequently near-universal coverage of the whole population for both home care and care in institutions. Voluntary private long-term care insurance does not play a significant role in Luxembourg.

Care levels in the public system are determined mainly according to the amount of time needed to provide necessary help with ADL (and to a certain extend IADL) activities and are assessed by a public service independent from the social insurance. Payment levels in both institutional care and home care are determined as product of hours of care needed and fixed amounts per hour. The number of hours of care is assessed on a continuous scale, unlike the system of discrete levels of care established in countries such as Austria and Germany.

Private households are required to cover any additional cost, which in the case of accommodation costs of institutional care can be substantial. Payments from social assistance are provided for people with long-term care costs higher than their means. The number provided for under this scheme is growing and amounts to around one in ten older people receiving long-term care benefits. Besides long-term care insurance (which is not means-tested), financial help for specially adopted accommodation for frail elderly is available.

Long-term care insurance is funded by three main sources: 1) general taxation (45% of the total cost in 2001), 2) a fixed one-percent contribution rate on salaries plus other sources of income (including pensions) (35%), and 3) a special taxation on electricity.

Long-term care services

Since 2001, the share of dependent older persons who are cared for at home has been steadily increasing, from 53% of all long-term care beneficiaries in 2001 to 60.4% in 2004.

Institutional long-term care

In 2002, 47% of all long-term care recipients aged over 60 received care in a care institution. The capacity for care in institutions was 4 328 beds in 2002, equivalent to 6.8% of the population 65+. In parallel with the introduction of social long-term care insurance, the capacity of nursing homes and other institutions to care for older people is currently expanding. The target of planned additional places is around 24%, of which two thirds are already under construction.

Home care

Consumers have a choice between benefits in kind or in cash or a combination of the two. In 2002, only 10% chose benefits in kind only. Almost half of all consumers (49%) choose cash only, and 41% a combination of both. Since the long-term care insurance system was introduced, the size of the home-care workforce has increased by 21% from 1999 to 2002.

Mexico

The Mexican health care system[2] is made up of three largely separate components, each of which provides for part of the population:

- The social security system provides health care for those in the formal labour market and their dependents – around half of the population in total.
- The health institutions run under the auspices of the Ministry of Health (SSA – Secretaría de Salubridad y Asistencia) provide health care to the uncovered population that is income tested. There is also a range of government programmes aimed at increasing access among the poor and mainly rural population.
- A large private health care sector providing services paid out of pocket. In total less than half of total health expenditure is public expenditure, with privately purchased health care playing a larger role than in any other OECD country.

The social security system provides primary and hospital care, including geriatric care, for its contributors. Health care for those outside the social security system is focused on providing basic primary care, with treatment for acute conditions in health clinics.

Long-term care services

There is a limited amount of institutional long-term care in hospitals and nursing homes provided under the social security system. For those not covered by the social security system, older people would only be admitted to hospital for care where they have acute conditions requiring hospitalisation. There is very limited capacity in local social assistance homes. There are around 300 private nursing homes providing services paid out of pocket (IMSS, 2003). In total only around 0.3% of the older population (65+) was resident in any care institution at the time of the 2000 census (IMSS, 2003).

Day centres providing meals, social care and other help for the elderly are provided by the social security system for those covered, and to a limited degree by other government programmes for those not covered by social security. The social security institution is surveying the incidence of mental conditions among older people as an aid to planning more specialised services for this group.

Help for informal carers

By far the most important supply of long-term care in Mexico is from the family in the form of informal care. Very few older Mexicans (aged 60 and above) live alone – around 7% at the most recent count (1994, in IMSS, 2003). 17% live with their spouse only, but over three quarters (76% in 1994) live as part of a wider household together with their children or others, by far the highest proportion of older people in extended households among the OECD countries. According to one 1999 survey of those aged over 60 in the Mexico City area, around half are entirely dependent on their families for income, with only a quarter in receipt of any pension income (IMSS, 2003, p. 18).

Those of working age who are insured in the social security system can in some circumstances receive payments for providing informal care to a disabled older person, and also receive advice and information.

Netherlands

The Netherlands has a system of insurance for health and long-term care comprising three different pillars: 1) health insurance, which is mandatory up to a certain income level, 2) private health insurance for those above the income threshold, and 3) a comprehensive public scheme for the total population to cover "catastrophic" or "exceptional" risks and expenditure that are regarded as "non-insurable". This last scheme (AWBZ) covers a broad range of long-term care services across a range of care settings. The AWBZ also covers expenditure on acute care needs arising from chronic conditions and other "exceptional" expenditure.[3]

The Netherlands has a policy of fostering home and community care, and 58% of recipients of long-term care live in their homes or in a community-based setting. Private long-term care insurance does not play a significant role for the general population.

Long-term care programmes

Institutional care

Nursing homes and other providers of institutional care are mainly independent non-profit organisations. There is a range of institutions providing long-term care for older people at various levels of dependency. Institutions also differ by specialisation (dementia patients, institutions for older persons with somatic functional limitations, or sensory loss). There are different pathways to these types of long-term care institutions: institutions providing more low-level care receive beneficiaries mainly from a home setting. The somatic nursing home receives many persons after a hospital stay. Psycho-geriatric institutions receive persons from home, other LTC institutions, and after hospital stays.

In 2000, of the approximately 240 000 recipients of long-term care in institutions, the majority were in nursing homes and similar institutions (170 000), 58 000 in semi-residential care for the disabled, and 12 000 in sheltered housing.

Waiting lists are reported for both institutional care and care provided at home. The waiting lists for institutional care (about 5% of recipients) are in 80% of cases passed on to home care institutions, which have to provide interim care for persons on the waiting lists for institutional care. Workforce shortages in the care professions are seen as hampering the reduction of waiting lists.

Home-based long-term care

Home care providers are predominantly (around 90%) private non-for-profit organisations. There is a broad range of home care services, from meals on wheels and home-making to more intensive home care, including day-care facilities and respite care, for a continuum of care needs. In recent years the boundary between community care and institutional care has been narrowing.

There are waiting lists for access to home care services (about 10% of recipients), although these are reported to have declined by 30% recently and a majority receive at least a temporary home-care arrangement while on the waiting list. Following the most recent reform in 2003, all new home care users have been offered the option of a consumer-directed budget in place of direct provision of services.

New Zealand

Responsibility for acute and long-term health care in New Zealand rests with elected District Health Boards (DHBs), which replaced the former Health Funding Authority in January 2000. Funding responsibility for long-term care was devolved to DHBs from the Ministry of Health in October 2003. It is the intention that bringing together acute and long-term care under one authority should enable the development of a more integrated continuum of care for older people.

Both acute and long-term care are funded from general taxation, with DHBs receiving block grants from central government. People assessed as needing long-term institutional care (continuing care hospitals, dementia units and rest homes) are subject to an income and asset test to determine access to a subsidy. The New Zealand Government has announced that asset tests for institutional care will be phased out in stages starting in 2005.

New Zealand has currently a relatively young society but is anticipating rapid growth in the older population by 2030. In 2002, New Zealand has published a comprehensive ageing strategy to provide direction to policies for improving the health and functioning of the older population.

Long-term care services

Long-term care is provided through certified continuing care hospitals and rest homes and by home support services. Entry to both institutional and home support services is subject to an assessment of need and ability to pay. Assessment, treatment and rehabilitation services are free to the user.

Long-term institutional care

In April 2003 around 61% of those who were cared for in an institutional received state subsidies through the *Residential Care Subsidy Scheme*. Access to these subsidies is income and asset tested, these tests being administered on behalf of DHBs by the Ministry of Social Development. The subsidy is designed to keep private cost-sharing below a certain payment per week. In order to qualify for the subsidy, the person must have assets below a certain level. The government has announced that asset tests for institutional care will be phased out in stages from 2005 to leave a system of income tests that will on balance be more generous to the user than the current system.

A small proportion of long-term care is provided in DHB-owned continuing-care hospitals. The majority of rest home and continuing care hospital beds are provided by

private sector agencies, both for-profit and not-for-profit. These must be certified by the Ministry of Health. Certification audits are required to ensure the facilities meet legal requirements. There is also a strong growth in retirement villages providing a range of supported living options within the same complex.

On average, rest home and continuing care hospital residents are older and frailer than they were 15 years ago but their average stay is shorter. However, the government has expressed some concern that the growth in institutional numbers has been higher in recent years than the growth of the older population, and that there should be more home-based options available for people needing care.

Home care

Home-care services include home help (*e.g.*, cooking, cleaning, etc.), personal care services such as help with bathing, and assistive technology such as wheelchairs, aids, appliances and equipment that help people to remain in their own homes. There is concern that there may be local inconsistencies in access to services and these are being reviewed.

Home-delivered personal care services are free to all who are assessed as needing them. People who are assessed as needing home help are expected to pay unless their gross income is below a set threshold. Full-time family or informal carers of an older dependent person can also be assessed for need, such as respite care or day care. It is not an entitlement and is subject to income testing.

The Ministry of Health and Ministry of Social Development are currently jointly reviewing the comprehensiveness and integration of policies to assist older people staying at home, to identify and address any gaps and inconsistencies.

Norway

In Norway, the government plays the dominant role in long-term care, as the public sector provides most services and these are largely financed by direct taxation. However, provision of long-term care services is largely decentralised and integrated at the level of the municipality.

Long-term care programmes

Public long-term care is provided and regulated under the *Municipal Health Service Act* and the *Social Service Act*. Most of the cost of long-term care services is covered by taxation, with moderate user fees. The municipalities have discretion within the framework laws to adjust eligibility criteria. Either a service provider or a team comprising members of different agencies will assess an older person's eligibility for services. The services for the elderly are divided into three groups; institutional care, sheltered housing, and home-based services.

Long-term institutional care

Institutions for the aged are of two types: residential homes and nursing homes. They are regulated by different laws, but both are the responsibility of the municipality. The nursing home sector has expanded in relation to the more traditional residential home sector in recent years and today approximately 70% of institutional beds are in nursing homes.

Both residential homes and nursing homes are mainly used for long-term stay, but nursing homes are also used for short-term accommodation for rehabilitation or respite care. Nursing homes may also function as a day-care centre for old people.

Ninety per cent of long-term institutional care is provided by the local community's public health system. The remaining 10% is made up of public non-profit institutions and private for-profit companies.

The number of beds in care institutions has been reduced since the 1980s, and in 2000 the number of recipients staying in institutions was around 6.0% of the population aged 65 and over. Residents in institutions pay a charge of approximately 80% of their public pension (up to a limit).

Sheltered housing

New types of sheltered housing have developed in recent years, which offer independent living, but combined with services and care. There is considerable variation within the sector and the boundaries between different types of institutions and special housing have become blurred.

Home-based care

A variety of home-based services exist, of which the two dominant services are home help and home nursing. The home helper provides domiciliary services and also has a social and supportive function. Home nursing is a professional medical service provided by nurses. The two services are regulated under different laws (social and health), but are under the same authority (the municipality), and usually integrated into a common organisation. The predominant supplier of home care services is the local public provider.

Home-nursing care is free of charge while home help is subject to a user payment (usually NOK 50 per visit in 2003) which the municipality can decide to drop in certain cases. Other community services such as meals-on-wheels, counselling, handy man service, respite services, etc., are available in most municipalities.

The provision of home care services expanded until around 1980 and then levelled off. In recent years provision has slightly declined relative to the number of older people. However, there has been a growth in the provision of 24-hour nursing care and home alarm systems since 1990.

Cash support for carers

In 1988 payments for informal care were introduced under the *Municipal Health Services Act* of 1986. Persons caring for elderly relatives or disabled children on a regular basis may receive a cash benefit from the municipality called caregiver pay.

Poland

Thus far, Poland has continued to rely for long-term care mainly on the traditional provision of informal care by families, but this may be difficult to sustain at the current level in the future. The most recent health service reforms, in 1999, did not specifically address the situation of older people or long-term care and there was no separate system of long-term care, as of 2004. Health services are funded by a combination of general taxation and contributions to national health insurance schemes

Long-term care programmes

The following programmes providing long-term care are available:

- Institutional care: nursing homes, residential homes.
- Home and community care: day-care services, home care/help.
- Support for informal carers: care allowances, paid leave.

Institutional long-term care

The number of elderly people in care institutions has traditionally been low and remains so. Residential homes are for less disabled older people who are not in need of any special social care or nursing. There are 109 residential homes catering for around 10 000 older people. Homes for the chronically sick are available for those people who have chronic diseases and disabilities requiring nursing and constant attention. There are also 175 private non-profit care homes run by Caritas. In addition there are a number of homes providing for particular occupational groups and military veterans.

In total, 534 social welfare institutions provide places for around 60 000 people, equivalent to 1.7% of the elderly. Older persons have to pay 75 % of their income towards care and lodging in public institutions, while there is no ceiling for those residing in private institutions.

Home and community care

Home help services are the responsibility of local government. These services are means-tested. Services are provided free of charge in cases where the per capita income of family members does not exceed the minimum state pension. Referrals can be made by the community health team, consisting of a doctor, community nurse and social worker, or by family carers, neighbours or friends.

Older people are entitled to apply for help from the *Fund for the Rehabilitation of Disabled People*, which provides a limited range of disability equipment and adaptation to the home. The recipient is required to make a contribution to the cost of these services. Other services, such as the provision of meals etc., exist on a more *ad hoc* basis, through agencies such as Red Cross nurses who may purchase and deliver a meal to an older person's home.

Support for informal care

Poland provides tax relief on expenses involved in the care of a dependent relative. Polish workers can also take time off work with compensation, up to 14 days per year.

Spain

Health and social care in Spain is the responsibility of the regions (autonomous communities) following a decentralisation of government functions. Responsibility for social care, which includes most long-term care, was devolved to the regions in 1995 (devolution of responsibility for health care was in 2002). Within regions, social care is mainly the responsibility of municipalities. There are considerable differences between regions in the pattern of social services, eligibility criteria and user charges. Most health care is provided free of charge whereas social care is subject to means-testing. The nature of the means-test varies between regions.

There is some concern that lack of coordination between the health and social service sectors and between levels of government may be hindering attempts to provide better and more integrated services for the elderly, as set out in the 2000-05 national plan for services for older people.[4] An "inter-territorial council" has been set up to co-ordinate policy across regions.

Traditionally most care for the elderly has been provided by the family. Around 70% of dependent elderly people in households receive care from family members, compared with only about 4% receiving formal help from public services and 11% using private home help.

Long-term care programmes

"Long-term care" has not been defined as a specific service within Spanish health and social policy until very recently. The health services have provided a range of services, some of which have been long-term, *e.g.*, in mental health facilities, or where elderly people have remained in hospital rather than been discharged due to shortage of alternatives. Social care has been provided locally by municipalities as a form of social assistance to those with needs for care but without the means, family or financial, to provide for them. Although expanding, the extent of services is more limited than in most other EU countries and many are of recent origin.

Institutional long-term care

In 1998, there were an estimated 2.8 institutional places for every 100 people over 65, while the target set in the national plan for ageing services was 5.0 per 100 (Costa-Font and Paxtot, 2003, p. 52). Currently there are known to be shortages of institutional care places in many areas, and several regions have begun specific programmes of building or subsidising new facilities.

Around 70% of long-term care beds are in the private sector (the majority through non-profit organisations) with the rest provided either by municipalities or regions. There is however considerable variation between regions in the distribution of providers; in eight of the seventeen regions the public sector is the main provider. Public sector institutions tend to be larger (more than 50 beds on average). In many areas, there are waiting lists to enter nursing homes. There is concern about the quality of staff and quality of care, in particular for some of the smaller homes.

Unless institutional care is provided in a health sector institution, *e.g.*, in a mental health facility, it is subject to a means-test, the nature of which varies between regions. Users contribute 75% of pension for institutional care plus payments related to other income.

Home-based care

Home nursing is provided by the health service free of charge at the point of delivery. Other services are provided by local government subject to a means-test. The number and type of services differ between regions and municipalities.

Public home help is unsually managed by municipalities through "social care centres". It has been estimated that only 1.5% of older people (4.4% of dependent older people) use public home help, while 3.9% of older people (11.2% of dependent older people) buy in private home help (Costa-Font and Paxtot, 2003, p. 51).

Most elderly at home continue to rely mainly on informal care. Costa-Font and Paxtot (2003, p. 53) estimate that, of elderly people in 2000 with at least one IADL restriction, around 75% relied exclusively on informal care.

Sweden

Most long-term care services in Sweden are funded from taxation and supplied by the public sector. Since 1992, the management of both primary health care and long-term care has been integrated at the level of the municipality. However, the two framework pieces of legislation regulating the supply of services remain the *Social Services Act* (1982) and the *Health and Medical Services Act* (1983).

Long-term care programmes

Eligibility and financing

Care of the elderly is almost entirely financed from taxes with moderate user fees. The largest share of the cost is covered by local taxation: local and regional tax revenues covered 83.8% of the cost in 2000.

Social care services are provided to all elderly people who meet the assessment of need. However, over the past 15 years or so the assessment criteria for home care services have been revised to target services on more disabled people.

Long-term care services

Municipalities are the main providers of care for older people. Public providers cover 95% of services for older people. However, the proportion of services provided by the private sector or the family has been increasing in recent years as the municipalities have been encouraged to contract out services for older persons as a way of cost containment. Some municipalities have introduced a separation of the purchaser and the provider function, often with a care manager in charge of planning and assessment of individual need.

Institutional long-term care

As part of the 1992 reform focusing services at the level of the municipality, a previous separation of management of care institutions by levels of government was replaced by unitary provision of housing for older people and handicapped people under one municipal programme, the so-called *Special Needs Housing* (SNH).

Assessment for SNH is carried out in the municipality home service unit and is governed by the *Social Services Act*. When screening the need for care a care manger reports on the health and housing situation of the applicant and often also on their family network. Income and assets are disregarded when assessing for a place in SNH.

Most facilities in SNH are publicly provided. Private housing provides services under contract to municipalities and with the same charges as for public housing. In recent years the proportion of older persons in SNH has declined on average, although local variations prevail among the municipalities.

Home care

The municipalities can make an assessment of the need for help on request by an older person, family member or their doctor. In many municipalities, a care manager is in charge of screening need and of planning the nature and scope of help. In these areas the care manager will usually decide the amount of help to be supplied.

From the 1980s onwards assessment criteria have become more restricted and help is postponed until there is greater need. A smaller proportion of older people therefore receive home help than previously.

In contrast to the fact that the number of persons receiving home help has decreased, the volume of service input per person has substantially increased on average. Home care is now targeted at those with a need for more comprehensive care. Most provision of home help is from the municipality. In 1999, only 7% of the total provision of services for the elderly was contracted out to private providers.

The main costs are borne by the municipality. The user pays only a fraction of the costs based on the number of hours used and on taxable income. In mid-2002, a new law was enacted and regulated the maximum level of charging (the ceiling) as well as the guaranteed amount of income (the floor) to be left, after the cost for housing, services and care is paid.

There is a comprehensive range of municipal services for the elderly to supplement home help and to enable the older person to stay at home. In most cases, these services are offered as subsidized services with user fees in addition to domestic service charges and are not provided on the basis of needs assessment.

Support for informal care

There are primarily three types of support: respite and relief services, support and educational groups for carers and economic support for caring.

Informal carers can be supported through *Home Care Allowance*, respite care for the older person in day-care centres or short-term stays for the older person in institutional care homes.

A number of cash benefits are available for informal care, and carers can be directly employed by the municipality to care for older people. This system is mostly used when the caregiver is of working age and in sparsely populated areas. A paid care leave is available if one cares for a relative or family member who is terminally ill.

Switzerland

In Switzerland, the financing of long-term care is fragmented and the system of providing care is devolved to the 26 regions (*Kantone*). Moreover, until recently, "long-term care" was not a focus of health policy in its own right, but part of a broader concern of providing for a continuum of services including post-acute care and rehabilitation, social services, long-term care services and specialised services for the younger disabled.

Public financing is additional to financing of individual care by mandatory sickness insurance. The main sources of public financing are from special programmes (*Ergänzungsleistungen*) under the social insurance system, such as supplementary benefits to old-age insurance, and from tax-based subsidies by the regions and municipalities to provider organisations or direct assistance to consumers. The contribution of cantons varies widely between the regions. In addition, private households contribute heavily to financing long-term care. Private long-term care insurance is risk rated, which is likely to make it unattractive as an alternative to the public system, in particular for women.

Recent health reforms have increased strains on the current system by creating financial incentives to earlier hospital discharge, and consequently the need for timely admission to home care or care in nursing homes.

Long-term care programmes

Institutional long-term care

Two-thirds of nursing homes and other providers of institutional care are public institutions (or subsidised) or non-for profit organisations, and one third is private for-profit institutions. In 2000, around 5.4% persons aged 65 and above were residents in institutions providing long-term care.

Home care[5]

Home care providers are predominantly (93%) non-for profit, private organisations, which is a prerequisite to receiving subsidies under old-age insurance. Over the past five years, there has been a tendency for larger provider organisations to emerge *via* mergers of smaller ones. Home care provider institutions in Switzerland come under the label of "hospital external care providers" (*Spitex*) and most of them provide a wide range of services, of which 44% are considered long-term care, and 56% additional (mainly household and social support) services. Around half the cost is met through public sources and half privately.

According to the most recent statistics, the volume and finance of home care services remained rather flat between 1997 to 2000, when the so-called "Spitex" providers are taken as representative of the home-care sector as a whole. In the future the home-care sector may not keep pace with growing demand.

United Kingdom

Since 1993, long-term care has been co-ordinated by local governments, which are the responsible bodies for assessment and care management.[6] Services may be provided by local government directly or by the private sector on contract to local governments. Funding for local government services comes mainly from general taxation, in the form of a central government grant related to local population characteristics, but also partly from local taxation and user charges.

Health services are provided by the *National Health Service* (NHS), which is funded through general taxation, and provided free at the point of use. The NHS contributes to long-term care in a number of ways, including community nursing, therapy services, and continuing care. Since 2002, the NHS has also been responsible for meeting the cost of nursing care provided in private nursing homes. Community nursing is provided free of charge through the NHS according to an assessment of need, either by the hospital or the general practitioner.

All nursing homes and most residential care homes are private, both profit or not-for-profit. The legal distinction between nursing and residential care homes was removed in 2002, but nursing homes provide nursing care in addition to the personal care available in residential care homes. Almost all social care services, including all institutional services, are subject to a charge depending on the user's income and assets.

Most elderly people needing care, however, receive it from an informal carer. According to a recent estimate (Comas-Herrera *et al.*, 2003). 53% receive informal care only, 34% both informal and formal care, and 9% formal services only. Of those with two or more ADL restrictions, 31% receive informal care only, 36% home-based formal care (sometimes together with informal care) and 32% received care in institutions.

Long-term care programmes

Institutional long-term care

There are estimated to be 5.1% of older people receiving long-term care in institutions: 3.1% in residential care homes, 1.7% in nursing homes and 0.3% in hospital (Comas-Herrera *et al.*, 2003). A minority of older people buy care privately in institutions (other than hospitals). Most older people receiving care in institutions (other than hospitals) have been assessed by their local government as needing to receive care, and will be charged according to a mandatory national scale. Those with assets over around EUR 30 000 are not eligible for support, while those with assets below this amount are required to pay a share that varies with income. From 2002, the NHS has financed nursing care provided in nursing homes, reducing the call on private assets.[7]

The level of fees for private institutional care, where this is paid for partly or wholly by local government, is subject to negotiation between the provider and each local government. Local governments acquired this responsibility as part of the "community care" reforms of 1993, and have used their powers to restrain the level of fees. There is evidence that some providers seek to recoup income by charging higher fees to all-private payers than to publicly-supported clients. The private institutional care sector has recently been declining in size, after considerable growth in the 1980s and early 1990s.

Home care

The United Kingdom provides a range of home-based services, with health services provided free of charge by the NHS and social care services either bought privately or provided through local government, generally carrying a charge subject to a test of income and assets. Local government is free to set its own charges and means-tests, although national government guidelines indicate the general principles that should be followed. The latest estimate from the 1998/1999 General Household Survey is that around one in five older people are receiving one or more of these services. Looking specifically at home help, around 4% of older people received local government-supplied home help, compared to an estimated 9% who bought it privately.

Policy towards provision of long-term care at home is that clients will, where possible, be offered alternatives to institutional care where this may help to keep them at home. Local government is subject to national government performance management in return for receiving central government grants, and one of the standards they are expected to meet is to increase the proportion of older dependent people who are receiving intensive home care packages. These have increased considerably in recent years from a low initial total. Recent legislation has also required local governments to offer cash alternatives to services (*Direct Payments*) to enable older people to make their own care arrangements.

However, local government-supplied home help is now much more targeted on the most dependent people. Over the past decade the percentage of older people receiving local government-supplied home help has shrunk from 8% to 4%, although at a more intensive level.

Cash support to carers

The United Kingdom provides a cash benefit known as *Carer's Allowance* to provide support to carers. To be eligible, carers must have limited employment income and be providing a minimum of 35 hours of care a week to a person who is themselves in receipt

of a benefit awarded to those dependent on others (*Attendance Allowance* or *Disability Living Allowance*). Until 2002, *Carer's Allowance* was available only to carers below the age of 65, but eligibility was then extended to those over this age. This mainly benefits carers with limited entitlement to state pension.

United States

Acute health care for older people is provided through the Medicare programme, funded by the Federal government through social security contributions. However, Medicare does not cover long-term care in institutions or home care services other than nursing for people with acute conditions. Older people who can afford to do so are expected to meet the costs of long-term care in institutions and home care other than acute care nursing. Where older people cannot afford to pay, the costs of assessed need are met through Medicaid, a means-tested social assistance programme that is joint-funded by the federal and state governments through general taxation.

Private long-term care insurance is available for those who wish and can afford to insure against the risks of needing care that is uninsured through Medicare. In 2001 there were 3.3 million people covered by such policies but the number of policies is growing. 15% aged 65 and older with annual incomes of USD 20 000 or higher now have private long-term care insurance coverage. At this level of income, the elderly can become eligible for means-tested Medicaid only if they "spend-down" their savings while in a nursing home.

From autumn 2002, under the Federal Long-term Care Insurance Program, people in Federal government service, including the armed forces, or related to someone in such service, a total of around 20 million people, have been able to buy long-term care insurance at discounted group rates from insurers that have been selected and approved by the government. A growing number of firms also offer long-term care insurance as an added option to private health insurance – currently around 3 500 firms do so.[8] However, while coverage is growing, currently private long-term care insurance covers less than 10% of long-term care expenditures.

Long-term care programmes

Institutional long-term care

Older people needing care in institutions are expected to pay for care unless or until their income reaches the level necessary to qualify for payment through Medicaid. Nursing home benefit is mandated by Federal law for all those Medicaid beneficiaries who are certified as requiring a nursing-home level of care. 94% of nursing homes are in the private sector, of which two thirds are private-for-profit. In 1999, 4.3% of those aged 65 and over were receiving care in nursing homes, a decline from 5.4% in 1985.[9]

In recent years there has been a growth in alternative forms of housing providing care, although this is still a small number of places by comparison with nursing homes. Assisted living is a type of living arrangement in which personal care services such as meals, housekeeping and assistance with activities of daily living are available as needed to people who can still live on their own in a residential facility. In most cases, residents pay a basic monthly rent and extra for those services they receive. Most assisted living facilities have to discharge residents who develop more severe needs.

Continuing care retirement communities provide different levels of care depending on what residents need over time. Residents may move from one setting to another as their

needs grow but still remain living within the community. This is a relatively costly care setting and requires a significant payment before the resident moves in, in addition to monthly fees.

Home care

There is a policy preference towards helping people to remain at home if possible, reinforced in 1999 by a Supreme Court judgement that upheld the right of individuals to receive care in the community as opposed to an institution, whenever possible.

As Medicaid is the public programme that covers nursing home costs where necessary, there has been a particular policy focus on developing ways to use Medicaid to prevent nursing home entry. From 1981, Medicaid has been able to be used by States that get the necessary Federal approval to support a range of different services that help to keep people from entering a nursing home (the Home and Community-Based Waiver program). The scope for using Medicaid to support a range of home care services has been expanded a number of times over these two decades.

However, as with other OECD countries, informal care from families and others considerably exceeds the extent of formal care services. An estimated one in four households are providing help to someone aged 50 or over with care needs.[10]

Notes

1. This annex provides a brief pen picture of the long-term care system in each of the 19 OECD countries taking part in this study. It is based on national replies to a questionnaire from the OECD, supplemented by official documents and other sources.
2. For a full account see OECD (2005), *OECD Reviews of Health Systems: Mexico*, OECD, Paris.
3. The numbers of expenditure and recipients of long-term care published in this study differ substantially from nationally published figures. They exclude acute care funded by the AWBZ programme and residential care homes not considered providers of long-term care according to the definitions used in this study.
4. Known as gerontological plans. The first was issued in 1993 and the current plan covers 2000-2005 (see Costa-Font and Paxtot, 2003).
5. All data refer to 2000, the latest comprehensive survey of the home care industry.
6. It is planned to begin phasing in a "single assessment process" from 2004, involving the health service.
7. Delivery of health and social care is devolved to the four constituent parts of the United Kingdom and the funding regime described here applies in England, Wales and Northern Ireland. In Scotland there is no means-testing for personal care at home or in institutions, and a means-test applies only to "hotel" costs.
8. US reply to OECD' questionnaire on long-term care and CMS Web site. *www.cms.hhs.gov/Medicaid/*.
9. National Nursing Home Survey.
10. *Source*: Family Caregiver Alliance. *www.caregiver.org*.

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The OECD Health Project

Long-term Care for Older People

Long-term care is a cross-cutting policy issue that encompasses a range of services for persons who are dependent on help for the basic activities of daily living. When the baby boom generation reaches the oldest age groups over the next three decades, demand for long-term care will rise steeply. How do governments in OECD countries respond to this growing demand? What has been done to increase access to long-term care and to improve the quality and affordability of services? Are there examples of successful strategies to improve the mix of services and policies to enable a larger number of older persons to stay in their homes? And has this helped contain the costs of caring for the elderly?

This study reports on the latest trends in long-term care policies in nineteen OECD countries: Australia, Austria, Canada, Germany, Hungary, Ireland, Japan, Korea, Luxembourg, Mexico, the Netherlands, New Zealand, Norway, Poland, Spain, Sweden, Switzerland, the United Kingdom and the United States. It studies lessons learnt from countries that undertook major reforms over the past decade. Trends in expenditure, financing and the number of care recipients are analysed based on new data on cross-country differences. Special attention is given to experience with programmes that provide consumers of services with a choice of care options, including cash to family carers. Concise country profiles of long-term care systems and an overview on demography and living situations of older persons make this complex policy field more accessible.

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