LIVINDHOME
Living independantly at home
Reforms in home care in 9 European countries

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1. Executive summary

1.1. Introduction

In the context of ageing societies, the need for home based care and support is likely to increase in the future. The number and proportion of the population aged 65+ will continue to grow and, despite the findings that disability prevalence rates have declined in some countries, the ageing of the population and the greater longevity will most likely lead to increasing numbers of people at older ages with severe disability and needing long-term care (Lafortune and Balestat, 2007).

The cost of long-term care for people aged 65+ is accordingly expected to rise from the present level of 1% of GDP across OECD countries to reach between 2% and 4% of GDP by 2050 (Oliveira Martins et al., 2006). Taking the needs of people with disabilities under 65+ into account as well, total public spending on health and long-term care could rise from the current average level of 6-7% of GDP to around 10% by 2050 (ibid).

The importance of home based care for older people and people with disabilities is accordingly growing as a more cost-efficient care solution. There is evidence in all OECD countries that home care services are seen as a way to provide care and support of independence for older people and people with disabilities in a financially sustainable manner. The number of recipients of institutional care has declined and home care arrangements now predominate in OECD countries, reflecting people with disabilities and older people’s preferences for home help and care but also an attempt to reduce reliance on expensive institutional care, particularly for recipients with lower levels of disability (OECD, 2005).

However, with falling rates of institutional living, more people rely on home care services, and this means that the home care systems have had to adapt to coping with higher levels of disability (Jacobzone et al., 1999). Furthermore, societal changes create pressures to find new and more cost-efficient care solutions. These changes include increasing female labour market participation; postponement of the retirement age for the workforce in general; changing family forms; and, in some countries, changes in attitudes as to who should bear responsibility for providing care for older people and people with disabilities. The question remains how national home care systems have been reformed to accommodate such changes and what have been the intended and unintended results of these reforms, in particular, how the reforms have affected the organisation, supply and quality of care.
1.2. The LIVINDHOME project

This executive summary summarizes the key findings from the project *Living independently at home: Reforms in organisation and governance of European home care for older people and people with disabilities (LIVINDHOME)*. The overall objective of the study is to identify how nine European countries have reformed their home help systems, in order to fund and deliver 1) high quality care which meets increasingly diversified and individualized needs, 2) an efficient and effective provision mechanism and cost containment, 3) a stronger user-orientation in the provision of care, 4) an optimal balance between formal and informal care and other resources, and 5) the best way to attract and retain home care workers.

The research questions focus on identifying the drivers of change in each country and that country’s responses with regard to the organisation, provision, regulation and quality of home care. The study captures a range of strategies and experiences of reforming home care for older people and people with disabilities. Each national study examines the following common questions:

- What have been the main driving forces for reforms in home care and what have been the reform strategies?
- What is included under home care?
- How is home care organized?
- How is home care financed?
- How is home care provided?
- Who are the carers?
- How is home care governed and regulated?
- How is quality of home care assessed?
- How are the policy changes overall related to outcomes for users?

The focus of the study is home care for older people and, to the extent that data is available, also for people with disabilities. Home care is in the study defined as help with bodily and domestic tasks in the home of the recipient. This may include assistance with tasks such as cleaning, shopping, getting dressed, bathing, preparing and eating meals, psychological support and help to participate in social activities. The study investigates services as well as cash benefits related to such tasks. The project concentrates on home care, but includes home nursing when this relates to the home care system, for example where there is integration or cooperation between nursing and care systems.
The study is based on national reports written by academic experts in social care policies and practice from each of the nine countries. The countries in the study cover a variety of welfare and care regimes and to some degree also a variety of countries within regimes. Countries included are: Austria, Denmark, England, Finland, Germany, Ireland, Italy, Norway and Sweden. Secondary data has been applied, including official statistics, policy analyses and social research conducted within and across the nine countries.

Draft and final versions of these reports were discussed at two meetings, held at the beginning and towards the end of the project. These meetings enabled inconsistencies in approaches to the country reports to be corrected, and common themes and issues to be identified. The researchers also worked in smaller groups to compile the summary matrix; to summarise the drivers of change in each country; and to pull together the comparative chapter and summary.

1.3. The drivers of reform

The findings are that, in all the countries in this study, actual and projected demographic trends are major pressures for reform. These have two main dimensions. First, there is the continuing increase in the proportions and absolute numbers of older people, particularly those aged 85-plus. Any improvements in health in later years mean that needs for help at home are concentrated in the last few years of life – but these needs are likely to be relatively intensive. Among younger age groups, numbers of people with very severe disabilities are also increasing. Secondly, demographic trends affect the supply of care. Increasing female employment, changing family structures and family breakdown all affect the supply of informal care, while declining birth rates will affect the supply of people available to provide paid home care.

These changes are taking place against a background of anxiety across many countries about current and future increases in public expenditure. Finding ways of managing demand, delivering more efficient and cost-effective home care, and maximising contributions from informal and voluntary sources are common concerns. A further common factor driving reform is a changing view of the welfare state, with future generations of older people expected to demand greater choice, personalised services and better quality home care support.

Given these contexts, it is not surprising that many countries in this study have introduced market-oriented mechanisms into their home care services, in order to drive down costs, improve
equity and increase opportunities for user choice and responsiveness, although the emphasis on each of these goals varies between countries.

1.4. Broad approaches to reform

Overall, each country’s approach to reforming home care services reflects its traditions, values and welfare state structures. However, two broad patterns can be identified among the countries in this study. In countries that have more family-oriented welfare traditions (Austria, Germany, Italy, Ireland), comprehensive approaches to long-term care have started to develop only relatively recently. Within these family-oriented countries, Germany and Austria have introduced new universal social rights relating to long-term care – including home care - that include changes to the traditional responsibilities of national and regional governments. Even so, their new arrangements for supporting people at home reflect each country’s structures and traditions. In contrast, despite increases in funding for long-term care, home care provision in Italy and Ireland remains highly fragmented, with major local variations in access to services.

The second group of countries (Denmark, England, Finland, Norway, Sweden) have had more or less comprehensive home care services in place for many years. These have been delivered by local authorities under a legislative framework set by central government. Reforms have here involved the introduction of market- and consumer-related mechanisms into the supply and delivery of home care. These include competition between home care providers and encouragement for new, for-profit providers to compete with traditional public sector providers. Associated with these market mechanisms, new ways of safeguarding service quality, increasing flexibility and improving efficiency have been introduced.

Nevertheless, in England, Finland and Sweden, local authorities have increasingly targeted their home care services on people with the highest needs for support. This has meant a major shift in the balance between formal and informal care. In the following, findings for each of the research questions are reported.
How does the state govern home care? The respective responsibilities of central, regional and local governments

In most of the countries in this study, national legislation and regulations play a major role in determining the levels and form of home care services, by setting out the responsibilities of regional and/or local governments. Significantly, this national government role pertains regardless of whether funding comes predominantly from national taxation (England), local taxation (Denmark), both national and local taxation (Norway), or social insurance contributions (Germany). Central government responsibilities can include setting eligibility criteria for home care, levels of user charges and quality assurance mechanisms, as well as ‘soft’ policy initiatives that do not require primary legislation.

The most extensive example of central government control is Germany, where federal legislation sets the levels of insurance contributions and benefits, eligibility criteria and assessment processes. The German federal government also regulates competition between providers, sets quality standards and encourages labour supply into the sector.

In Finland, Sweden, Norway, Denmark and England, regional and/or local governments are responsible for implementing national legislation and regulations. Here, regional/local governments determine the scope of home care services, how services should be organised and to whom; and ensure that services meet national quality standards. These divisions of responsibility reflect long-established constitutional arrangements.

However, in Italy and Ireland, central governments have to date had little overarching responsibility for ensuring adequate or equitable provision of home care services by regional or local governments. Consequently there are major regional and local inequalities in the availability and quality of services. In Italy, lack of central government responsibility has led some regions to develop their own home care services, thereby exacerbating geographical inequalities.

Our conclusion is that overall responsibility by central government for provision and regulation is essential in securing adequate levels of home care services, safeguarding quality and reducing local inequalities. Within this national framework, local authorities can make detailed arrangements for the scope, access, supply, quality and efficiency of local home care services.

What mechanisms contain costs and promote efficiency?

Some cost containment measures are set by national governments; others are initiated by local or regional governments. Among those legislated by national governments, again Germany stands out,
with long-term care insurance contribution and benefit levels set nationally; unmet needs for home care are met by relatives or the private employment of care workers on the grey labour market. The German federal government also promotes competition between providers to keep down costs and has relaxed some social protection regulations to reduce labour costs.

More generally, cash-based care allowances (Italy, Austria, Germany) are effective mechanisms for containing costs. They generally cover only part of a recipient’s care costs, at any level of need; can be frozen while care costs rise; and can be adjusted so that fewer people, with higher level needs, are eligible.

A widespread mechanism used to promote efficiency is the introduction of competition between provider organisations, in the expectation that this improves quality and drives down costs. Competition between providers – and particularly the encouragement of new, private providers to compete with traditional monopoly provision - has been encouraged in Germany, Denmark, Sweden, Finland and England. In Italy, most home care services are contracted out by municipalities. In England, personal budgets allow more personalised home care support to be purchased, thus improving cost-effectiveness.

Other cost-containment mechanisms are less formal and reflect local responses to funding pressures rather than national policy. They include removing domestic help from the scope of home care services and restricting eligibility for services to those with the highest support needs. Some Nordic countries have tried to improve efficiency by regulating the time spent by home care workers on individual care tasks.

Examples of measures intended to reduce demand for home care include self-help schemes (Denmark); re-ablement approaches (England); and annual preventive visits (Denmark).

**Cash or services?**
Cash allowances in lieu of services can be introduced for different reasons: to stimulate market developments in home care services; to support family-based care; to contain costs; or to improve quality or equity. Some countries have made cash allowances the cornerstone of their policies for supporting older people and people with disabilities at home; others have introduced them in a more limited way. Generally, cash allowances remain relatively limited in the Nordic countries, where they have been used mainly to support family care. In Ireland, Italy and, in a more regulated manner Austria and Germany, there is a marked emphasis on cash payments, albeit with different outcomes.
In Germany, the insurance cash option mainly supports family care. In Italy, in the absence of local home care services, the cash allowance is commonly used to employ migrant care workers.

Cash options sometimes aim to empower older and people with disabilities, by offering more choice and control over home care support, as in England. In Denmark and Sweden, cash options play a very limited role and consumer choice is facilitated by allowing choice between home care service providers. As noted above, the costs of cash options are more easily contained. Particularly given the experiences of Italy and Austria, there is no evidence on the effectiveness of cash options in stimulating new, quality home care services.

**Boundaries between public and private care**

Home care combines public and private responsibilities in many different ways. Home care can be financed from public or private funds; provided by public or private sector organisations; and delivered by publicly or privately employed carers such as personal assistants or live-in carers, who are nevertheless paid from public funds such as care allowances. Even when privately purchased and provided by private organisations, home care services are still likely to be subject to public regulation and quality control. Family members are of course a major source of home care and may be supported by publicly-funded care allowances or benefits.

A common combination, for the countries in this study, is for home care services to be publicly funded, provided by private organisations and supplemented by family care. Indeed, many countries have introduced mechanisms that allow new, private home care provider organisations to enter the market and compete with traditional public or other monopoly providers. The entry of new providers has occurred to varying degrees, in Sweden, Denmark, England, Italy and Germany.

However, marketisation can have other consequences, particularly when reforms involve the provision of care allowances with which recipients can purchase home care. Rather than stimulating the growth of private home care provider organisations, care allowances have led to an increase in privately employed, live-in migrant care workers in Austria, Italy and, to a lesser extent Germany. In Germany and Austria, this has prompted the introduction of new regulations relating to the terms and conditions under which migrant care workers are employed, thereby arguably moving such arrangements from private to semi-public status.

A common reform process – by accident or design – involves shifting responsibility for funding and providing at least some home care support from the state to the individual and family. As a consequence of freezing levels of insurance benefits (Germany), limiting the scope of state-
funded home care packages (Ireland) or raising eligibility thresholds for home care (England, Sweden), at least some aspects of home care must be met from private resources. In Finland and Sweden, tax deductions for household work have incentivised higher income people to purchase care services privately from for-profit providers.

Denmark excepted, heavy reliance on families to supplement publicly-funded home care services is widespread. Low income family carers may receive benefits in their own right (England and Ireland); in other countries, carers (of all income levels) are supported from the care allowances received by the older or disabled person (Germany, Austria, Italy). Indeed, the cash benefit option in the German long-term care insurance scheme has been remarkably successful in sustaining family-oriented care. In the Nordic countries, in contrast, a division of labour has emerged whereby publicly-funded home care services provide personal care and families provide social support and domestic help. However, this is changing, with new responsibilities to support family carers being introduced in Sweden.

In many of the countries, the way that older people and their families respond to shortfalls in the levels or coverage of publicly-funded home care services depends on their socio-economic situation: more affluent older people and their families are more likely to purchase additional services from their own private resources; less wealthy individuals are more likely to supplement publicly-funded services with (unpaid) family care.

**Recruiting and retaining home care workers**

Recruitment and retention of workers in home care services (whether public or private) is a common problem for the countries in this study. Care work is often low status and low waged, and working conditions poor, leading to high staff turnover and vacancy rates. Indeed, some reforms may exacerbate these problems; measures to increase efficiency can reduce home care workers’ job satisfaction by reducing their autonomy and ability to develop rewarding relationships with clients (Norway, Denmark). Encouraging the entry of new private home care provider organisations can disperse responsibility and make compliance with regulations more difficult (Norway). Nevertheless, in the Nordic countries working conditions appear broadly comparable between public and private service providers. This is not the case in Ireland, where workers employed by for-profit home care providers are required to be more flexible, and on average have lower wages and weaker social rights than their non-profit or public sector counterparts. The lower costs
anticipated from marketisation and provider competition may, therefore, have damaging effects on the private sector care workforce.

Workforce recruitment and retention can be helped by professional training; such measures can also help improve the quality of care. Overall, in the Nordic countries home care managers and needs assessors usually have higher educational qualifications in social work or nursing and front-line staff often have some professional training as well. Indeed, Denmark has raised the educational level of its home care workers as a means of encouraging recruitment to the sector, as the care qualification can be the first step to professional nursing training. In Germany and Austria too, reforms to training programmes have aimed at improving the qualifications and professional identity of home care workers.

On the other hand, cash-for-care options can offer new, less formal employment opportunities and these may attract more people, albeit without qualifications, into the home care sector. The private employment of migrant care workers in Austria and Italy, partly funded by care allowances, shows this clearly; in Italy, expenditure on privately employed migrant care workers is now more than double that on formal home care services. Personal budgets in England may, in the longer term, also encourage more people into flexible, but largely unregulated, home care work.

Recruiting migrant or foreign-born workers is also a means of increasing the formal home care workforce (Sweden, Ireland and Denmark).

**Quality regulation**

Quality of care has multiple interpretations but becomes critically important when resources are scarce and increasingly individualised provision is demanded. Norway illustrates the range of activities covered by ‘quality’-related measures. These include: a national accountability arrangement, where municipalities must set up audit systems and written procedures on how they are meeting national quality guidelines; management tools to improve efficiency; and collaborative agreements with trades unions.

At an organisational level, in the Nordic countries, national legislation specifies that local governments are responsible for regulating the quality of home care services. In England, home care provider organisations must register with an independent national body; in order to register, providers must comply with minimum financial, operating and quality standards, including staff training plans. Regular independent inspections of home care agencies are also conducted. At the
other end of the spectrum, in Ireland and Italy there is no involvement by the national government in quality regulation, leading to widespread variations in quality across the regions.

Service quality can be improved by the integration of different functions, such as domestic, personal and nursing care. This is true of many providers in Austria; in Germany, a comprehensive network of local care management services has been created to promote service co-ordination. In many countries providers also use care and case management tools to customise, plan, co-ordinate and evaluate home care service packages.

Users have different opportunities to influence the quality of services, including regular national user surveys (England, Finland, Sweden, Denmark). These surveys can reveal differences in satisfaction between different home care providers. However, few older people apparently see changing to a different provider as a means of improving the quality of their home care services.

**Equality and equity**

Levels of geographical equity in the levels, organisation and delivery of home care services are partly determined by how far central governments play a strong role in setting legislative and regulatory frameworks. Local variations are most marked in Italy, where central government plays no role in relation to home care; as a consequence northern and central regions have much higher levels of home care services than the southern regions, where the balance of support is in the form of cash payments. In Ireland too, the lack of national guidelines on assessment, eligibility and quality assurance results in widespread local variations in access to home care services. In England, although there is an extensive national legislative and regulatory framework, actual eligibility depends on the financial situation of individual local authorities, resulting in extensive local variations.

The Nordic countries have tried to improve consistency and equity in access to and levels of home care services by, for example, standardising maximum levels of user charges (Sweden, Norway); rights to assessment (Finland, Sweden, England); standardisation of assessment tools (Denmark); and other procedural rights (Norway). Nevertheless, given the extensive autonomy of local authorities in these countries, local variations are apparent.

Major geographical inequalities in home care services can prompt major reform programmes. In Austria, big regional differences in home care services prompted the development of the national cash allowance scheme. German long-term care insurance has similarly introduced universality and equity into care arrangements that were previously characterised by fragmentation.
and significant inequalities in access, quality and levels of funding for care. Subsequent modifications to the long-term care insurance scheme have also enhanced diagnostic equity, by improving access to long-term care insurance by people with cognitive impairments.

All countries (apart from Denmark) concentrate home care services on those with the highest levels of need. England additionally takes into account help given by families, so that people with very high levels of need provided by family carers may not qualify for home care support (though their carer may be eligible for some help, instead). Age-based inequalities are apparent in some countries, particularly England where personal budgets are more generous for working age than older people; and Sweden, where there are inequalities in access to services between people who acquire a severe disability before and after age 65. On the other hand, care allowances in Austria and Italy, and long-term care insurance in Germany make no age distinctions; people above and below retirement age are eligible on the same terms.
2. Introduction

This report concludes on the findings from the project *Living independently at home: Reforms in organisation and governance of European home care for older people and people with disabilities (LIVINDHOME)*. The study provides a timely overview of recent and current reforms in the organisation and governance of home care systems in nine European countries, and analyses the intended and unintended results of these reforms, in particular, how the reforms have affected the organisation, supply and quality of care.

2.1. Background

The background for the study is that in the context of ageing societies, the importance of home based care is growing. There is evidence in all OECD countries that home care services are seen as a way to provide care and support of independence for older people and people with disabilities in a financially sustainable manner. The number of recipients of institutional care has declined and home care arrangements now predominate in OECD countries, reflecting people with disabilities and older people’s preferences for home help and care but also an attempt to reduce reliance on expensive institutional care, particularly for recipients with lower levels of disability (OECD, 2005).

The need for home based care and support is likely to increase in the future. The number and proportion of the population aged 65+ will continue to grow and, despite the findings that disability prevalence rates have declined in some countries, the ageing of the population and the greater longevity will most likely lead to increasing numbers of people at older ages with severe disability and needing long-term care (Lafortune and Balestat, 2007). With falling rates of institutional living, more people rely on home care services, and this means that the home care systems have had to adapt to coping with higher levels of disability (Jacobzone et al. 1999).

The cost of long-term care for people aged 65+ is accordingly expected to rise from the present level of 1% of GDP across OECD countries to reach between 2% and 4% of GDP by 2050 (Oliveira Martins et al., 2006). Taking the needs of people with disabilities under 65+ into account as well, total public spending on health and long-term care could rise from the current average level of 6-7 % of GDP to around 10% by 2050 (ibid). Furthermore, societal changes create pressures to
find new care solutions. These changes include increasing female labour market participation; postponement of the retirement age for the workforce in general; changing family forms; and, in some countries, changes in attitudes as to who should bear responsibility for providing care for older people and people with disabilities.

Women who enter the labour market may take up work in the care sector, yet most countries are experiencing difficulties in attracting and retaining caregivers to what is often perceived to be physically and mentally demanding work. Countries therefore need to consider how to meet the growing demand for long-term care workers. This might involve the employment of migrant care workers, in the formal carer sector or as informal care providers in the home; and new measures to retain those currently working in the sector, where working conditions, salaries and status are often poor.

The increase in female labour force participation also means that informal care resources are less likely to be readily available. An additional factor is that with increases in women’s educational attainments, the opportunity costs of caring for older people and people with disabilities rise. Family caregivers – of whom many are women - also report lost income and benefits, having to reduce work hours and quitting work (Lamura et al, 2004).

Expansion of public care systems has in many countries relieved family carers from some of their caregiving tasks. Care systems which provide generous and high quality formal care may in fact ensure the continuous involvement of informal carers, as there is evidence that increased public services leads to increased informal care (ter Meulen, Arts and Muffels, 2001, Künemund and Rein, 1999). However, as we have found in this study, we are also witnessing trends towards informalisation and marketisation, as older people turn to the market or the family when levels of public home care services are reduced (Szebehely, 2007)

Older people (and people with disabilities) thus seem to have access to different types of care resources, but as studies by Daatland and Herlofson (2003) have shown, it is not always family care which is preferred. Older people often prefer to receive home care provided by professionals and to maintain residential independence by not having to move in with relatives (European Foundation for the Improvement of Living and Working Conditions, 2004).

Many countries are facing new challenges in meeting increasingly diversified and individualized needs. Stronger user orientation may be achieved through the introduction of various choice options, such as cash support for informal care or opportunities to choose between providers of formal care (Burau, Theobald and Blank, 2007). The introduction of cash for care allowances has
in many countries been accompanied by a general trend towards market-inspired reforms sometimes termed ‘New Public Management’ (NPM), as a way to make services more cost-efficient and effective (Vabø, 2003; Knijn, 2000; Ungerson, 2000; Szebehely 2007). However, the tight specification and routinisation of care tasks may affect the job satisfaction of workers and the quality of the care received by clients.

2.2. Aims and objectives

The LIVINDHOME study aimed to investigate what reforms have been and are being introduced across a number of European countries in order to meet these challenges, mainly focusing on the period 2000-2010. The overall objective of the study was to identify how nine European countries have reformed their home help systems, in order to fund and deliver 1) high quality care which meets increasingly diversified and individualized needs, 2) an efficient and effective provision mechanism and cost containment, 3) a stronger user-orientation in the provision of care, 4) an optimal balance between formal and informal care and other resources, and 5) the best way to attract and retain home care workers.

The research questions focused on identifying the drivers of change in each country and that country’s responses with regard to the organisation, provision, regulation and quality of home care. The study captured a range of strategies and experiences of reforming home care for older people and people with disabilities. Each national study examined the following common questions:

- What have been the main driving forces for reforms in home care and what have been the reform strategies?
- What is included under home care?
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- How is quality of home care assessed?
- How are the policy changes overall related to outcomes for users?
The national studies address these common research questions, but also highlight special national features of reform where relevant. For example, the English study focuses on the theme of markets in home care and the continuing - and growing - blurring of the boundaries between public and private domains. The Danish study focuses on tools for measuring quality. The Finnish study looks especially into the complementarity between formal and informal help. The German and Austrian reports look particularly at the increasing role of migrant home care workers; and the Norwegian study looks especially at the processes of governance.

2.3. Structure of the report

The report is structured in the following way: The first part of the report gives an overview of the study. This includes in the next chapter, Chapter 3, an account of the methodological approach and data applied. Following this, in Chapter 4 is a comparative account of the main findings. This is organized in three sections, first giving an overview of drivers of reforms and reform trajectories, which is followed by an account of the policy reforms. Finally, a matrix provides a comparative overview of responses to the research questions. The national reports are found in the second part of the report.
3. Methodology

3.1. Focus of study and definition of home care

Given that most research on home care is focused on older people as the recipients of home care, this project also reflects this focus, but includes data relating to home care for younger people with disability where these are available and relevant. The project concentrates on home care, but includes home nursing when this relates to the home care system, for example where there is integration or cooperation between nursing and care systems.

Home care is defined as help with bodily and domestic tasks in the home of the recipient. This may include assistance with tasks such as cleaning, shopping, getting dressed, bathing, preparing and eating meals, psychological support and help to participate in social activities. The study investigates services as well as cash benefits related to such tasks.

3.2. Choice of countries

The choice of countries in the study is based on recent experiences of reforms in home care systems and on care regime theory (Anttonen and Sipilä, 1996; Bettio and Plantenga, 2004). The latter distinguishes the Scandinavian countries (here represented by Finland, Sweden, Norway and Denmark) as having universal public services; the Southern European countries (here represented by Italy) as having a family care model; the Continental countries (here represented by Austria and Germany) as having a state-supported subsidiary model where the family takes on responsibility first supported by public cash payments; and the residual model (here represented by England and Ireland) which provides publicly-funded help to only those who are less affluent. The study therefore covers a variety of welfare and care regimes and to some degree also a variety of countries within regimes.

3.3. Participants

Academic experts in social care policies and practice from each of the nine countries prepared reports on their respective country. Draft and final versions of these reports were discussed at two meetings, held at the beginning and towards the end of the project. These meetings enabled
inconsistencies in approaches to the country reports to be corrected, and common themes and issues to be identified. The researchers also worked in smaller groups to compile the summary matrix; to summarise the drivers of change in each country; and to pull together the comparative chapter and summary.

3.4. Data

The study is based on secondary data – official statistics, policy analyses and social research conducted within and across the nine countries. As the comparability of national statistics is still under revision (e.g. recent OECD studies or Huber et al, 2006), no attempt has been made to provide comparative overviews of e.g. take-up of home care. However, we have compiled a summary matrix to compare the national systems and reforms, in order to ensure consistency in the data presented for each country.
4. Comparative perspective

4.1. Overview: Drivers of reform and reform trajectories

In this section we summarise the main factors that have shaped recent developments in home care services in the countries in this study. First, in all the countries, actual and projected demographic trends constitute a major pressure. Foremost among these trends is the increase in the proportions and absolute numbers of older people, particularly those aged 85-plus who are most at risk of needing help with domestic and personal care. However, simple population ageing is not the only demographic trend. There are arguments, for example, that increasing longevity is associated with a ‘compression of morbidity’, whereby needs for additional support are increasingly restricted to the last few years of life so that needs for care are relatively short-term but also relatively intensive. Among younger age cohorts, developments in medical techniques and technology mean that people with very severe disabilities resulting from, for example, extreme prematurity or accidents are increasingly likely to survive and be able to live outside hospital settings, albeit with intensive personal and social support.

Demographic trends also shape the supply of care. Changing family structures – particularly trends towards later family formation, women’s labour market participation and family breakdown and reconstitution – affect the supply of informal care. Changes in the relative proportions of younger and older people also mean that, without inward migration, working age populations are in relative decline, leading to a decrease in the supply of people available for employment as home care workers. On the other hand, to the extent that increased longevity is accompanied by good health for all but the last few years of life, younger retired people may increasingly be available to provide both paid and unpaid care for the very old.

These trends are occurring against a background of growing anxieties about current and future increases in public expenditure, as European countries struggle to maintain global economic competitiveness. Some projections suggest that expenditure on long-term care could easily double over the next 40 years. Consequently, there is widespread interest in ways of increasing the efficiency and cost-effectiveness of home care services; by reducing (or slowing the increase in) demand for care; and by maximising the contributions of (lower cost) informal and voluntary carers.
Another factor influencing reforms in home care is what has been assumed to be a crisis of the welfare state. There has been an alleged decline in the popularity and resilience of the traditional, solidaristic post-war welfare state. Current and future cohorts of people reaching retirement and ‘old’ older age have experienced several decades of increasing emphasis on individualisation and consumerism. These experiences are likely to shape their expectations of the nature and the quality of the home care they receive in their ‘older’ old age. Thus more people may expect to be able to obtain home care services that are personalised to fit their own circumstances and priorities; that reflect the specific balance they desire between formal and informal sources of help; and that are responsive to market-style mechanisms such as price in the same way as other commodities they are accustomed to purchasing. These broader cultural and ideological considerations are also common factors shaping reforms. It is therefore perhaps not surprising that many of the countries in this study have, deliberately or by default, introduced market-oriented mechanisms into their reforms of home care services.

In these contexts, interest in the policies and practices of other countries, and their effectiveness in delivering high quality care at modest costs, is unprecedentedly high. However, while these background trends are shared by all the countries in this study, their responses have been rather different. Home care services, like long-term care services in general, are embedded within the traditions, values and structures of individual welfare states and any convergence between the approaches of different countries is likely to be constrained by these different contexts. Thus the approaches of the countries in this study to reforming home care services differ in their starting points, reform strategies and time frames.

Nevertheless, among the countries in this study, two broad clusters can be distinguished. Within the more family-oriented countries - Austria, Germany, Italy and Ireland – more comprehensive long-term care approaches have developed only since the 1990s. In contrast, Denmark, England, Finland, Norway and Sweden had longer histories of formal home care services which have been subject to considerable restructuring since the 1980s.

Among the first group of family-oriented countries – two broad patterns of change can be identified. In Austria and Germany, a lack of universal funding for long-term care, poor care service infrastructure and considerable local/regional budgetary pressures triggered the introduction of national, universal long-term care arrangements. These reforms took place within a corporatist system based on traditions of negotiations between politicians and social partners (employer and employee representatives). In both countries, new social rights relating to long-term care were
introduced; however, the specific impacts on home care services have reflected institutional structures and traditions, including the constitutional responsibilities of central and regional governments.

In contrast, in Ireland and Italy, despite the lack universal access to home care and limited public funding, central governments have not introduced new social rights in the form of improved funding for and access to home care services. Funding for home care and service provision were greatly expanded in Ireland for a period of about seven years starting in 2000, at least partly to resolve pressures on the acute hospital sector. This has led to a growth of private for-profit providers and the establishment of a care market with both private for-profit and non-profit care providers. Only recently (2010) has media attention to malpractices in home care prompted concern about regulation of the sector. In Italy there remains an absence of comprehensive, national policies for home care, with major variations in levels of provision between regions and municipalities. The most important national measure (and one that has been introduced by some regions and municipalities as well) is a cash allowance. However, the shortage of home care services and the traditions of family care have led to a major growth in migrant care workers often illegally employed within the family.

The second group of countries - Denmark, England, Finland, Norway and Sweden – have had well-established, extensive home care services in place for a number of years. Here reforms have involved restructuring and, in particular, the introduction of a range of market and consumer-related mechanisms. Here central governments have set overarching policy frameworks, with municipalities and local authorities responsible for their implementation. Although other reform trajectories – shifting the emphasis from residential to home-based care, integrating health and social care – have also been involved, the main feature of reform has been the introduction of market orientations in the supply and delivery of home care. These have included introducing competition between home care service providers and encouraging for-profit providers to compete with traditional public sector providers in the provision of publicly-funded care. At the same time, home care users are expected to choose between providers in order to secure the service inputs that suit them best; in England, home care service users are themselves able to become purchasers through the allocation of personal budgets. Further reforms associated with the introduction of market mechanisms into home care include new mechanisms for assuring service quality and increasing flexibility.
However, despite an absence of formal legislative changes, in Sweden, Finland and England there has also been marked targeting of home care services on those with the highest support needs. Whether this reflects a deliberate policy (as in Finland) or not, the effect has been a major shift in the balance between formal home care and informal care.

4.2. Policy responses

This section of the Final Report will draw together and discuss the details of the reforms in the individual countries. We aim in this section to identify the lessons for policy learning and transfer from the individual country accounts. The account will also attempt to highlight the tensions and balance between national reforms that are embedded in local histories, traditions (welfare state, gender and families), and any convergence towards common trends. Reforms are discussed under the following headings:

- **How does the state govern home care?** What are the roles of central, regional and local government in funding, quality assurance, contracting, regulation and accountability? What are local vs national responsibilities and discretion; what roles do national governments play in ensuring rights and consistency?

- **What mechanisms are used to contain costs and promote the efficiency of home care services; how effective are these; and what consequences do they have?** What kinds of markets exist and how effective are they in promoting efficiency and quality services? What roles do different types of providers – in-house, non-profit, for-profit play? What managerial and other regulatory mechanisms are used to increase efficiency?

- **Cash vs service options.** Under what conditions (especially what types of regulation) do cash payments deliver optimum outcomes for users of home care services? Potential outcomes might include choice, quality and equalities/equity.

- **Public vs private realms.** What are the balances between public and private funding for home care; between public and private sector organizations delivering services; and between care delivered by formally employed carers, ‘grey’ labour and informal care?
• *Effective workforce strategies*. What measures appear to promote the recruitment, training and retention of home care workers, including: recruitment and retention strategies, professionalization and qualifications and the role of migrant workers?

• *What quality regulation mechanisms are employed* (including mechanisms for co-ordinating home care with other services); at the organisational level (provider registration, inspection etc); at the individual service user level (complaints mechanisms, exit, voice strategies); and for service co-ordination mechanisms – care management, professional co-ordination, informed consumers?

• *Equity and equality.* To what extent do patterns of funding and organising home care services lead to equality? How can personalised approaches to the delivery of home care services be combined with equity in relation to access and quality of services, between younger persons with disabilities and older people, between people in different geographic regions, between different diagnostic groups (especially physical disability vs dementia) and in relation to class/socio-economic inequalities?

*How does the state govern home care? What are the respective roles and responsibilities of central, regional and local governments?*

In all but three of the countries in this study, central governments play a major role in shaping home care services, although in no instance is central government responsible for the actual delivery of services. Rather, through national legislative and regulatory mechanisms, central governments clearly set out the responsibilities of regional and/or local governments in relation to home care services. Significantly, this pattern of overarching central government responsibility pertains regardless of whether funding for home care services is derived predominantly from national taxation (England); local taxation (Denmark); is split equally between the two (Norway); or is derived from individual insurance contributions (Germany). Thus, central government legislation can variously set out the eligibility criteria for home care services (e.g. in Germany in the form of in-kind insurance benefits); the levels of user charges (Sweden); and, particularly common, measures to safeguard the quality of services (England, Norway, Denmark). Central governments also issue many more ‘soft’ policy measures, special initiatives and guidelines, that shape the nature and levels of local home care services but which do not require primary legislation.
The most extensive example of central government regulation of home care is in Germany, where home care services are funded through the Long-term Care Insurance scheme. Federal government legislation specifies the levels of insurance contributions and benefits, eligibility criteria and assessment processes (which are standard across the country). The Federal government also regulates the home care provider market, by setting out the conditions under which providers can register with insurance fund purchasers; specifies quality management systems; and initiates measures designed to increase the supply of home care workers.

However, in most other countries, the implementation of national legislation and other regulatory instruments rests with regional and/or local governments. Within central government legislative frameworks, regional and local governments are generally responsible for determining the scope of home care services (whether, for example, they include health-related or domestic/housework tasks); and how services should be provided, to whom and by whom. Thus, in Finland, Sweden, Norway, Denmark and England, regional or local authorities are responsible for organising, funding and delivering home care services; for assessing eligibility for services; and for monitoring service quality, according to national standards. To some extent, these divisions of responsibility reflect long-established constitutional arrangements in the Nordic countries (and to a lesser extent England), with their strong traditions of local autonomy.

In three countries in this study, however, central governments take little or no overarching responsibility for ensuring the provision of home care services by regional or local authorities. In consequence, there are very marked local variations in levels of services; in eligibility and access arrangements; and in the quality of those services that are available. These consequences can be clearly seen in Italy and Ireland, where major regional and local inequities in the availability and quality of services are apparent. Indeed, the absence of national government responsibility in Italy has led some regions to develop their own home care services, thereby increasing regional inequity even further. In Austria, regional variations that were prominent in the early 1990s have been substantially reduced. This was a consequence of a state-provinces agreement on the development of long-term care services and of strong regional commitment to developing home care.

In both Austria and Italy national governments do nevertheless play an important role, through the funding of cash-based care allowances for older and younger people with disabilities. These can be used without restriction to purchase care. However, in Italy because of the lack of national government commitments to, and clear regional/local government obligations for, the development of home care services, adequate local services are rarely available.
In general, therefore, we would argue that central government responsibility for the overall provision and regulation of home care services is essential in securing adequate levels of provision; in safeguarding quality; and in reducing local inequalities. However, this does not mean that all changes are wholly dependent on national legislation or regulation. Local pressures – particularly those arising from budget constraints – can reshape national arrangements and patterns of services. Thus in Finland, England and Sweden, there has been a marked shift towards the provision of intensive home care services to much smaller numbers of clients, without any changes in the formal legislative framework. Similarly, in Finland, local integration of health and social care services has changed the nature of home care to include nursing as well as personal care, while housework (as in England too) is now rarely part of home care services.

What mechanisms are used to contain costs and promote the efficiency of home care?

Countries may apply a number of measures to contain costs and promote the efficiency of home care services. Overall, cost containment measures fall into two groups: those legislated for and promoted by national governments; and those that, as noted above, are initiated locally (albeit on a widespread scale) by local and regional governments responsible for the provision of services.

Among the first group of measures, the German Long-term Care Insurance scheme stands out as containing multiple cost-control measures. Contributions are determined by central government and these in turn determine available benefit levels. Both contributions and benefits were frozen between 1995 and 2008 (although this was only partially successful in capping total public expenditure as it led to an increase in demand for means-tested social assistance to cover outstanding care costs). Otherwise, unmet home care needs are met by informal care or by the private employment by care workers on the grey labour market. Federal government also encourages competition between home care providers and has allowed providers to offer unqualified workers lower wages and social protection commitments and to recruit volunteers for some home care tasks.

More generally, cash-based care allowances, as in Italy, Austria and Germany, are effective mechanisms for containing costs. First, they cover only part of a recipient’s total care costs at any level of need. Unmet needs for help at home are then met through unpaid family care; through the private purchase of additional home care by more affluent groups; or by the employment of low waged care workers employed on the grey labour market. Secondly, levels of allowances and eligibility criteria can be adjusted so that, for example, fewer people become eligible. This practise
can be seen in a number of countries; for example, in 2011, Austria made access to the lower benefit levels one and two more restrictive, although the coverage of the Austrian care allowance remains broader than in any other country with cash benefits. Another measure promoted by some national governments aimed at improving efficiency, is the introduction and extension of market mechanisms into home care services. By introducing and increasing competition between providers, marketisation is assumed to improve quality – and more indirectly drive down costs. The German Long-term Care Insurance legislation opened up the home care market to new non-profit and for-profit providers. In Denmark, Sweden, Finland and England, private sector providers have been encouraged to compete with public sector home care service providers. In Italy, most home help services are contracted out by municipalities. In England, individuals are increasingly offered a personal budget that allows them to purchase services directly from home care providers (rather than the local authority purchasing on their behalf). While not necessarily reducing costs, it is expected that this will enable more personalised home care to be delivered and therefore improve cost-effectiveness.

Across the countries in this study, a number of other cost-containment measures are apparent that appear to reflect local responses – rather than national policy - in the face of widespread funding pressures. Removing domestic and household help from the scope of home care services is one such strategy. This occurred in England and Finland during the 1990s; currently domestic help is being scaled down in Danish and Norwegian home care services, for example. Restricting the coverage of publicly-funded home care services mainly to those people with the highest levels of need is a further, widely used cost-containment measure; this has occurred in Sweden, Norway, Finland and England. As a consequence, more intensive home care services are now provided to far fewer households, with very few households receiving low levels of home care of a few hours a week.

Three of the Nordic countries in this study, Denmark, Norway and Sweden, have explicitly introduced managerial measures that aim to improve the efficiency of home care workers. All three countries regulate the time of home care workers, by restricting the tasks that home care workers perform to only those specified on the care plan.

The study includes examples of locally organised, client-level initiatives to reduce demand for home care services. In Denmark, the ‘help-to-self-help’ programme encourages older people to take responsibility for their own functional ability in the hope of reducing demand for formal home care services. Norway had previously adopted similar practices, which critics alleged was primarily
a cost-cutting measure. Today Norway has toned this down and now is more concerned about delivering predefined services, with little or no focus on the empowerment principles. In England, many people needing home care now receive an initial intensive period of re-ablement that aims to improve their self-care skills and confidence and reduce their longer-term needs for services. Another initiative aimed at reducing demand is the Danish preventive visits scheme. Here national legislation requires local government to carry out annual preventive home visits for people aged 75+, and with clear evidence of a preventive effect.

While this study has identified a range of measures aimed at containing costs and/or promoting efficiency, it has not always been able to establish how effective these measures actually are. In all countries, however, extensive reliance on informal care remains the most common mechanism for containing costs on formal care services. This point is elaborated below, in discussing the balance between private and public responsibilities for home care.

**Cash vs. service options**

A cash option may be introduced in order to increase choice for users; to stimulate market development in home care services; to support family-based care; or to increase quality or equity. There is considerable variation in the extent to which countries in the study have introduced cash options or made them the cornerstone of their policies for supporting older and people with disabilities at home. Some countries have made cash options the mainstay of their home care policy, others have only experimented with them in a more limited way. Generally speaking, cash options are still relatively limited in the Nordic countries. In Ireland, Italy and, in a more regulated manner, Germany and Austria, there is a notable emphasis on cash options. The German Long-Term Care Insurance cash option is usually used to support private, family home care or to employ migrant care workers. In Austria, in the majority of cases, the Care Allowance is used to support family care. A growing number of recipients also use the Care Allowance to pay for home care services (as co-payment) or to employ regularised migrant care work. In case of residential care, the Care Allowance is paid directly to the nursing home. The most extreme case of reliance on cash options is Italy, where public expenditure on the national cash allowance towards the purchase of home care services exceeds the combined public expenditure on residential care and formal community services provision.

The introduction of cash options is argued by some to mark a shift towards greater autonomy for older people in making decisions about their own care. Users’ ability to choose the
care and support they need is argued to lead to consumer empowerment and ultimately better quality of services, as providers compete for the business of individual service purchasers. In some countries, especially England, the trend is towards more flexible use of cash options, so that service users can purchase a very wide range of help, including paying relatives and friends or buying commercial services. Notable exceptions to the trend are Denmark and Sweden, where cash options play only a very marginal role and consumer choice is instead facilitated through the opportunity to choose between a public and several private for-profit providers. Some systems in fact offer a choice between cash options and services in kind. For instance, the German Long-term Care Insurance offers a choice of cash or in-kind benefits (or a mix of both). As the majority opts for the (lower value) cash benefit, this has helped the financial sustainability of the insurance scheme. In England, too, personal budgets can be taken as cash payments and used to pay helpers or managed by local authorities and used to buy formal services.

\textit{Boundaries and divisions between public and private domains}

Home care crosses the public and private domains in many different ways. For example, formal home care services may be funded from public or private resources. They may be provided by public sector or private organisations, including charitable, non-profit and for-profit agencies. Home care may be provided by privately employed workers such as personal assistants, who are nevertheless funded from public resources such as care allowances or personal budgets and employed by service users or their families. A common combination for many of the countries in this study is that home care services may well be publicly funded, but supplied by private for profit providers. However, even home care services that are privately purchased (from users’ own financial resources) and provided by private, for-profit organisations, are likely to be subject to public regulation and quality control. And, of course, families and informal carers are major providers of home care and may be supported, to a greater or lesser extent, through public funding such as care allowances or carer benefits. This section highlights just some of these complex intersections.

One reform process involves a shift in responsibility for funding (some) home care services from the state to the individual or family. This shift can occur by accident or by design. The freezing of long-term care insurance benefits in Germany and the rising eligibility thresholds for local authority funded services in England are examples of policies that have had the consequence of forcing more people to fund at least some of their home care from their own (or their family’s)
financial resources. In Ireland, state-funded home care packages are supplemented with private financial contributions. In contrast, in Finland and Sweden, tax deductions for household work (and, to a more limited extent, service vouchers) have incentivised higher income people in particular to purchase care services directly from a growing number of for-profit private providers. Here a limited public subsidy is also encouraging the growth of a private market in home care service provision.

Many of the countries in this study have introduced mechanisms that allow new, private home care providers to enter the market and to compete with traditional public providers. Only in Norway is virtually all home care provided by public sector organisations. Introducing private providers was a feature of the reforms in England in the 1990s, where the majority of publicly-funded home care services are now provided by private firms. In Sweden, approximately one fifth of home care hours are now provided by private, for-profit agencies and recent legislation in both Denmark and Sweden has sought to increase user choice by allowing individuals to select between private and public home care providers. The proportion of local authorities in Sweden who have created opportunities for choice has grown steadily from a situation 20 years ago when almost all home care services were delivered by public sector employees.

In some of the countries in this study, market mechanisms have had rather different impacts; rather than stimulating the growth of private service providers, cash allowances have led to a major growth in home care provided by privately employed migrant workers. Approaches to the employment and regulation of migrant care workers vary between countries. There is a legal scheme for recruiting migrant care workers in Germany, where recruiting agencies must comply with labour and social security laws, but there is also a significant illegal (self-employed) migrant worker population. A growing grey economy of care in Austria, where workers from Central and Eastern European countries provide 24-hour live-in care, has led to a major – and, in terms of take-up, successful – regularisation in 2007. This regularisation involves not only a new law for ‘personal care workers’, but also clarification of job descriptions and a means-tested financial support scheme. In Italy, expenditure on privately employed migrant care workers is now more than double that on formal home care services, a development encouraged by a range of structural and socio-demographic factors, in particular the decreasing supply of informal carers and the fact that cash benefits are more widely available than formal home care services. In England, the growth of personal budgets may lead to a future increase in unregulated, privately employed (non-migrant) personal assistants providing home-based care.
Very different approaches to the private contributions of informal carers are adopted by the countries in this study, with only Denmark specifying that the availability of informal carers should in principle not be taken into account when assessing needs. Austria, Germany, Ireland, Italy and England take a more familistic approach, but their approaches to supporting family carers vary. Low income carers can receive financial benefits in England and Ireland. In Austria, Italy and Germany, carers have no entitlement in their own right to a care allowance, although they may benefit indirectly from the care allowance received by the older person, if this is used to support family care.

Family care can also be encouraged indirectly if levels of public support are inadequate, especially if older people or their families are unable to afford to buy additional home care services themselves or where there is a traditional preference for family care. In Germany and Austria, additional care needs are often met by families. Only a minority of German insurance beneficiaries purchase formal home care services privately from their own resources; these tend to be in higher income groups. Otherwise long-term care insurance benefits are usually supplemented with informal care. Long-term care insurance in Germany has promoted and sustained a family-oriented care strategy; the use of formal services has increased only slightly since the scheme was introduced.

The Nordic countries have traditionally not provided high levels of support for family carers. Rather, a division of labour tends to emerge, where formal home care services provide personal care and family members provide more practical, domestic help and companionship. However, this is now changing, especially in Finland and Sweden. In Sweden, municipalities have new responsibilities to support carers, including ensuring carers have breaks from care-giving and also here do we see an increasing role played by informal carers, as a result of cutting down in public support for the older people, but with clear variation: elders with financial means substitute public support with privately purchased home care, while elders with few financial means must turn to their families.

**Effective workforce strategies**

Recruitment and retention of staff in the formal care sector is a common problem for many of the countries in the study. This section identifies the various measures that may promote the recruitment and retention of home care workers. These include strategies to professionalize care work through the upgrading of qualifications and the introduction of educational programs. Other
strategies focus on increasing the overall number of carers, for example by accommodating and facilitating the recruitment of migrant carers.

Within the formal care sector, care work is often low status and low waged, leading to problems in recruiting and retaining home care workers. Staff turnover and vacancy rates are accordingly high, although some countries seem to do relatively well - for example Sweden where the staff turnover rate remains relatively low (under 15 %). Even so, poor working conditions are often reported in this sector and may in some countries have become worse due to on-going efforts to rationalize service provision, as in Norway. Here, studies suggest that psycho-social work conditions have worsened in the home care sector due to increasing time pressures on care visits. Also, with the introduction of a purchaser-provider split in Norway, responsibility for working conditions has become dispersed and accordingly more difficult to comply with. In Denmark as well as in Norway, the introduction of control mechanisms such as strict time management of home care visits, new documentation routines and inspections are reported to have undermined care workers’ autonomy, increased the burden of paperwork and left less time for actual care work. Such developments are not however, universal; in Finland research indicates that working conditions in home care have in fact improved.

In the Nordic countries, working conditions seem to be comparable across the public and private home care sectors. This is not the case in Ireland, where care workers employed in the private for-profit home care sector have on average worse conditions than their colleagues employed in the public or non-profit sectors. Here, more flexibility is required from private sector care workers, in terms of the range and combination of care duties, and workers here also tend to have lower levels of remuneration and weaker social rights than non-profit or public sector workers. This suggests that worsening of working conditions may be one tangible way in which marketisation and the introduction of private providers in home care may reduce costs.

On the other hand, cash for care options that are now available in many of the countries may offer new possibilities for employment which are preferable to public sector employment conditions, particularly where these are tightly regulated; this may in turn help to attract more workers into the care sector. In England, the growth of personal budgets may encourage some staff to leave home care provider organisations and work privately for individual employers; alternatively new workers may be encouraged into the sector by being employed by personal budget holders.
In Finland, Denmark, Sweden and Norway, home care managers and needs assessors usually have higher education level degrees, often in social work, social care or nursing sciences. In Denmark, educational reform has raised the education levels of home care workers, partly as a means of improving recruitment, as the care qualification can be used as a stepping stone to nursing education. Even so, Denmark still has the lowest levels of education among home care workers, compared to other Nordic countries. Finland has the highest proportion – 51 per cent - of care workers with 2-plus years professional training, compared with 25 per cent in Sweden, 32 per cent in Norway and 19 per cent in Denmark. In Norway, the majority of qualified staff are auxiliary nurses. This training used to be an attractive vocational training for middle aged, unskilled care workers, but as the training was integrated into the overall secondary education system it has gradually lost status.

In England, skill levels are slowly increasing from a very low baseline and most care workers (in both public and private organisations) have work-based qualifications. In Germany a standardisation of occupational training programmes for ‘elder carers’ has raised the professional level of home care workers. Here, the introduction of Long-Term Care Insurance led to an expansion in the formal care labour market and care workers are relatively well-qualified. There are now increased wage differentials between qualified carers and assistants. In Austria, a recent standardisation of training programmes has aimed to facilitate professional mobility across the country and create a stronger professional identity.

The employment of migrants can be seen as a strategy to increase the number of care workers, and within the countries in this study this has taken place both within the formal and the informal home care sectors. For instance, in the formal home care workforce in Sweden and Ireland, approximately one fifth of care workers are foreign-born, and one in ten in Denmark; conversely the role of migrant formal home care workers is limited in Finland, due to a different patterns and levels of migration. In Denmark, an explicit strategy to increase recruitment into the care sector has been to encourage the take-up of care training among first- and second-generation migrant populations, where there is an unused pool of labour. There is no evidence of migrant workers employed as informal live-in carers in the Nordic countries; some evidence of this in Ireland; and employment of migrants in the informal sector is particularly widespread in Germany, Austria and Italy, in all three country cases helped along by the introduction of cash benefits. In Germany, recruitment of migrant care workers by families, as well as formal providers, has been encouraged, the former through tax deductions to create a market for household services. Around five per cent of German Long Term
Care Insurance beneficiaries living at home receive 24-hour care from live-in migrant carers, mainly from the newer EU member states. In Italy, a tax allowance for privately employed care, in combination with a widely used cash benefit, has enabled a major increase in migrant workers employed by families to care for older relatives. Receipt of the tax allowance requires carers to be employed on formal contracts, but use of the cash benefit carries no such obligation. In Austria, the 2007 regularisation of 24-hour care migrant care workers employed in private households could make this arrangement an integral part of long-term care provisions.

**What quality regulation mechanisms are employed?**

Quality of care seems to be something of a buzz-word when resources are scarce and service provision increasingly has to accommodate diversified and individualised need. Several attempts are currently being made across the countries in this study to ensure quality is regulated at the organisational level; at the individual service user level; and through service co-ordination mechanisms.

At the organizational level, local governments in the Nordic countries are obliged by national law to organise and carry out quality regulation, although there are no strict national guidelines for supervising the quality of home care. In Ireland, consideration is currently being given to the regulation of home care services; if regulations are introduced, they will contain mechanisms for monitoring some aspects of quality, most likely inputs such as the supervision and qualifications of care workers. Quality control in England is the responsibility of an independent body, the Care Quality Commission, that oversees the quality of all health and social care services. All home care providers (whether local authority or private) must register with this body; registration requires compliance with minimum financial, operating and quality standards, including staff training plans. Regular (announced and unannounced) inspections are conducted by the CQC, and also following changes in the organisation or the receipt of complaints from users. At the other end of the spectrum, in Italy, there is no involvement of the central state in quality regulation, because central government responsibility is limited to funding of the main cash benefit for care. This results in extensive variation in quality regulation across the regions. The same can be observed in Austria, where quality regulation of home care is a provincial responsibility, leading to substantial variations across the country. Depending on provincial regulations, quality in the provision of services is assured by provincial inspection authorities and by applying certification programmes. At the provider level in Austria, increasingly care and case management tools are
being applied in order to customise, plan, coordinate and evaluate home care and care packages, a development also seen in other countries in this study.

The Norwegian case, exemplifies how the label ‘quality’ can be used to describe a range of measures, some of which have rather different objectives. As noted in the Norwegian report, the call for better quality in home care for older people is a recurrent issue in public debates. Here, ‘quality’ measures include: a national accountability arrangement, where municipalities are required to set up systems of internal control (audit) and written procedures stating how they intend to fulfil national quality guidelines; management tools (like Total Quality Management) borrowed from the consultancy industry to enhance value for money; and collaborative improvement strategies based on agreements between national /local authorities and trade unions.

Improving quality of services through increasing integration of services can also be noted, such as home care and home nursing being provided by the same provider. Such integration is found in many provider organisations in Austria; in Germany a comprehensive network of local care management services in order to promote co-ordination has recently been created.

Users may influence the quality of the services through complaints, or by switching to a different service provider in those countries where choice of provider is available. National quality surveys are conducted regularly in many countries. In England a National User Experience Survey of a sample of home care service users is run annually by Government, to assess changes in satisfaction and the factors affecting these. In Finland, a recent survey revealed that one fifth of home help recipients felt the service was inadequate to cover their needs. Biannual national user satisfaction surveys are conducted in Sweden. Studies conducted in Stockholm, where consumer choice between different home care providers has been available longest, show that home care users generally appreciate the opportunity to choose between providers, but regard it as more important to be able to influence the actual content of the care provided than to choose an alternative provider. Very few older people make use of their right to change providers, and a significant proportion are not even aware of having such a right. In Denmark, in measurements of user satisfaction users of home care generally report high levels of satisfaction overall with the services, but complain about the lack of time and continuity of care workers. Users of private-for-profit care are generally slightly more satisfied with services than users of public care, but users of private-for-profit services mainly receive practical assistance and rely less on intensive care.
**Equality and equity**

With the extensive role played by regional and/or local governments in the implementation of home care policies, variations in service provision between local and regional governments tend to be high. In Italy there are particularly marked variations between regions and municipalities in the north and south of the country in the proportions of people receiving home care, with more service provision in the northern and central regions than the south. Organisational arrangements for home care services also vary between regions and municipalities. In the south, the balance of support is in the form of cash payments; in the centre and north support tends to be service-based. In Ireland, too, the delivery of domiciliary care services is fragmented and uneven, with enormous variations around the country. The lack of national guidelines on needs assessment, eligibility and quality assurance leads to inconsistency in provision of home care services. Access to home care services in Ireland is more closely related to the area of residence and availability of support within that area than to care needs. These problems are symptomatic of the lack of national guidelines on the delivery of home care services. There is also a lack of other factors, such as electoral accountability or funding allocations by national government to local authorities, that might lead to more consistent practices and equitable outcomes. In England, even though national guidelines specify common approaches to assessments of need and of users’ financial contributions to home care services, actual eligibility depends on the finances of individual local authorities; this local inequity is widely criticised by organisations representing older people.

Although the Nordic countries in particular have aimed to increase consistency and equity in the delivery of home care services, even here socio-economic inequalities in access to home care services are apparent as a consequence of recent economic retrenchment. Although home care services in both Finland and Sweden are provided regardless of income or assets and generally used across all socio-economic groups, significant access and quality problems in publicly organised home care services have resulted in growing inequalities between low-income older people who need to depend on their families and high-income older people who increasingly purchase private home care services. Access to publicly-funded home care may also depend on the user’s financial situation, as is the case in England, where access to publicly-funded home care services varies not just according to level of need but is also restricted only to people with low levels of income/assets. Here, the availability of informal care also affects eligibility for publicly-funded home care services.
All countries concentrate home care provision on those with the highest needs, apart from Denmark where a relatively high proportion of older people with low or moderate needs still receive domestic and personal care services. This results in the exclusion of older people with low needs or, as in England, the possible exclusion of even people with high levels of need, depending on the financial situation of the local authority, the level at which local eligibility thresholds are set; the person’s financial situation; and the availability of informal care. There are also variations between English local authorities in the charges that users have to contribute towards the costs of their home care.

National initiatives have over time sought to address some inequalities, such as variations in user charges; for instance Swedish and Norwegian laws have set a maximum level of payment for home care services, and other rights for users have also been introduced. In Finland since 2009, everyone aged 75 and over has had a legal right to have their needs assessed within a week. The same right was given also to younger people with high care needs. This legislation does not guarantee access to services, but it has nonetheless contributed to a small growth in the proportion of people receiving home care. In Sweden, too, people have a general right to assistance if the need ‘cannot be met in any other way’, but without detailed regulations or specific rights. An individual who is not satisfied with the decision can appeal to court. In Norway, service users have gained similar procedural rights such as the right to an individual needs assessment; the right to make their views known, receive a written and well-founded decision; and the right to appeal to a higher court. More substantial rights have also been introduced, including the announcement of local standards of service provision. In Denmark, local authorities are similarly obliged to inform citizens about local service levels. Here, a national standardization of assessment tools has also been implemented in the attempt to ensure more equal assessment of needs across the country.

The age of the care user may also be important, for instance levels of home-based support (whether in kind or through a personal budget) are in England generally more generous for working age people with disabilities than for older people. In Sweden, people with certain extensive functional impairments (not caused by normal ageing) are entitled to services to ensure a reasonable standard and quality of life; however, the same does not apply to older people, causing a major disparity in access to services for people with earlier-acquired, longer-standing disabilities and those who develop disabilities after the age of 65.

In some cases, geographical differences have triggered national legislative interventions. For instance the former huge regional disparities in home care provision in Austria (with some remote
areas entirely devoid of community care services) prompted the development of the national cash allowance scheme. The introduction of Long-Term Care Insurance in Germany and the Austrian Care Allowance has to some degree introduced an element of universalism in care systems which were previously characterised by great inequalities in access, quality and levels of funding for care. These schemes provide universal social rights and people with similar levels of ‘care dependency’ are entitled to similar levels of benefit. In Germany, eligibility criteria and assessments are in this way defined by Federal law, thus reducing regional inequalities, although the outcomes of assessments appear to be less favourable for lower socio-economic and migrant groups. Access to long-term care insurance benefits has been improved for people with cognitive and psychological impairments, thus enhancing diagnostic equity. Health insurance provides universal access to home nursing services. All schemes are equally available to older and younger people with disabilities. The same applies for the Italian and the Austrian home care systems, in that no differentiation is made by age of the care user.

4.3. Matrix of research questions

The following matrix contains a comparable overview and perspective of the research questions included in the study.

Each national rapporteur has summarized the main points in regards to the 1. Overall characteristics of the long-term care system; 2. Organization, regulation and governance of home care; 3. Provision of home care, 4. Funding of home care; and 5. Quality assessment.
<table>
<thead>
<tr>
<th>HOME CARE IN EUROPE</th>
<th>Austria</th>
<th>Denmark</th>
<th>England</th>
<th>Finland</th>
<th>Germany</th>
<th>Ireland</th>
<th>Italy</th>
<th>Norway</th>
<th>Sweden</th>
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<tbody>
<tr>
<td><strong>The Long-term Care System</strong></td>
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<tr>
<td><strong>General</strong> Role of family, state, market; public LTC policies</td>
<td>Familialistic orientation; public support: cash for care (national responsibility), services (regional responsibility).</td>
<td>Public orientation, public support: service provision (local responsibility).</td>
<td>Public orientation; residual means-tested public funding; extensive marketisation; high levels of private purchase and informal care.</td>
<td>Public orientation; role of family and market is increasing; public support: service provision (local responsibility).</td>
<td>Familialistic orientation; public support: cash for care (federal state as regulator and financier of public LTC insurance).</td>
<td>Familialistic orientation, increasing role of formal home care; great increase in private sector last 10 years.</td>
<td>Familialistic orientation; public support: cash for care; involvement of migrant care workers; territorial differences.</td>
<td>Public orientation; tax funded; public support: service provision, home help partly private provision.</td>
<td>Public orientation; local responsibility; important role of family in home care.</td>
</tr>
<tr>
<td><strong>Driving forces and reform strategies</strong> Cost containment, disability groups, regional initiatives, addressing long-term care as a social risk.</td>
<td>Cost containment, transparency, equality, disability groups.</td>
<td>Cost containment, marketisation, increasing personalisation of funding and service delivery.</td>
<td>Cost containment, marketisation, increasing personalisation of service housing; amalgamation of home-based social and home nursing; integration of informal family care.</td>
<td>Cost containment, introduction of universal support, maintaining domestic care within the family framework.</td>
<td>Economic growth until 2005; increased labour force participation; delays in hospital discharges to which home care seen as solution.</td>
<td>Regional initiatives, low pressure by LTC lobbies.</td>
<td>Cost containment, proximity and social integration, a quest for transparency and accountability “upward”.</td>
<td>Cost containment in the 1990s, today empowering users and increase quality.</td>
<td></td>
</tr>
<tr>
<td><strong>Definition</strong> Home care / help</td>
<td>Home care / help: personal care; assistance for nurses, basic care tasks, household activities.</td>
<td>Home help: personal care and help with household tasks or activities outside the home.</td>
<td>Home care: personal care and help with household activities, combined with home nursing tasks, performed by professionals.</td>
<td>Home care: personal care and help with household activities, partly qualified staff, integrated provision with home nursing.</td>
<td>Home help: domestic tasks such as cleaning; home care: domestic plus personal care.</td>
<td>Home help: help with activities of daily living.</td>
<td>Home help: domestic tasks and social care; home nursing: personal care, by registered nurses or semi-skilled nurses.</td>
<td>Home care: personal care (including some medical tasks) and help with household activities, by qualified staff.</td>
<td></td>
</tr>
<tr>
<td>HOME CARE IN EUROPE</td>
<td>Austria</td>
<td>Denmark</td>
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### Organisation, Regulation and Governance of Home Care

#### Target group

**Differentiation older persons and persons with disabilities?**

- **No differentiation in major policy approaches.**
- **No differentiation in major policy approaches.**
- **Local authority eligibility thresholds the same for older and working age people; older people receive lower value support.**
- **Home care covers both groups but only severely people with disabilities have a subjective right to personal assistance (from 2009).**
- **No age differentiation in LTC insurance; additional further universal support for people with disabilities.**
- **No differentiation in principle; but people with disabilities have right to needs assessment, whereas older people do not.**
- **No differentiation in major policy approaches.**
- **No differentiation in public policy, but different approaches by user groups.**
- **No differentiation in home care, but personal assistance only for younger than 65 (can be kept after 65).**

#### Role of central, regional, local authorities

- **Regional and local level:** responsibility for organising, providing, financing, regulating home care; regional variation in home care organisation.
- **Local level:** responsibility for organising, providing, financing and regulating home help and institutional care; little local variation.
- **Regional level:** responsibility for organising and financing home care and institutional care, autonomy of municipalities; large local variations.
- **Central level:** policymaking; regulatory power of municipalities for home care.
- **Local level:** responsibility for needs assessment, whereas older people do not.
- **Central level:** responsibility of regulation and co-funding; local level: organisation of care; local variations of service profiles and levels of quality.

#### Provision of Home Care

### Eligibility, needs assessment

**Standardised needs assessment? Who is assessing needs?**

- **Regional regulations; no standardised assessment scheme; individual needs-assessment by provider organizations.**
- **Local level:** responsibility for needs assessment; local resource-related threshold.
- **Regional level:** standard nationwide needs assessment system; organised on regional level; conducted by medical service of health insurance funds.
- **Central level:** policymaking; regulatory power of municipalities for home care.
- **Central level:** policymaking; regulatory power of municipalities for home care.
- **No standardised scheme; needs assessment by municipal official, academic social worker; increasingly restrictive local guidelines.**

#### Providers

**By sector**

- **Provider mix: non-profit providers dominate, followed by public providers and for-profits.**
- **Provider mix: 75% private, 25% public sector (local authority provision).**
- **Provider mix: Public (municipalities); Private: 25% for- and non-profits (publicly funded home care).**
- **Provider mix: for- and non-profits; 61.5% for-profit providers (2009); funded by LTC insurance.**
- **Outside Dublin: public sector predominant; Dublin and larger cities: growing presence of private providers, non-profit providers still predominant (but lose ground).**
- **Provider mix: 50% contracted providers (non-profit, increasingly for-profit).**
- **Public sector: 99%**
- **Provider mix: 83% public, 17% private providers (absolute majority for-profit); both publicly financed.**
### Funding of Home Care

<table>
<thead>
<tr>
<th>Public vs. private</th>
<th>Share of public / private funding</th>
</tr>
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<tbody>
<tr>
<td>Public funding; private contributions only for intermediate home help.</td>
<td>Mix of public (tax-funded) and private contributions; 2/3 public, 1/3 private.</td>
</tr>
<tr>
<td>Mix of private purchase (40% of home care users) and/or informal care; high level of eligibility threshold for public funding.</td>
<td>Municipal home care: central grants, local tax-funding, user fees.</td>
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<tr>
<td>Mix of public (social insurance) and private contributions (mainly related to residential care).</td>
<td>Variable private contributions for home help; state-funded home care packages, supplemented through private inputs.</td>
</tr>
<tr>
<td>Mix of public (tax-funded) and private contributions.</td>
<td>Mix of public (tax-funded) and private contributions.</td>
</tr>
</tbody>
</table>

### Calculation of user fees

| Regional differences; in general: care allowance related flat-rate contribution plus means-tested contribution. | Framework set by national government; detailed implementation decided by local authorities, local variations. |
| Income-related user fees; private options may be cheaper for people with larger income | Lump-sum benefits are granted independent of the income; costs exceeding the benefits have to be covered privately. |
| No official guidelines; where provider is non-profit, they exercise discretion. | No national framework; criteria to set user fees decided at regional level. |
| Home nursing is free of charge; home help: state-funded home care allowances, means-tested. | Home nursing is free of charge; home help: income-related contributions; low income users are protected; great local variation. |

### Qualification of Home Care Professionals

#### Types of care workers

| Formal: social workers, nurses, care assistants, home helps, personal care workers; informal: kin, 80% women |
| Formal: home care helpers and assistants. |
| Formal: home care workers, personal assistants/carers employed privately. |
| Formal: practical nurses, home care assistants; informal: kin, 75% women |
| Formal: social workers, nurses, elder carers, nurse/elder care assistance, unqualified home helps; informal: kin, 73% women; paid 24-hour care workers. |
| Formal: home helps, personal care attendants, home care workers; small presence of live-in (migrant) care workers. |
| Formal: social workers, nurses, home care assistants, home care workers; small presence of live-in (migrant) care workers. |
| Formal: nurses, auxiliary nurses, low-skilled home helpers/care workers, non-skilled (temporary) care workers. |
| Formal: assistant nurse, nurse’s aides, 90% women; informal: few paid care workers in the informal economy |

#### Training and competences

| Social care workers: 3-year/1-year training; care assistants: 1-year training; home helps: 6-months training; personal care work: training/previous experience. |
| Care helper: diploma: 16 months training; Care assistant: diploma: 20 additional months training. |
| Front-line home carers: register for work-based qualifications; no qualification requirements for privately employed care workers. |
| Practical nurses: integrated social and health care, 3-year training; home help manager: 3.5 - 4 years full-time studies in Polytechnics. |
| Social workers: 3-year training (bachelor degree); nurses: 3-year occupational training; nurse assistants: 1-year occupational training; home help: without occupational training. |
| Personal care attendant: short vocational training; private home help/home care no formal requirements, companies expect some basic training. |
| Social care workers: 3-year training. |
| Registered nurses: 3-year training (bachelor degree); auxiliary nurse, care worker: 2-year training, secondary school. |
| No mandatory qualifications; assistant nurses: 2-3 years training; nurse’s aides: shorter; supervisors: academic degree. |

### Quality assessment in the home care sector

#### Quality management

| No standardised scheme; regional/provider responsibility; pilot programmes. |
| Regular checks by local authorities; national and comparable user satisfaction surveys. |
| Regular inspections of all providers by national independent Care Quality Commission. |
| No standardised scheme; national recommendations about care and services; local user satisfaction surveys. |
| (Federal) law on quality assurance and consumer protection; external check-ups once a year; internal quality assurance for home care are in preparation. |
| Currently there are no standards or regulations to govern quality; quality guidelines for home care are in preparation. |
| No standardised scheme at national level; huge differences among regions. |
| Regular quality assessments by central authorities; internal control based on quality regulations; user satisfaction survey on local level. |
| No standardised scheme; local quality assessment tools; central authorities introduced “open comparisons” of care quality. |
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PART 2
NATIONAL REPORTS
1. Home Care in Austria
August Österle & Gudrun Bauer

1.1. Introduction

Long-term care policies in Austria are built on the three main pillars of family care, a cash for care scheme and social service provision. Family orientation strongly characterises Austrian long-term care policies till today, while the introduction of the cash for care scheme in 1993 and related reforms in the social service sector mark a significant move from social assistance oriented public policies to policies that combine universalist principles with individual and family responsibilities. From the 1980s, proposals for a comprehensive long-term care reform covering those in need of care of all age groups and with a universal cash benefit at its centre have been put forward, in particular by representatives of the disabled people. A few provinces then became forerunners in introducing a cash for care scheme from the early 1990s. The reform debates in the 1980s and the early 1990s were supported by a growing consensus on the need to harmonise a highly fragmented support system for people in need of long-term care, to extend personal social services in the community, and to support family care-giving. The 1993 reform builds on two main elements: a national cash for care system and a state-provinces treaty on the development of home care and residential care. Even though the provision of the cash benefit is not strictly linked to service use, there has been a substantial growth in home care provision in this country. In particular, earlier huge regional inequalities were reduced. Also, care work provided by commuters from Central and Eastern European countries in the private home of users became an increasingly popular element of long-term care provision. In 2007, following a major public debate on this previously grey economy of care, an important reform effort resulted in a regularisation of this so-called 24-hour care arrangement. The current debate is dominated by cost containment considerations (linked to austerity programs in response to the financial crisis) and by debates about a new long-term care fund pooling financial means for long-term care.

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Care and help provided in the private home of the user is understood as a main objective of long-term care policies in Austria, to be achieved by supporting the role of informal care, by providing people with cash for care and by strengthening the development of social services in the community. This report will analyse how home care is structured in this country in terms of regulation, organisation, provision and funding, and how the broader context of family orientation and public long-term care policies has shaped the development of care and help at home. In the following section 2, the report starts with an outline of the welfare approach towards long-term care and the major drivers that have shaped long-term care policies in this country. Section 3 introduces home care in Austria by defining home care and by outlining the qualification requirements for home care workers. Then, this section focuses on the regulation, organisation, provision and funding of home care. Given the importance of provincial and local levels in the governance of care, more specific information on selected provinces will exemplify the variation in the specific approaches across the country. Section 4 will then discuss the outcomes of long-term care policies in the past two decades for home care and will briefly address the major current debates. A brief summary in section 5 concludes the report.

1.2. The Austrian welfare approach towards long-term care

Till the 1993 reform, public policies towards long-term care in Austria were highly fragmented with various cash and in-kind provisions for different groups of beneficiaries. Social service provision was provincial and local responsibility and was dominated by residential care provision while community care provision varied largely across the country and has been almost non-existent in parts of the country (Österle, 2001). In 1990, cash provisions accounted for about 60 percent of public expenditure, while 33 percent were spent on residential care and just 7 percent on community services (Tálos, Wörister, 1994).

Debates on the future of long-term care intensified from the 1980s against the background of slowly recognised demographic changes and with the major objective of moving from a fragmented system of care related support measures to a more comprehensive long-term care system. Reform debates have emphasised concepts of autonomy and choice and a strong preference for care in the community. Major drivers for a reform were disability groups and Austrian federal states, both emphasising their preference for an extended and universal cash benefit scheme as the main public response (Tálos, Wörister, 1994; Behning, 1999).
The UN International Year of Disabled Persons in 1981 has created an important impetus for the debates by increasing the awareness for the situation of people with disabilities. In the 1980s, a couple of reform proposals have already been emphasising a strong preference for a universal cash benefit, but also the need to extend personal social services, to recognise and to support the important role of informal care, and to strengthen the professionalization of the nursing discipline. The various proposals were advocating for a universal long-term care reform, not limiting provisions to specific age groups. In order to harmonise a highly fragmented system, it was proposed to replace the principal of causality (benefits varying between different groups of people with disabilities) by the principle of finality (equal benefits for equal level of need). From the 1980s, associations representing the disabled and an umbrella organisation of these associations have been the major drivers in the policy debates towards the 1993 reform. From the second half of the 1980s, some provinces as the competent governmental level also became increasingly active in developing new policies towards long-term care. In 1990, the province of Vorarlberg introduced a seven level cash for care support scheme with monthly benefits ranging between € 168 and € 1,149 per month. This then became the model case for the Austrian wide cash for care scheme introduced in 1993 (Behning, 1999). In the early 1990s, before the implementation of the new law, two issues have been at the centre of the debates. Firstly, while there was strong and broad support for cash orientation, the province of Vienna, representatives of provider organisations and some political representatives have been favouring an in-kind approach. The second debate was around financing. Some provinces and some political actors have been referring to the financial burdens involved with the new system and have been calling for a slower step by step introduction of a new long-term care system. Despite these concerns, however, there was broad support across political parties and interest groups for a new cash oriented long-term care system (Behning, 1999).

The new legal framework was finally implemented in 1993, becoming effective from 1 July 1993. At the core of the reform is a universal federal care allowance system. The care allowance (Pflegegeld) is defined as a contribution to care-related costs, it is not means-tested and paid to people of all age groups in need of permanent long-term care and help due to physical, sensory or mental disability that is expected to last at least six months (BMASK, 2010a). Based on an assessment by a physician the benefit is paid in seven levels ranging between € 154.20 in level 1 and € 1,655.80 in level 7 in 2011.
The second pillar of the long-term care reform is an agreement between the federal level and the nine provinces, confirming provincial responsibilities for the development of long-term care services. Provinces agreed to ensure coverage with residential, semi-residential (day care) and home care services according to regional development plans detailing the current and future needs for service provision. These plans are covering the period 1996 to 2010. The agreement between the state and the provinces lists the services to be ensured and provides some very general specifications on quality criteria. There are, however, no nationwide benchmarks to be achieved by 2010 and there are no sanctions attached to these plans and the self-defined objectives. Before the long-term care reform, it was estimated that just about 10% of those in need of care of all age groups did at least temporarily use services. Huge regional disparities in home care provision were evident. In some remote areas community care services have not been available at that time (Tâlos, Wörister, 1994).

With the introduction of the universal cash for care scheme and the agreement between the federal level and the nine provinces on the development of social care provision, long-term care has finally been recognised as a separate social risk (Österle et al., 2011; Badelt et al., 1997; Fürstl-Grasser, Pallinger, 1997; Pfeil, 1994). It has created a coherent and needs-oriented care benefit scheme covering the entire population in need of care, regardless of age and disability. The care allowance was designated as a contribution to cover care-related expenses, to support family care, to ensure autonomy and to allow free choice for users, and to support the development of the social service sector via improved purchasing power. While the cost-containment objective has not been the main driving force of the reform in the early 1990s, the new cash-oriented scheme was understood as a cost-effective way to address long-term care. And, cost containment has increasingly shaped policy developments in the years to come.

Although the care allowance has substantially improved the economic situation of those in need of care, the main pillar of care provision still remained within the family and with women as the main informal caregivers (Österle et al., 2010). Studies indicate that about 80 percent of people in need of care are fully or to the largest part cared for by relatives and to a smaller extent by friends. About 80 percent of these informal carers are women. While many women providing family care are in their 40s, 50s and 60s, most men providing care are retired and mostly provide care to spouses (ÖBIG, 2005; Streissler, 2004; Badelt et al., 1997). The cash for care scheme has been introduced as a measure to also support informal family care. And it was widely appreciated by family carers as a first time recognition of the work they are providing. However, a continuing
reliance on family members also came under increasing pressure, in particular when long hours of care and help are needed. A major response to this situation was the influx of Central Eastern European women commuting into Austria for the provision of 24-hour care in private households. The development of this fast growing grey economy of care has been ascribed to an unregulated cash for care scheme, family orientation together with increasing pressure on the availability of family care, the emotional bond to the private home as well as the availability of relatively cheap labour in neighbouring countries (Österle, Hammer, 2007).

The arrangement with a migrant care worker providing caring labour for older people in private households was well known in the social care field and among potential users. While migrant care workers usually had regular stay in the country, the work arrangement was outside labour and social security regulations. Although social service organisations emphasised the need to regulate this growing grey care market, there was long no broader public debate on the issue and the state was rather reluctant in developing a response. Only when several individuals have been sued for illegally employing migrant care workers in their private homes and, in particular, after families of political leaders became accused for illegal employment of migrant care workers, a media-driven debate arose during a national election campaign in the summer 2006. This debate dominated the political agenda for a couple of weeks. But the debate was almost exclusively focusing on the need to regularise this kind of care arrangement in private households, rather than a broader debate on the future of long-term care. The short-term response was an amnesty for migrant care work, implying that the work status was still illegal, but that there was no prosecution. From July 2007, this was then followed by the introduction of a new law on personal care work in private households (Hausbetreuungsgesetz) offering options for regularised work of migrant care workers in private households based on self-employment or based on an employer-employee relationship. In addition, to secure affordability of regularised migrant care work, a means-tested financial support scheme was introduced (see below) (Schmid, 2009).

Overall, long-term care policies remained relatively stable since 1993. The benefit level has only partially been adjusted to price developments leading to a lowering in the purchasing power it represents. There have been some changes in terms of needs assessment and defining the levels of needs, but the general characteristics of the system remained untouched. In the social service sector, there has been a substantial growth in services and a reduction in regional inequalities in service availability. Expenditure on home care increased by 46 percent between the years 2000 and 2008. In the same period, the amount of service hours provided increased by 29.4 percent (BMASK,
2010a). While coverage with home care has substantially enhanced, hours of home care often remain limited for service users requiring either substantial informal care input or additional private purchase of services. Also, efforts to harmonize provincial systems remained limited. The development of 24-hour care and the regularisation as personal care work has been a major public issue in 2006 and 2007 and has a significant impact on long-term care in this country and on home care in particular. In the following sections, home care, its position in the Austrian long-term care system and the ways in which it is shaped by the cash orientation and the emergence of migrant care will be discussed in more detail.

1.3. The regulation, organisation, provision and funding of home care

As a result of the regional responsibility in this sector, the understanding of what constitutes home care has historically largely varied across the country. Additionally, difficulties arise with terminology (Weicht, 2011). In the German language, Pflege is often used as an umbrella term for different types of care and help provided to ill, disabled or frail older people. Also, it is used when describing the policy field of long-term care. At the same time, it is used to define professional boundaries, in this case more specifically addressing nursing care. In the Federal Long-term Care Allowance Act 1993, the need for care (Pflegebedarf) is used as a term covering both the need for nursing care and personal care as well as the need for help. In the following sections, home care will be used as the general umbrella term for services other than medical services provided to people in need of care and help in their private home.

What is home care? What are the qualification requirements?

Generally, in Austria home care provision is understood as the provision of home nursing and home help. Services are provided by qualified nurses, health care assistants, social care professions and workers without specific qualification. The definition of social care professions until recently was defined by provinces. From 2005, a standardization of qualification requirements took place.

Home nursing is defined as the comprehensive care and support of people in need of care of all ages in their private homes with the aim to support and retain their autonomy. Home nursing substitutes a hospital stay and is only provided if ordered by a physician. It covers the provision of specifically defined care and medical tasks that are only allowed to be performed by qualified nurses. Additionally, health care assistants work on behalf of nurses and are responsible for basic
care tasks such as personal hygiene and mobilisation. The qualification requirements of the health care professions (qualified nurses and health care assistants) are standardised by the federal Health and Nursing Act for the entire country. Qualified nurses obtain a diploma in nursing after a three-year training period (4,600 hours), while health care assistants working under the supervision of professional nurses have a 1-year training with 1,600 course hours (Schwamberger, 2008). There are no requirements for special training of nurses working in the home care sector, but specific trainings such as home care related specialisations are offered as part of continuing qualification and quality assurance programs.

Home care and help services generally provide support for housekeeping (e.g. cleaning, cooking, washing), daily living activities (e.g. organisation of visits to the doctor or the pharmacy) and basic caring activities (e.g. personal hygiene) for people in need of care and help of all age groups. Concrete qualification requirements and job descriptions in home care and help (except for those working as nurses and nurse assistants) have differed between provinces. Only in 2005, a process of standardisation has started (see below). In addition to these core services, meals on wheels, visiting services and companionship as well as cleaning and laundry services are offered. As social care is provincial and local responsibility and as national provisions only set few selective specifications, types of services and the ways in which they are provided vary largely across the country (Wild, 2001).

Considerable variations and inconsistencies in defining qualification requirements and the tasks to be performed did not only lead to large variations in the organisation of home care across Austria, it has also hindered the validation of social care educations and the mobility of workers. In 2005, this situation has led to another agreement between the federal level and the nine provinces with the aim to establish a common modular educational system for the social care professions. It provides a coherent nationwide system of educational standards with a uniform curriculum and transparency in terms of competences and duties. The agreement, however, could only define the standards, which then had to be implemented in respective laws on the provincial and the federal level. Three types of social care professions are defined: home helper (HeimhelferInnen), social care worker (Fach-SozialbetreuerInnen) and social care worker with diploma (Diplom-SozialbetreuerInnen). The social care worker qualification offers specialisations for work with older people, the disabled and with families (Schwamberger, 2008).

Home help training includes 400 hours of theoretical and practical education. The main tasks are defined as support for daily life activities and household activities (e.g. cooking, cleaning
or personal hygiene) for people in need of care of all age groups. The training for the social care worker is two years (2,400 hours), for the social care worker with diploma three years (3,600 hours). In general, the profession of the social care worker is defined by supporting the normalisation of living conditions (e.g. activation, support, companionship, individual measures to cope with daily life), social integration and self-determination of clients. Specific tasks performed by social care workers derive from their field of specialisation (work with older people, with disabled people or with families) and from the possibility of the delegation of basic care tasks (Schwamberger, 2008; Gratzer, 2008). The training module “Support with basic care needs” is a major new element in the qualification programme, introduced with the standardization of qualifications. The module defines practical care tasks such as support with personal hygiene, dressing and undressing, supporting mobility, ingestion and medication. After completing this module, home helpers and social care workers are entitled to perform these basic care tasks after instruction and under supervision of qualified health care persons. In contrast, social care workers with a diploma are qualified to provide tasks as health care assistants (see above) whose education is included in the curriculum of social care workers with diploma.

In 2007, the effort to regularise previously illegal “24-hour care” in private households has led to the introduction of a new professional profile in the Health and Nursing Act, the personal care worker (PersonenbetreuerIn). Personal care workers only require a low level of qualification: either the completion of a training course of 168 hours, the proof of respective work experience for at least 6 months or the delegation of care tasks by a professional health care person. In practice, personal care workers are self-employed live-in carers staying on fortnightly or monthly shifts in the private household of the user (Österle, Bauer, 2010). Core tasks include household activities and entertainment. Even though the personal care profession does not require a specific qualification for the provision of basic care and medical tasks such as personal hygiene, medication, administration of selected injections or checking blood sugar level, they are allowed to provide these services after instruction and delegation by professionals. The delegation of these tasks is based on an amendment of the Health and Nursing Act and has become an integral part of the personal care workers’ job description. In contrast to personal care workers, home helpers and social care workers are only allowed to perform basic care tasks (no medical tasks) and only after instruction and under supervision of professionals. This implies that the social care professions are actually more limited in the tasks they are allowed to perform, even though their formal qualification is more extensive than that of personal care workers. The argument behind this is that personal care workers are seen
as a replacement of family carers (who are allowed to perform these tasks because of their kin status) rather than a replacement of professional social care workers.

In the context of these debates on care work qualifications, the quality of health and nursing care training has become a crucial issue in Austria. In contrast to most other European countries, the training of qualified nurses is still based on diplomas rather than University education. With a view to nurse shortages, professional representatives and social service organisations have repeatedly stressed the need for improving the nurse training curriculum on an academic level. While several attempts have been made to improve the situation (e.g. with the introduction of the discipline of nursing sciences as a University degree), the inclusion of personal care as an independent profession in the Health and Nursing Act was often seen as rather disadvantageous for the intended professionalization of the nursing discipline.

**How is home care organised/regulated/governed?**

Home care (as residential care) is largely provincial and local responsibility in Austria, whereas the cash for care programme is a federal programme. The Act regulating the care allowance scheme includes some minimum standards for services and for quality assessment to be implemented on the provincial level. Additionally, in the aforementioned 1993 contract between the state and the nine provinces, provinces agreed to establish plans for social service sector development and to ensure comprehensive coverage with residential, semi-residential and community care services. However, no general benchmarks and no sanctions are attached to this agreement.

In terms of regulatory power, competences in the home care field are largely with the social sector. An exception is health sector responsibilities which are limited to medical home nursing and specific services by medico-technical professions (e.g. physiotherapy, logopaedics, etc.) provided in the private home of the user. Respective services are limited to specific tasks and provided by qualified nurses or therapists for a predefined period as ordered by a physician. These services are funded or co-funded by the respective social health insurance fund. Regulation, organisation and funding in the social sector is provincial responsibility, which results in substantial variations across the country. Within provinces, the organisation of home care usually is the same for different groups of potential recipients, except for specific services such as personal assistance for disabled persons or counselling services addressing particular groups of the disabled or the chronically ill.

Following a classification by Egger da Campo (2008), three different models of home-based care provision in Austria can be identified. In the Western provinces of Vorarlberg and Tyrol, a
bottom-up model with associations as the main organisational form prevails. In Vorarlberg, home care is based on local Home Nursing Associations (Krankenpflegevereine). About two thirds of all the citizens in this province are represented as members (based on paid household membership) in 66 local associations providing services across the entire province. Nurses are employed by these associations, while directors of the associations are acting on a purely voluntary basis (Österle et al., 2011; Hauskrankenpflege Vorarlberg 2010; Landesregierung Vorarlberg, 2009). Members of the association have access to services without further co-payments or just small co-payments, while non-members have to pay extra fees for using services provided by the associations. The second element of home care provision in Vorarlberg is the so-called Mobile Help Service (MoHi) accessible to almost 99% of Vorarlberg’s population. About 60 percent of Mobile Help Services are part of the Home Nursing Associations, while others are organised as public services by the municipalities or as part of local social service organisations. Different from funding of the aforementioned Home Nursing Associations, persons in need of care have to pay an hourly fee of about € 8.50 (€ 12 on weekends) when using mobile help services (ARGE Mobile Hilfsdienste, 2010; Landesregierung Vorarlberg, 2009). A third element of home care provision in Vorarlberg has been implemented from 2007. The so-called “Betreuungspool Vorarlberg” – a cooperation of Mobile Help Services and Home Nursing Associations – arranges the placement of personal care workers for those who need care and support 24 hours a day (Betreuungspool Vorarlberg, 2010; Landesregierung Vorarlberg, 2010).

The top-down model characterises home care provision in the provinces of Salzburg and in particular in the capital city of Vienna. In these provinces, public administration plays a strong role in the organisation and in the assessment of social, health and care services. In Vienna, the main governance body is the Social Fund Vienna (Fonds Soziales Wien, FSW), a district based centre for care and help at home. The FSW cooperates with 21 accredited non-profit organisations (May 2010) that act as providers of the whole range of home care and help services. Accreditation is based on applications by the respective providers. The system attempts to ensure that people in need of care are able to use the required social services, regardless of their private financial situation. The contribution users have to make takes the type of service, the number of required service hours as well as income situation, care allowance level, rental charges and the personal situation of the user into consideration, whereby the maximum co-payment per hour is set at € 22.13 for home nursing or € 16.86 for home help (FSW, 2010). Different from other provinces, there is no upper limit for the use of home nursing and home help services.
In the other 5 provinces (Burgenland, Carinthia, Lower Austria, Styria and Upper Austria), welfare organisations operate on behalf of public authorities in an intermediate *public-private-partnership model*. While the public authority commissions the contracts with social care providers, these can act rather autonomously in the assessment and the provision of services. In Upper Austria, for example, both regional and local authorities are involved in the provision of home care services. A total of 64 social counselling centres act as the first contact point for those searching for help in the private home. The services are provided by 18 social welfare associations. The calculation of co-payments takes the care allowance, the income of the user and of spouses into consideration. Different from the aforementioned province of Vienna, the use of home help is limited to 80 hours a month, the use of home nursing limited to 30 hours a month. Most social service providers offer a range of additional services, with the exception of meals on wheels which is provided by municipalities in Upper Austria (Landesregierung OÖ, 2006).

The actual provision of long-term care services in Austria is characterised by a mix of public providers, private non-profit and private for-profit providers. In the residential care sector, public providers (47 percent of beds) dominate over private non-profit providers (33 percent of beds) and for-profit providers (19 percent of beds) (own calculations based on BMASK, 2010b). In the home care sector, availability and quality of data on the provider mix is quite limited. There is, however, consensus that the private non-profit sector dominates home care provision, with some providers being active across the country (with substantial variation in the relative importance of single providers) and others being active only in single provinces or regions. Similar to the residential care sector, for-profit provision is playing a slowly increasing role in home care, in particular in urban areas. So far, however, for-profit organisations tend to be relatively small, focusing on users paying out-of-pocket and on provisions established social care organisations are limited to provide if these services are not covered under the agreements with municipalities or provinces.

*Who pays for home care?*

Split responsibilities between federal and provincial levels, the variation in the ways in which long-term care services are organised and a lack of harmonisation in the data collection limits the availability and quality of quantitative information on the long-term care sector, and not least on public long-term care expenditure (BMASK, 2010a; Pratscher, 2010; Mühlberger et al., 2008). According to the annual long-term care report by the Ministry for Labour, Social Affairs and Consumer Protection, public spending on long-term care amounts to € 3,275 billion in 2008,
including € 2,098 million spent on care allowances (64.1 percent), € 288 million on home care (8.8 percent), and € 887 million on residential care (27 percent) (BMASK, 2010a). Over the past decade (2000-2008), total public expenditure has increased by 37.4 percent, home care expenditure by about 46 percent and residential care expenditure by 72 percent (see table 1.1). The quality of the data on home care and residential care expenditure, however, is limited as data collection is not harmonised across provinces. Also, figures for home care and residential care expenditure are net expenditure. There is no detailed information, to what extent the long-term care benefit is used to pay for services (BMASK, 2010a; Pratscher, 2010; Mühlberger et al., 2008).

Almost two thirds of total public long-term care expenditure is paid to those in need of care as a cash benefit. Users are free to co-pay for services in the residential and home care sector (for levels of use see below), to pay for personal care work, to transfer it to informal carers or to contribute to disposable household income. The care allowance scheme is generally seen as an equitable approach to support people in need of care regardless of their age or their personal situation and without predefining a specific care arrangement. In administrative terms, the organisation of the care allowance is split between the federal level and the provincial level accounting for 85 percent and 15 percent, respectively, of total expenditure on care allowances. In terms of eligibility and assessment, there is no difference between the federal and the provincial care allowance. Since the introduction of the care allowance programme in 1993, expenditure on this public benefit has increased proportional to the number of care allowance recipients. Price adjustments, however, have been limited so that the real value of the benefit has decreased by about 20 percent till 2008 (Rudda, 2008).

TABLE 1.1
Long-term care expenditure in Austria (2000-2008), mio and percent

<table>
<thead>
<tr>
<th></th>
<th>2000</th>
<th>2005</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total long-term care</td>
<td>2,383 mio</td>
<td>2,829 mio</td>
<td>3,275 mio</td>
</tr>
<tr>
<td>Care allowance expenditure</td>
<td>1,671</td>
<td>70.1 %</td>
<td>1,858</td>
</tr>
<tr>
<td>Home care expenditure (net)</td>
<td>197</td>
<td>8.3 %</td>
<td>213</td>
</tr>
<tr>
<td>Residential care expenditure (net)</td>
<td>515</td>
<td>21.6 %</td>
<td>758</td>
</tr>
</tbody>
</table>

Source: BMASK, 2010a, 2005, 2000

The funding of residential care and home care is based on a mix of public (tax-funded) and private contributions. While social assistance orientation dominates residential care funding, funding arrangements in the home care sector are based on a mix of private co-payments and public
coverage of the difference between private co-payments and the tariff contracted with social service providers. Additional public funding is available for investment costs and for specific programmes or projects. Private contributions vary between provinces and account for an estimated one third of home care expenditure in Austria. In general, co-payments consist of a care allowance related element (as a flat rate co-payment) and a means-tested element considering the income of the user, and – differing in the nine provinces – rental charges and/or the personal situation of the user. Additionally, most provinces define minimum and maximum co-payment levels per service hour or other service units. For example, in the region of Upper Austria, the minimum individual contribution for a single person ranges between a minimum contribution of € 0.82 and a maximum contribution of € 30.61 per hour. If the user is a recipient of the care allowance, a flat rate contribution of € 4.13 per hour is added to the means-tested co-payment (RIS, 2010). In Vienna, the maximum co-payment is € 22.13 for home nursing and € 16.86 for home help, but there are no minimum contribution rates in this province (FSW, 2010).

For a personal care worker arrangement, the regularised 24-hour care arrangement (see above), additional financial support was made available in order to cover those costs arising because of the regularisation of this previously mostly grey economy of care. The means-tested benefit is paid for care provided to users in benefit level 3 or higher, and in case of dementia care. It amounts to a maximum of € 550 per month in the case of self-employment and to a maximum of € 1,100 in the case of employing a personal care worker in the private home in 2010. In most cases, the care allowance plus the aforementioned benefit will not cover full costs of personal care. Not including travel, board and lodging, costs for a self-employed personal care worker will amount to about € 2,000 per month, but might be considerably higher depending on tasks and qualification. In this case, costs could only be fully covered by the care allowance and the additional personal care worker benefit for those in benefit level 7. (For an overview of benefit levels see table 1.2.) In benefit level 3, for example, the maximum support is € 993 per month (including € 443 as care allowance in level 3 and € 550 as personal care subsidy), requiring about € 1,000 per month to be covered privately.

The introduction of the care allowance scheme did also aim at support for family care. Additional measures supporting family care in the private home include respite care services and a financial support scheme for periods when family carers are unavailable due to illness or holiday (amounting to between € 300 and € 550 per week). While social protection coverage for family carers has been partly subsidised from the mid 1990s, social pension insurance contributions are
fully covered from 2009 for family carers providing care and support to a user in benefit level 3 and above (BMASK, 2010a). In 2009, public expenditure for supporting family carers amounts to about € 8.2 million, an increase of 22.4 percent compared to 2007 (Bundessozialamt, 2010).

Who provides home care? Who are the carers?

The introduction of the care allowance scheme was – among other objectives – seen as a measure to induce a growth in service provision. In 2008, care allowances were paid to a total of 422,173 people in need of care, accounting for about 5 percent of the Austrian population. (see table 1.2) About two thirds of recipients are women. Every second recipient is over 80 years of age, four out of five recipients are over 60 years of age. Recipients in levels 1 and 2 account for 55 percent of all care allowance recipients. In international comparison, the Austrian cash for care scheme is characterised by broad coverage of care needs. From a total population of 351,043 persons over 80 years of age, nearly 60 percent (202,533) are recipients of the care allowance.

| TABLE 1.2 |
| Care allowance recipients by age and benefit level in Austria (2008) |
| Age | Level 1 €154.2 | Level 2 €284.3 | Level 3 €442.9 | Level 4 €664.3 | Level 5 €902.3 | Level 6 €1,242 | Level 7 €1,655 | Total |
| 0-20 | 2,494 | 2,555 | 2,698 | 1,492 | 729 | 898 | 730 | 12,596 |
| 21-40 | 4,134 | 5,810 | 3,045 | 2,309 | 1,637 | 1,629 | 932 | 19,496 |
| 41-60 | 12,357 | 15,564 | 6,994 | 5,249 | 2,890 | 1,612 | 1,099 | 45,765 |
| 61-80 | 37,088 | 50,039 | 21,941 | 18,143 | 8,988 | 3,466 | 2,118 | 141,783 |
| 81+ | 35,287 | 66,846 | 33,112 | 35,663 | 19,040 | 6,139 | 3,446 | 202,533 |
| Total | 91,360 | 141,814 | 70,790 | 62,856 | 33,284 | 13,744 | 8,325 | 422,173 |

Source: BMASK, 2010a

Information on service consumption in general and on service consumption of those receiving care allowances, is rather limited. Earlier information indicated that about 20 percent (80,000 persons) of care allowance recipients have been users of home care (Schneider et al., 2006). Recent statistics (see table 1.3) indicate a substantially larger share. Accordingly, across the country, 32 percent of care allowance recipients have been using home care services. In Vienna, the respective proportion is 29 percent. The number of those living in institutions amounts to 14 percent in Austria, and to 17
percent in Vienna. Following these figures, about 50 percent of those currently receiving a care allowance fully depend on informal care provision. Taking into account that home care use mostly works as a complement to informal care, it is estimated that 75 percent to 80 percent of all care arrangements involve informal care-giving. More specific information on the socio-economic background of home care users is very limited and not harmonised between provinces. In Vienna, in 2009, about 80.2 percent of all clients have been using home help, 29 percent home nursing, 29.3 percent meals on wheels, 28 percent visiting services and 14 percent cleaning services. The average age of users is 82 years both for home help and for home nursing. Women account for 73 percent of home help users, 66 percent of home nursing users and 74 percent of cleaning service users (FSW, 2010).

**TABLE 1.3**

<table>
<thead>
<tr>
<th>Benefit recipients, residential care users, social service users (2008)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recipients of Care Allowances</td>
</tr>
<tr>
<td>-------------------------------</td>
</tr>
<tr>
<td>Austria 422,173</td>
</tr>
<tr>
<td>Vienna 83,776</td>
</tr>
</tbody>
</table>

Source: BMASK 2010a

Data on staff in the home care sector again is limited. According to a 2006 survey (ÖBIG, 2008), 37,819 health and care professionals were employed in the home care and the residential care sector, including 17,500 in the home care sector (and among these 16,200 working mainly with older people). About 54 percent of total care staff is working part time, 42 percent is working full time and 4 percent is working under special work time arrangements. In the period 2003 to 2006, the number of employees has increased by 12 percent, in the home care sector by 36 percent. At the same time, the average level of qualification among the staff has also improved. Despite the increase in staff numbers, however, there still is a notable shortage of social care personnel, in particular in the home care sector (AMS, 2009). There is little information to what extent this shortage in the home care sector is covered by migrants. According to Simoens et al. (2005), 6.75 percent of nurses in the residential care sector are of foreign origin. For 2008, another study shows that 10.5 percent of nurses working in residential care settings have had their professional training in another country. The data also indicates that there has been a significant shift towards nurse migration within the EU (Lenhart, 2010). No systematic studies have been published for the home
care sector, but social service organisations indicate that the proportion of those with a migration background is substantially larger in this sector.

From the 1990s, the use of 24-hour care (personal care) has offered an increasingly attractive option for care in the private household, in particular in arrangements with a self-employed personal care worker. Recent figures for June 2010 indicate that about 23,000 personal care workers provide care and help to about 11,500 recipients. This type of care work is almost exclusively provided by commuters from Central Eastern European countries (Österle, Bauer, 2010).

**How is the quality of home care assessed and ensured?**

Concerning quality assessment and management, the Federal Long-term Care Allowance Act only provides very general clauses. Quality assurance is determined by provincial legislation and by provincial orders and leaves considerable room for providers of home care services. In this context, provider organisations increasingly emphasise the importance of care and case management. The Austrian Association for Care and Case Management emphasises customisation, planning, coordination and evaluation of care and care packages. According to the Association, the focus of case management is on the management of individual cases over time and across services, while the focus of care management is on the organisation and coordination on the system level. The case manager, typically a qualified nurse, coordinates existing resources, examines necessary service types and arranges for adequate service packages. There is, however, little standardisation in the ways in which case management is implemented. Also, in general, case management is not funded as a separate element of service provision, but rather a service to be covered from the overall tariffs agreed with provinces or municipalities.

Depending on provincial regulations, quality in the provision of services is assured by provincial inspection authorities and by applying certification programmes (e.g. EFQM or ISO 9001). While provincial legislation defines general quality criteria, the actual interpretation and implementation is left to the social service organisations. The absence of a standardised quality system limits the potential of comparability. There are, however, a number of recent pilot programmes attempting to strengthen quality management in the home care sector. These programmes include cooperation in international projects, quality certification and the development of quality management systems. Other quality programmes have been focusing on the quality of informal care by providing advice and support for family carers or, more specifically, for informal
carers of dementia patients and their families. Also, there is a scheme of randomly examining the quality of home care by nursing professionals during visits in the home of care allowance users (BMASK, 2010a).

1.4. Outcomes and perspectives

The introduction of the cash for care scheme in 1993 and the regulation of domestic migrant care work in 2007 have been the two most outstanding national reform steps in Austrian long-term care policies in the past two decades. Developments in the home care sector have been shaped by these reforms, but have also been driven by local and provincial policies gradually strengthening the home care sector. This section discusses these developments and concludes with a view to major current challenges and perspectives.

Cash for care: Driver or hurdle for the development of home care

Enabling individuals in need of care to be cared for in their private home as long as possible, was one of the major objectives of the 1993 long-term care reform. It was seen as a means to strengthen autonomy and choice and to improve quality of life. It was expected that the new scheme supports informal care-giving while at the same time it induces consumer driven developments in the social service sector.

Compared to a previously fragmented system of often means-tested benefits varying largely between different groups of beneficiaries, the care allowance scheme provides a universal benefit to those in need of care of all age groups. The benefit is not limited in terms of use and hence contributes to an increased purchasing power in the hands of the users. After the introduction of the care allowance scheme, many social service providers – because of the underlying contracts with regions and municipalities – reacted with an increase in co-payments. As these co-payments are mostly means-tested, they do not generally exclude those with low income from use. But, as publicly co-funded consumption of home care services is limited in terms of service units in most provinces, there are limitations in the extent of service use, most importantly for those unable to cover full costs of additional service units. In addition, over the past 18 years, limited price adjustments have continuously reduced the value of the benefit (Hammer, Österle, 2003). Despite these limitations, home care provision has seen an extension towards previously underserviced areas, a diversification of service packages and an increase in service consumption. This is seen as a
result of both the availability of cash for care and specific measures taken by provinces and municipalities towards extending home care services. Despite these developments, the use of social services remains limited for most potential users, both in terms of availability (because of limited availability over night and during weekends) and in terms of financing. As a consequence, home care for extended hours per day either requires the use of additional private means to employ care workers or to buy services, or it requires substantial inputs from the informal sector (Hammer, Österle, 2003: 49).

The cash for care scheme has been introduced as a contribution to care related costs (rather than full coverage of costs) and as a means to support not only formal service development but also informal care provision. Formal home care services, therefore, work as a complement rather than a substitute to informal care. They usually do not work as an option for users and/or their families searching for home care provisions that can replace informal care. In these situations, 24-hour care in private households opened up as a new option – and as an alternative to residential care – from the 1990s.

“24-hour care”: Substitute or complement to traditional home care?

From the second half of the 1990s, migrant care workers in private households – in Austria known as 24-hour care – became increasingly known as an option to arrange for the necessary care, in particular where attendance and supervision for most of the day was required. Till 2006, arrangements were mostly made outside labour and social security regulations. Recruitment was either based on word-of-mouth, individual recruiting or via commercial agencies. With the Home Care Act, the 2007 reform (see above) offered a new framework for regular employment of 24-hour care workers (with the regularisation named personal care workers). They can work as employees or on a self-employed basis. Because of work time restrictions and larger social security costs of an employer-employee relationship, most arrangements work with self-employed care workers. As a response to the clients’ needs, the field of tasks personal care workers are allowed to perform has been extended beyond household activities. After instruction and delegation by professionals, personal care workers can also perform basic care and medical tasks as stated in the Health and Nursing Act (Schwamberger, 2008; BMASK, 2009; Österle, Bauer, 2010). In order to reduce the risk that a more costly regularised employment of personal care workers will lead to further irregular employment, a financial support scheme was introduced as a second major element of the
2007 reform. The benefit is means-tested and is limited to users receiving a care allowance in benefit levels 3 to 7 and to those with dementia (see above) (BMASK, 2009; Schmid, 2009).

Given that the number of regular personal care workers soon reached the estimated number of previously undocumented migrant care workers is seen as a sign of successful regularisation. In June 2010, about 23,000 personal care workers have been active in 11,500 households. Even if the financial support scheme does not fully cover the extra costs of the regularisation, the advantages of regular employment are increasingly recognised by users, their families, personal care workers and social service providers. While home care services are commonly used as a complement to informal care, personal care work arrangements are established to largely substitute for informal care. A major development is that social service organisations as traditional home care providers become involved as placement agencies. This could also help to start developing case and care management programs that involve personal care. Respective developments are only at initial stages and so far not sufficiently backed up by the regulatory system, but this could contribute both to quality assurance and the development of domestic personal care work and social service provision as complements rather than substitutes (Österle, Bauer, 2010).

**Challenges and perspectives**

The 1993 reform not only was a response to a previously highly fragmented and unequal system of support for people in need of care and a response to the challenges arising from an ageing society. The reform has also substantially changed the understanding of long-term care. Even if family orientation remained strong, long-term care was no longer understood as part of social assistance, but as a separate field of social welfare. The most obvious sign of this transformation is the universal care allowance paid in seven different levels to about 5% of the Austrian population, a personal coverage rate going far beyond similar programs in other European countries. From the 1990s, there has also been a significant growth in home care services to be attributed to policies on provincial and local levels, to the increased purchasing power of potential users, and to an increased willingness to use such services. But there are also limitations to these developments. Care allowances have only partially been price-adjusted leading to a loss in purchasing power of about 20 percent. The use of home care services is limited, be it because of limitations for service provision during nights or weekends or because of the limitations in publicly co-funded service units. This, not least, has led to a growing grey economy of care which became regularised from 2007. This option allows people to stay in their private home even if they need care and support by
someone from outside informal networks for longer hours than what is covered by traditional home care services. But the option usually requires substantial private means on top of the care allowance and a means-tested personal care subsidy. Overall, in the past two decades, social security in case of long-term care has been substantially improved. The introduction of the cash for care system signifies a move from a principle of causality to a principle of finality and – with regard to the cash benefit – a move from social assistance orientation to universality. Major debates are about the adequacy of the assessment and the (in the current system missing) direct connection between cash provision and service provision. In terms of home care services, the past two decades have been characterised by an extension of services, both in terms of regional coverage and in terms of service density. Despite these developments, considerable limitations remain, including limitations in service provision during nights or during weekends, existing upper limits for publicly co-funded service units or substantial co-payments to be made for service consumption.

Current debates about the future of long-term care in Austria are not so much dominated by these limitations in the availability and the adequacy of long-term care provisions, but by economic concerns, cost-containment and the future of funding long-term care. Limited price-adjustments in the care allowance scheme, tightening access to benefit levels 1 and 2 from 2011 or a proposal in one province to re-introduce recourse to children in case of residential care are major examples of how long-term care policies attempt to contain public expenditure. At the same time, debates on the future funding of long-term care have intensified. Despite a strong social insurance tradition in this country, long-term care – except for specific tasks of home nursing – is fully tax-funded. Preliminary proposals for a new funding scheme favour a long-term care fund pooling long-term care related financial means, but without introducing a new social insurance pillar. If the new fund would pool financial means for all long-term care benefits, necessary harmonisations among currently split responsibilities between the national level (most cash benefits) and provincial levels (services) will most probably create the major challenge in this endeavour.

1.5. Conclusion

A complete re-organisation of the home care sector was not at the centre of the major reforms Austria has seen in the past two decades, but the priority for care in the private home of the user was a major underlying objective in all these efforts and is regularly emphasised in broader public
and in expert debates. Policies to achieve that objective include the care allowance scheme, support for family care, professionalization and further extension of services.

The 1993 reform – with a care allowance scheme at its centre –, was a response to a previously highly fragmented and unequal system of support for people in need of care and to the challenges arising from an ageing society. Even if family orientation remained strong, long-term care increasingly became understood as a distinctive and major field of social policies in this country. From the 1990s, there has been a significant growth in home care services to be attributed to policies on provincial and local levels – also related to a state-provinces treaty signed in 1993 – to the increased purchasing power of potential users because of the care allowance, and to an increased willingness to use such services. But home care still mainly works as a complement rather than a substitute to informal care. This not least resulted in the growing use of migrant care labour in private households, a previously grey care market that became regularised with a major reform effort in 2007.

Existing deficits in care provision, together with growing care needs and pressure on traditional family care arrangements, will require further efforts in extending adequate home care provisions. These developments are also welcome in the light of home care as a major future employment sector. At the same time, already existing staff shortages in the home care sector and financial pressure on public budgets create considerable challenges for future policies.
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2. Home Care in Denmark

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2.1. Introduction

Like in the neighboring Nordic countries, care in the home for the old and disabled is in Denmark mainly organized, financed and provided within the public realm. The Nordic welfare states are in general characterized by the extensive public services that are available. These are based on the principle of universalism, which means that there is generally a uniform standard of services across the country even though services are organised at the local level, and that services are available for all. Characteristic for the Nordic countries is also that care provision takes place within a highly regulated and formal setting, with mainly professionalised and qualified staff members (Antonnen and Sipilä, 1996; Rostgaard, 2004). The goal in Denmark of the main home care service, home help, is to provide for everyone of need, regardless of age, means, income and potential available informal care givers. The arrangement of work and care in Denmark is that women participate in large scale on the labour market – and make up the bulk of employees in the care sector – and that care is based on formal provision within the public care system, and mainly provided by public providers, the municipalities. Voluntary organisations and family carers are also involved in the provision of care, but tend to provide supplementary services only. For-profit service providers have, however, entered the home help system and their role has been steadily increasing since the early 2000s. The provision of home care is relatively generous in Denmark, as it reaches a high number of citizens, while at the same time is free of charge. Yet it is also a sector which is often under heavy attack by the media and in public opinion polls. And it is a job sector of low status and with poor working conditions, why it is difficult to attract labour.

In this account of the changes in home care in Denmark, in addition to describing the main characteristics of the home care system, focus will be on describing the drivers of change for reforms, which includes the seemingly conflicting goal of individualising and standardising the provision of care in the home. Also the main reform strategies which in recent years seem to evolve around quality will be investigated in the conceptualisations, instruments and indicators of quality in care.

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2.2. Main driving forces for reforms and reform strategies

**Overall reform movements**

Overall, ageing of the population is in Denmark as in other countries projected to result in increasing social costs for caring. Denmark has already been through its first period of ageing from the 1940-1990, and population ageing is occurring less rapidly than in many countries. Still the number of those aged 65 and over is projected to increase by 50% over the next three decades but is likely to see an increase especially in the age groups 80+ (OECD, 2005). The cost for elder care has remained stable at 1.8-1.9 % of GDP in recent years (2002-2007) (Eurostat, n.d.; Nielsen and Andersen, 2006). If care for disabled is included, the proportion of GDP spent on this area is 3 % (2002) (Nielsen and Andersen, 2006).

The demographic changes have in recent decades not resulted in major reforms of the main principles of the home help in regards to financing of care, nor has it made Denmark divert from the policy of ageing in place. However, private for-profit provision of home help has been introduced, and has gained ground in later years, in the combined attempt to increase productivity, improve quality and adhere to user choice. Of equal importance for this policy area are also the various organisational changes, and especially the changes in governance, control and steering mechanisms which have affected this sector more than any other public sector since the 1990s.

Often these reforms have addressed at the same time several desired outcomes, including professionalization, accountability, control, equity, cost-efficiency etc, yet ‘quality’ and the search for it, seems to have been a common overall denominator for many of the reforms to modernize elder care in recent decades and has become the key steering instrument for the development within the sector. It is used both as an end goal, to increase quality, but also as a term which is used to name the various reform strategies. And paradoxically, the quality reform strategies have often been guided by the principles of both individualism and standardization, why the reform course has at times seems somewhat shifty.

The focus on quality follows a period of politics since the early 1980s of welfare retrenchment, during which the program for modernizing the Danish welfare state which - although it initially had greater ambitions - came to focus at cutting costs and decreasing the size of the public sector, both in number of employees and in proportion of GDP (Melander, 2008). This mainly economic strategy was later criticized for having endangered the quality of the public services, both from the perspective of users and staff, and for in fact having failed to increase cost-
efficiency. In order to regain users’ trust and motivation among staff members, the strategy of modernisation was in the 1990s changed to focus on quality improvements, and this was to take place through the introduction of modern rational steering principles, such as performance management and contract steering (Melander, 2008).

Since then, the quality terminology has been visible also in reforms of elder care in the emphasis on development of quality provision, quality assurance, quality standards, indicators of quality and lately a quality reform has been implemented. Many of the changes thus carry with them the promise that the changes are necessary and have the potential to improve quality for the end-user, and are not merely reform strategies aimed at e.g. cost-containment. One fundamental element is to assure that services respond to individual needs and preferences. Most of the initiatives are accordingly focused on the out-put for the user and use instruments such as more user choice, user involvement and flexibility in service delivery which should ensures that care is provided according to individual preferences.

Another fundamental element of the reform strategies in the elder care sector is to be able to rate and document quality. Many resources are used to document not only how users value the provision of care, but also to evaluate whether the use of resources is in accordance with the set (quality) goals, and quality in this sense becomes something which must be measureable, and preferably on the individual level. It has led to what critics in the sector has called insurmountable documentation, including obligations such as counting the number of sinks and regularly weighing the elderly in nursing homes. Parallel to this has been the wish to obtain more standardized and comparable local indicators of use of resources, not so much to document local variation but for the purpose of better administrative steering. Such reform strategies aim at ensuring more predictability and transparency for the user as well as for local and central policy makers, and the strategies which have been implemented have rather focused on more standardized care solutions and ways of communicating about care needs.

Reforms 1980-present day
More specifically, reforms in elder care has since the 1980s overall aimed at the adjustment and modernisation of the main principles behind the provision of care, but were in the early 1980s concerned especially with principles of care, exemplified by the work of the National Commision of Ageing, which emphasised continuity and normalisation as main principles in care service provision. Professionalising care provision and care assessment was another main principle.
Since the 1990s, reforms have had more procedural focus, aimed at improving governance and steering, and have consisted amongst other of the implementation of New Public Management (NPM) strategies in home care, such as control of time, codification, governance of details and contract steering. Equity in assessment of needs was an essential idea as was also the introduction of quality standards, which ensured a certain level of provision, while at the same time home help services became targeted on the most needy. From the turn of the millennium, ensuring flexible and individualised care and increased quality of care have been the focus points, as has also the search for more cost-efficient ways of providing care. This includes the increasing use of technology used in the steering and documentation of care provisions. It also includes contract steering which makes more explicit the rights and obligations of the home help user. In recent years, a new reform named ‘The Quality Reform’ is also aimed at ensuring and developing quality within the elder care sector. The reform is amongst other aimed at improving management and leadership, cutting red tape, and developing comparable indicators of user satisfaction in elder care.

Overall, the various reforms may not have led to overall transformational changes of a paradigmatic nature to the elder care system in Denmark, but the more piecemeal reforms focussed on governance especially after the turn of the century seem to have led to more incremental changes in the system.

2.3. Main overall policy goals and objectives behind care provision

The main objective behind Danish elder care is ‘ageing in place’, i.e. to provide community care which enables older people to remain in their own homes for as long as possible, and Denmark has more than any other EU country given explicit priority to community care over institutional care. This principle was strengthened with the 1987 Act on Housing for Older and Disabled People which prohibited the continued building of traditional nursing homes with shared living facilities. Since then, conventional nursing homes have gradually been replaced by the so-called nursing home facilities (plejeboliger) which contain individual living units where the elderly have their own kitchenette, living room, bed room and bathroom and with access to common facilities. These facilities are either situated in converted nursing homes or in new buildings. In addition to these are also the special housing for elderly (ældrebolig).

In general, the provision of care for elderly and disabled in Denmark is based on principles of 1) continuity, 2) autonomy and empowerment, and 3) help-to-self-care. As was stated by the
concluding report from the National Commission on Ageing in the early 1980s, social care provisions should ensure continuity in living conditions and former lifestyles despite the need for care (Ældrekommissionen, 1981). The report further stressed that public support should ensure that older people should feel empowered, regardless their need for care, and eg have a say over which services they would like to make use of.

The recommendations from the National Commission also emphasised the necessity to use early preventive measures, and this has informed new initiatives such as the preventive visit offered annually to elderly 75+. The report also stressed the integration of services and systems, such as health care and social care. The final main conclusion from the report dealt with the recognition of the resources of older people. Public support for persons in need for care in accordance aims at active ageing, rehabilitation and the principle of ‘help-to-self-care’, in that elderly to the widest degree should be assisted in helping themselves.

2.4. The services of home help and its users

As a consequence of the policy of aging in place, home help is regarded as one of the main pillars in community care. According to the Social Service Act of 1997, it covers ‘personal care and services’, but in daily terms Home help services (hjemmehjælp) is used. It includes help with housekeeping and personal care, i.e. IADL task such as cleaning, laundering, bed making, and in some cases shopping also, and various ADL tasks such as assistance with toileting, dressing, bathing and hair combing. Psychological intervention may also be part of the provision of home help, e.g. time may be set of for the home helper to comfort an elderly who has lost a spouse or otherwise is in a life crisis.

The home help service originates from the post-war ‘housewife relief’ (husmoder afløsning) which was introduced in 1949 as a temporary service to relief housewives e.g. during their illness or hospitalisation but it could also be awarded to older people. This service was temporary and income-dependant. From 1958, a new law on home help and home care introduced the possibility to receive permanent help in the home, but the service was still focused on household chores, and included no personal care. According to Fuglsang (2000) three significant structural time periods can be identified: The first during which the service developed from being mainly short-term compensation for the housewife to a more permanent but still provision of simplistic domestic services as described above (until the mid 1960s). This period was characterized by the need to
establish home help as a universal welfare state entitlement. This was followed by a period (mid-1960s-mid-1980s) focusing on the professionalization of care provision via obligatory training for the municipally employed home helpers. This period was also characterized by an increase in volume of the care sector, a strengthening of the role of the municipality in the assessment of care which was previously with the local GPs, and by the inclusion of personal care and round the clock care and the introduction of the principle of help-to-self-care. A third period (from mid-1980s until today) has especially involved changes towards more technical and standardized service production and includes changes in organization and governance of home care. One example of this is the more strict division of work, in that daily organization of work was moved from the individual home helper and became the responsibility of local group leaders. Home helpers also now had to work in teams and from late 1990s several municipalities operated with purchaser-provider model. This change is by Lewinter (2003) interpreted as a change from “home care, where emphasis was placed on coherence and cooperation between various professional groups, recipients and relatives, to a home care system delimited by strictly set tasks, tight control of time and less emphasis on coherence and cooperation. A form of Taylorising of the care work has taken place” (Lewinter, 2003, p. 33-34; author’s translation).

Home help is the main service provided to elderly or disabled in their own home, but other social services may be provided. The Preventive home visit which every municipality by law has to offer yearly to every elderly 75+ (this has now been changed to a voluntary practice as part of recent de-bureaucratisation measures) is also one of the main services. The Preventive visit has been introduced after several randomised controlled trial studies proved this service cost-efficient in that it reduces the risk of becoming hospitalised or admitted to a nursing home, and proved to have a positive effect on mortality also (eg. Vass et al, 2002).

In addition to home help services, adaption to the home, free use of various equipment, and local transport, and day centres is organised and financed entirely by the municipality. Home nursing is also provided and financed through the municipality and is free of charge.

Home help is provided either as temporary or permanent assistance. The service reaches relatively many elderly people in international comparison. There is no stigma or loss of status associated with the receipt of this service. Home help is by principle given to all citizens in need for care, but mainly to elderly 65+. This service expanded as previously described from the mid-1960 with the consolidation of the welfare state, where the state took increasing responsibility for the provision. According to Colmorton et al (2004), however, the expansion up to the 1970s was also
due to the need to create new jobs in the public sector, but also the introduction of de-institutionalisation policies has caused an increase in the use of home care. Looking at the changes over time, it is apparent that coverage has increased mainly among the 80+; this is due both to an increase in the number of elderly in this age group, i.e. demographic reasons, but also due to higher coverage for this age group, i.e. expansion in services, with the shift from institutional care to home care:

The number of recipients of all ages of home help has nearly doubled from 141,253 in 1982 to 203,261 in 2005. This mainly includes elderly over 67+, and less than 1% of the population under 67 has during this period received permanent home help. In this period, overall coverage rates 67+ went from 18% in 1982, to the peak of 29% in 2002 (Rostgaard and Fridberg, 1998; Nielsen and Andersen, 2006). The increase is found especially among the 80+ where coverage has increased from 36% to 60% in 1982-2002. By 2005, this age group received 61% of all home help hours (Nielsen and Andersen, 2006).

In recent years, coverage rates have dropped somewhat. By 2009, 18% of the 65+ and 44% of the 80+ received home help. 82% of users are today 67+ (Danmarks statistik, 2010). A combination of factors is causing these changes in take-up rates. It reflects both the general improvement in health and functional ability among the elderly (Platz, 2006), but as well as a consequence of administrative changes in the statistical accounts. However, the main cause seems to be a tighter assessment practice where elderly need today to be frailer before they can receive services. As home help is organised at the local level, the decision to introduce stricter assessment criteria is taken at the local level, and will criteria therefore vary across the country.

Yet, the national level of provision is still high in comparison to other Nordic countries: Using 2008 NOSOSCO figures for the Nordic countries, provision in Denmark was second highest for the 65+, only superseded by Iceland (20%), whereas provision in the other Nordic countries ranged from 6-12% of the 65+ (NOSOSKO, 2009).

But the changes are evident when looking into the number of hours awarded. In recent years, one of the changes in the provision of home help system has been the polarisation of resources, whereby more users get only a little help and more get more help, i.e. a practice of combined

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3 Temporary home help is registered in separate statistics and data is only available for a limited period of time, but in the period 2006-8, around 16,000 recipients have received home help as a temporary service.
4 Taking into account double counting in nursing homes, see next footnote.
5 Statistical historical accounts are problematic as some municipalities included older people living in nursing home (until 2000) and maintain differing practices of counting hours of care.
intensification and spreading of resources. This is not a nationally formulated strategy, but has been the applied practice by local governments to keep up with demand. As a result, many elderly receive help with domestic chores only fortnightly or only every third week and often of a duration of only ½ hour, compared to the early 1990s where it was not unusual to receive cleaning several times a week (Hansen et al., 2002). Help has in this way for some users of practical assistance become more symbolic as it is not possible to provide much help within this time span. The home care system has not surprisingly received much coverage and criticism in the media. Also members of staff report that they find themselves to be under strict time constraint, with more users and shorter time for each user which makes it more difficult for them to recognize individual needs and preferences (Ipsen et al., 2002).

The changes can be seen in the proportion of recipients who receive less than 2 hours weekly which has increased from 43% in 1999, to 57% in 2005 and to 62% in 2009. At the same time the proportion of those who receive more than 12 hours a week has doubled (6% in 1999, 13% in 2005 and 3% in 2009). On average elderly 65+ with home help received 5,30 hours a week in 2005, somewhat more to the 80+ (6 hours) per week than the 67-79 year olds, (4,37 hours weekly). In 2009, the average is now 3,6 hours for the 65+ and 3,8 hours for 80+ (Nielsen and Andersen, 2006; Danmarks statistik, n.d.)

That the cuts are made in the practical assistance have been evident in that the proportion of all home help hours devoted to practical assistance, which has decreased from 26% in 1999 to 16% in 2005. Since then it has increased to 22%, but one must take into account the overall drop in coverage rates, which means that fewer elderly today receive services (Nielsen and Andersen, 2008; Danmarks statistik, n.d.) Overall, the policy still adheres to providing only little time for practical assistance and to a fewer share of the elderly.

2.5. Services or cash?

Empowering the user in the decision on which form of care is best suited to his/her needs has so far in Denmark not led to the general introduction of a widespread used cash for care schemes as an alternative to home help services, as are available in other neighbouring countries. Home help for the majority of users comes as a service benefit only, although a pilot project of personal budgets was carried out in 2004, inspired by the Dutch Personal Budget scheme. It covered personal care and assistance with daily practical tasks and the budget holder was in charge of administering the
amount and for finding providers of care, which could be a for-profit provider or a family member. An evaluation showed that the users, who were mainly elderly home help recipients, were generally satisfied with the opportunity to receive a cash-for-care benefit but they experienced problems with the administrative tasks (Socialministeriet, 2006).

There are, however, a number of exceptions in the legislation on home help in the Social Service Act, which enables the payment of cash, and these are especially intended for citizens under 65 needing help and care for great parts of the day and night. This includes the Cash supplement (Kontanttilskud) which gives the local authority the option to pay out cash for which the care recipient must employ a carer, which can be a family member. This option is available if the local authority cannot provide the necessary care, perhaps because the care recipient lives in a remote area, or if the care recipient rejects the offered services from the local authority. This scheme is also available for those in need of more than 20 hours of care a week. There are no statistics available on the (aged) take-up, but it is estimated that most users are below 65 of age. In addition, there a cash scheme available for palliative care for terminally ill persons (Pleje af døende i eget hjem) which was introduced in 1990. This scheme compensates relatives for the loss of income they experience while caring.

Another cash option outside the home help system is available for so-called active care recipients, the Citizen-Managed Personal Assistance (Borgerstyret Personlig Assistance, BPA) which replaced the former Disability Assistant Scheme (Handicaphjælperordningen) in 2009. Persons who have severely and permanently reduced physical or mental functional capabilities can apply for this scheme if they are in massive need of care, monitoring or escort assistance, or have needs that cannot be met by conventional personal help and care under the provisions of social legislation. The scheme is the equivalent to UK Direct payment scheme and was also in Denmark introduced following pressures from organizations representing disabled persons for more independence.

The changes in the scheme reflect the learning from the pilot scheme of personal budgets, although the main target groups of users are now disabled persons. The care recipient must still act as an employer and the contract is strictly between the care recipient and the provider, why the municipality cannot terminate the contract, but the care recipient can now transfer the allowance to a family member, or a non-profit or for-profit organization for them to administer the allowance. A family member must however not be employed to provide the care. The change of name is also to signify that this is a citizen-led scheme. There are no upper age requirements, and elderly 65+ could
in principle be entitled also. In 2006, 1,209 persons received the allowance when it was named Disability Assistant Scheme, this statistics is, however, not divided up according to age. There is great variation in the sums of money which municipalities pay out as a subsidy for the administration of the scheme and the Disabled Peoples Organisations Denmark reports that municipalities seem see the scheme as a way to save money\(^6\). As a recent television program ‘Operation X’\(^7\) has revealed the introduction of such free choice cash schemes also challenges traditional notions of public control and accountability. The program highlighted that even though private for-profit companies continuously and deliberately over-report the provision of hours of care and use of (costly) temporaries, and thus charge the municipality for more than what has been provided, the municipality cannot end the contract with the provider.

2.6. Management and organization of home help

Problems of accountability and control when care is outsourced to new actors in the field are thus not unknown, and the municipalities, the *kommunes*, have in recent years gained a new role as manager, purchaser and regulator of the services which may now also be provided by other actors, such as market based providers. The municipalities are thus the most important administrative level in regards to the social services. After a reform in 2007, the former 271 municipalities now make up only 98. The re-organization means that in many cases new procedures, work routines and organizational cultures should be established or harmonized, and this was assumed also to negatively affect home help, in the efficiency and quality of care and potentially also in the recruitment and retention of staff (Borg et al, 2007).

At the central level, the government is responsible for legislation concerning social services, such as the Social Service Act of 1997 which governs the field. The legal basis of the public social services is thus the Social Service Act which requires municipalities to provide the necessary supply of services. However, each individual municipality can make its own policy in regard to provision, and it is largely up to municipalities to assess whether the services are sufficient. This extensive liberty of municipalities implies some variations in quality and quantity between municipalities and between counties. Although substantial problems in comparing expenditure data across the municipalities render it difficult to estimate the local variation (Nielsen and Andersen, 2006), there is some indication that local autonomy leads to extensive variation in local spending (Jensen and

\(^6\) http://www.handicapportalen.dk/nyheder/samfund-politik/artikel/skandaleaar-med-bpa.html
\(^7\) http://omtv2.tv2.dk/index.php?no_cache=1&i=4882&page=7&page2=2
Lolle, 2010). There are, however, also other indications that as financial resources become fewer, municipalities tend to provide more uniform and low levels of services.

2.7. Financing of home help

Municipalities also have the main role in financing of home care due to the tradition of local provision, and social services for those in need of care are up to 99% financed by municipalities. Municipalities do, however, receive reimbursement for around 10% of expenditure through various subsidies, block grants and equalization grants. The remainder is mainly funded through local taxes which municipalities are free to levy at a rate which must be negotiated with central government. Permanent home help has been free of charge since 1992. Temporary home help is charged according to the actual costs, but the question of user payment for permanent home help is a recurrent issue in the public debate. Also the OECD has recommended the introduction of user payment as a strategy to keep demand under control (OECD, 2008) but so far is has been backed off, not least because home care is considered one of the central elder care services: In analysis of voter preferences, there is consensus along all party lines (98 % of all voters) that home help should be financed over the tax system (Juul, 2002). This is despite general poor evaluation of the actual service level in voter surveys, where home help comes out as the poorest rated services, compared to public libraries, day care services, the primary school, and the hospital sector (Valgundersøgelserne, quoted in Nielsen and Andersen, 2006).

2.8. Providers of home help

Reflecting the generally positive attitude to elder care as a publically financed service, the tradition of public provision of home care has also been strong in Denmark and home care services have until a number of years been provided by public providers. Several independent non-profit organisations have operated in the nursing home sector and they make up the bulk of providers, but in the home help sector independent non-profit organisations are not active.

For-profit providers are on the other hand gaining ground as providers of both personal care and practical assistance in home help. The home help sector has since 2003 been opened up to private providers of care who operate along side municipal providers. The introduction of market mechanisms has been one of the main strategies by the sitting Liberal-Conservative government to improve quality in the field, as users are expected to choose the best providers and hereby ensure
that poor providers must close down (ref.). The introduction of the market mechanism in home help was also intended to improve efficiency as poor (private) providers will be run out of the market as well as improve the quality in care as the users are expected to choose the best providers. Finally, it was intended to empower the user and individualise care provisions. One of the problems is, however, that many users are unaware of the possibility to choose between providers, only 65% according to a survey (KL, 2009).

It is mainly new users and the least frail who opt for private providers, presumably because they must exercise the choice when entering the system, but also because they are less dependent and therefore less risk-adverse (Rostgaard, 2007). This is apparent in that the majority of those who choose a private provider are the ones who receive practical assistance. 31% of recipients of practical assistance use a private provider, compared to 5% of recipients of personal care (Danmarks statistik, n.d.). By 2009, 611 private home care companies operated in Denmark, and only 4 out of 98 municipalities did not have private provision of home help. Excluding Copenhagen, where 57 companies operated, on average 6 companies operated in the municipalities with the free choice (Danmarks statistik, n.d).

Municipalities set up contracts with the private providers, and users are free to choose between municipal and private providers. Home help is free of charge regardless whether a private or municipal provider is used, but private providers can provide and charge for extra services, which has made the municipalities criticize the system for creating unfair competition.

Most often for profit providers are approved (Authorisation model) by the municipalities and must provide services according to a set price. This model entails that all providers who can deliver services within the set price can ask to be authorised by the local authority. 95% of municipalities made use of this model in 2004. Another model is to contract out delivery of services (Tender model) before entering into a contract with a for-profit provider. In this model, a contract has to be set up specifying which categories of services will be provided (personal care, practical assistance etc). The number of for-profit providers must not exceed five within each category of services (Den Sociale Ankestyrelse, 2004).

In regards to the care workers, formal care workers are employed by the municipality or a private provider on the terms negotiated with the main trade union representing care workers, FOA. As the care system is based on a formal provision of care and there are few cash for care benefits, there is no grey sector for carers outside the formal care system.
2.9. Informal care

Because of the extensive scale of provision of formal care, care provided by family members and relatives is of supplementary nature, especially the care provided for older people by adult children, whereas spouses more often provide care for each other. The question is whether the cuts in practical assistance mean that elderly have to rely on other sources of help, such as the market and family members. Informal caring at least is not unusual, even in a welfare setting with relatively generous provision of home care. One in three relatives report at the moment to provide care for one or more elderly 65+, either in the home of the elderly or in an institutional setting (Ældresagen, 2009).8 Partners thus often help with e.g. cleaning, shopping, laundry, cooking or bathing, and 44 % of elderly 67-87 years with need for care and living at home, receive such help and care from their partner, while 24 % report to receive such help from their children or other relatives and friends (Analysis of Ældredatabasen, www.sfi.dk/ældredatabasen).

Informal caring may thus also take place when the elderly is no longer living at home, and where the informal carer steps in to coordinate the care. In fact, many relatives report that the nursing home and the home care system explicitly make demands that they become involved, in e.g. transporting the elderly to the doctor or shopping medicine. They also report that the coordination of care is demanding and can be difficult to combine with working (Ældresagen, 2009).

As has been evident from other studies of informal caring in the Nordic countries, informal caring often consists of making the elderly feel safe. In the survey among informal carers quoted above (Ældresagen, 2009), many informal carers report that they are engaged in such activities (visiting, keeping an eye on, calling on the phone, 69 %) or help with practical tasks (shopping 53 %, assistance in getting out-door 50 %; transport 43 %) and with administrative tasks (communication with doctor, home helper, municipality 39 %; finances and paying bills 33%) but one in five also help with personal care (19%). Considering the cuts in practical assistance in the home help, it is also interesting that 26 % of relatives report that they help with cleaning. And a relatively high proportion do this regularly, 14 % daily while 3 % round the clock, 18 % help 3-4 times weekly and 32 % 1-2 times a week. And more than one in four (28 %) of informal carers provide care because they find the public care insufficient.

There is also indication that the market to some degree compensates for insufficient public home care. At least it is more common among elderly with need for care to use help from a private

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8 Survey among relatives to elderly consisting of partners, children(in law), grandchildren, neighbour, or friend, aged 18-74 years.
market provider, outside the home care system, i.e. they may purchase cleaning or shopping services. With increasing needs, elderly 65+ are more likely to use privately purchased help and care; 14% of elderly 67-87 years with 1-2 IADL or ADL needs thus buy market services and 19% of elderly with 3-5 needs (Analysis of Ældredatabasen). These may be bought through the Danish Home Service Scheme (*Hjemmeserviceordning*), which entitles early retirement or old age pensioners to a 30% discount for the purchase of domestic services.

### 2.10. Assessment of quality of care

In each local authority an appointed Social Welfare Committee supervises provision of social services and decides on such issues as the number and the type of institutions to be established, the ratio of trained to untrained personnel and the number of users to staff members, the content of the home help service. The Social Welfare Committee also supervises local social service provision.

Regulation and inspection is carried out by different boards of appeal and through supervision by central government agencies (*styrelser*) and ministries. The independent National Board of Social Appeal (*Den Sociale Ankestyrelse*) is the highest appeal courts in the social field.

Users of home care can complain directly to the person who has assessed the need and, if necessary, further to the social Welfare Committee, if they disagree with an assessment of care.

As described above, national indicators for user assessment of quality have been developed and these have so far mainly been used locally, but as part of the Quality reform these will also be made available as comparisons between municipalities. This reflects the criticism that the results of the user satisfaction surveys were seldom used in policy making (Bjørnholt, 2006). Analysis has, however, shown no significant local differences in level of satisfaction (KL and Finansministeriet, 2005). Another criticism has concerned the lack of reflection of the results in daily practices in the home help system.

Experience also shows that users are generally highly satisfied with the services, whereas more dissatisfaction is evident when questions relate to the various elements of the home help. The third national user satisfaction survey was carried out in 2009 and showed – like in previous years - that far most of users were satisfied or very satisfied. Between 86% of users of practical care and 92% of users of personal care were satisfied with the provided care. Stability in the care delivery and continuity in staff members has over the years been one of the areas where most users were critical. 75% of users of home care with practical assistance and 85% of those with personal care were in
2009 either satisfied or very satisfied with stability. 67% of users of home help with practical assistance and 69% of users with personal care were either satisfied or very satisfied with the frequency in number of staff members (KL, 2009). Private providers generally score higher on questions related to flexibility in care provision and the frequency of staff members, but not on questions related to staff friendliness and on how much care is provided (Nielsen and Andersen, 2006).

The user satisfaction survey tool is applied in most municipalities and used as an instrument to measure

### 2.11. Care assessment

Entitlement to home care based on need and residence permit only. According to the Social Service Act, any person lawfully living in Denmark who is in need of care is entitled to receive such care, irrespective of age, financial means, income or family situation. This means that needs assessment should take into account the individual situation of the elderly, and not consider whether an adult child, a partner or spouse or other family member would be able to provide the care instead. Any person who is unable to carry out personal care or domestic tasks on their own due to temporary or permanent impairment of physical or mental function or special social problems is entitled to home care (Social Service Act). There are no minimum requirements as to the level of need for care, and provisions of home help can be less than 1 hour per week and in principle up to 24 hours a day.

The municipalities are in charge of assessing need and a special corps of assessors is in charge of this. This profession was set up in the early 1990s, in order to professionalise and improve the quality of the needs assessment, which was formerly carried out by home helpers. It did, however, also add a new professional and organisational distance between the provision of need and the needs assessment, which has in recent years been strengthened by the requirement that all communication between care assessors and home helpers about changes in the needs of the elderly must be in written form. This requirement was introduced in order improve the documentation of needs, but seem also to have has complicated communication and exchange of knowledge (Rostgaard, 2007).

Assessors as a minimum receive a 2 weeks course in assessment. Many of these have worked as home helpers before and often have experience in the field, e.g. a survey carried out in
2007 showed that care assessors on average had worked within the care sector for 3.5 years (Rostgaard, 2007).

For the assessment of need and allocation of time, most municipalities use the common generic assessment system, *Common Language* (*Fælles sprog*), which provides a standardized system of categorizing functional capacity as well as the services which are provided by the local authority. In this way, it offers a codification of need and a general conceptual framework for the various actors, be it care assessors or care providers, but is also a tool for the creation of statistical indicators which can be used at the local political level, as well as for benchmarking between municipalities (Dahl and Hansen, 2005).

The Common Language system describes only four levels of functional ability and a catalogue of care services which match the need for care. This simplifies the regulation of allocation of time by setting of a certain number of minutes for specific tasks, but has also been criticised for standardising the assessment of care needs, which does not take into account individual care needs (la Cour and Højlund, 2001) and which does not enable the identification of complex needs (Petersen and Schmidt, 2003).

### 2.12. Accountability

Control of the time that home helpers spend on care is possible amongst other through the introduction of new technological tools such as Electronic Data Programming and the use of Palm Pilots in the provision of care, where the home helper can report her use of time and the tasks performed and this is used for documenting and controlling what is provided. An investigation by the trade union representing social care workers in 2005 found that 44% of employees had to register time and these employees were in general more dissatisfied with their work environment and experience that they deliver poorer quality of care (FOA, 2005).

Over the years, many procedures to control time and document the use of resources have been introduced by decree from the central government, and in later years this has received much criticism, e.g. great parts of the election campaign debates in the mid-2000s dealt with what was termed ‘tyranny of minutes’ and ‘bar code tyranny’ in home help. The later refers to the practise in some municipalities of setting up bar codes on the older person’s door frame that the home helper must register when entering and leaving the home of an elderly. New reforms of de-bureaucratising are now rolled out in order to accommodate the criticism. This follows a much debated event where
several influential government officials in a national newsletter in 2007 officially apologised for their involvement in the introduction of NPM strategies in the public sector (Gjørup et al., 2007)

Accountability is also one of the reasons behind the introduction of the Provision contract (Aftaleskemaer) which is written as part of the assessment of need. This contract steering instrument was passed as a law in 1995 and is a way of formalising and introducing elements of accountability in the service delivery. It make more explicit the various expectations and obligations between the user and the provider. In the contract, which is made between the assessor and the user, the provision of care which will be delivered is described, giving the user a claim to services, but also emphasising the boundaries of care, ie what will not be given.

The provision contract includes a description of the allocated provisions and the specified goal or purpose for providing the care. That care is given on the basis of a specific goal and not only on the basis of need, is a new principle, inspired by NPM strategies of goal-oriented governing doctrines. It also serves to remind that care may not be given on a permanent basis, but in accordance with the principles of rehabilitation, only as long as there is a need for it.

Contract steering is also used to ensure quality of care. A Law on Quality standards (Lov om Kvalitetsstandarder) has been passed in 1998 whereby users’ rights and obligations are made more transparent, also across municipalities. Municipalities now must make public local standards of quality, e.g. making explicit how often cleaning is provided. Some municipalities describe down to the detail, e.g. how many rooms can be cleaned and how often.

The principle of accountability was originally also at stake in the introduction of the purchaser and provider split in 2003, after a ministerial report in 1997 criticised the local variation in the allocation of care. A more equal allocation procedure was desired in order to ensure that citizens received equal treatment and in order for the municipalities to better control use of resources. The purchaser-provider split was recommended to achieve both goals. It was also a step on the way to the introduction of market forces in the provision of home help, which came later. However, in combination with the Common Language, the purchaser-provider model has been criticized for leading to standardization of care which disempowers members of staff as well as users of care and leading to new care practices where members of staff in order to feel that they provide proper quality of care, provide more care than what is the administrative standard (Hjort-Hansen, 2001).
2.13. **Flexibility in care provision**

Even though the provision of service is described in the provision contract it is, however, not given that the elderly will know the exact number of minutes or hours which is set of for service delivery. The municipalities apply different strategies as to whether they inform about the time, which are set of for each care task. Some municipalities only inform about the tasks which will be carried out. This is to preserve some flexibility in the daily delivery of care, where the individual home helper can adjust the care provision to daily needs, and is also to avoid focus on the variation in care allocations in-between the elderly. This is, however, also a practise which has received much focus and criticism and which goes against the principles of accountability.

Some flexibility has, however, also been introduced for the user of care, in the *Law on flexible home help* from 2003, which was a reaction against the criticism of the standardisation of home help. The flexibility scheme entitles the care user to exchange services within the same category, as long as the home helper can provide these within the same time span. Is also re-introduced some agency and room for daily negotiation of needs and services between the home helper and the care recipient.

If the same service is consistently exchanged over a period of time, a new assessment of need may be carried out. In practise, few users are aware of the rules on flexibility, 68% according to the 2009 user satisfaction survey, and few make use of them. The organisation representing elderly in Denmark, Ældresagen, reports that users experience problems, because they 1) do not know exactly how much time they are allocated, 2) there is often too little time set of to exchange services, 3) or that the local authority ‘threatens to make a re-assessment after the exchange of services two times’ (Ældresagen, n.d.).

2.14. **Recruitment and retention**

Among one of the dimensions identified as an important issue for the quality of care is the continuity of staff, and the recruitment and retention of care staff is a common problem for many municipalities. One fourth of formal care workers are 54 years or more, and will be retiring within the next 8-11 years. It is estimated that there will be a shortage of 6,200 full-time positions by 2015 (Rostgaard et al, 2011). In addition, it is difficult to attract employees as the work is characterised by low salaries, hard working conditions and low status.
A reform of the education of care workers has taken place which in addition to raising the level of education of workers in this sector, is also a means to improve recruitment. The reform of the care education which took place in 1990 resulted in the introduction of two new care educations. One is the 16 months Care helper education (Social og sundhedshjælper) which is focussed on the provision of practical assistance, and 20 months Care assistant education (Social- og sundhedsassistent), which is also focussed on the provision of personal care. The student receives a salary during the education. The two educational tracks include extensive periods of practise in the field, in order to motivate for further training and to address recruitment problems (Leeson, 2004). The care education has been streamlined with other educations, and can be used e.g. as a stepping stone for a later up-qualification as a nurse.

Another strategy has been to encourage especially the take up of the care education especially among the first and second generation migrant population, as there is an unused pool of labour as a relatively high proportion of migrant women are outside the labour market. Also, it is seen in general to contribute to the integration of these women and their children (Rostgaard et al, 2011). Many municipalities accordingly attempt to recruit care workers among the migrant population, and around 11% of the care workers have a migrant background, defined as being born abroad or being an immediate descendant of a person being born abroad. However, there is still great concern about the future recruitment of staff, and a focus on bringing down sickness absence. A new initiative in the Quality reform is also to encourage senior care workers to remain on the labour market and a special fund has been set up for this purpose.

2.15. Conclusion

Home care in Denmark has in the last two decades undergone important adjustments and changes, not so much in overall principles as in the service level and focus of service provision. In the overarching policy goals and objectives, Danish elder care still adheres to the Nordic care regime in its overall principles of universalism, formalization and professionalization of care. The objective of ageing in place or ‘as long as possible in own home’ as is the Danish term for this policy, is continued, as are also the objectives of help-to-self-care, integration and prevention which were introduced in the late 1980s. The institutional setting and policy instruments used to obtain these goals have not changed in the sense of mode of access to services and cash benefits (citizenship and need), nor in the organization (local responsibility) and financing (state/local financing an no user
contributions), while in the provision we now see more for-profit providers. We also see some change in the benefit structure towards a cash orientation, which has been influenced by the disability movement. But most changes at this level have taken place in the institutional setting, through the introduction of new ways of governing the home care system, inspired by NPM ideology but also of the conflicting principles of individualization/standardization. This includes the introduction of principles of accountability and goal-oriented governing, but also the introduction of more flexibility in care provision and standardized forms of communication. Finally, also in the setting of instruments do we see changes, in the level of benefits, as is visible in the polarisation of home care resources and the focus on personal care.

It seems national reforms in recent years have especially been procedural, and not deliberately aimed at changing the main principles of care, although we see as mentioned more weight on individual preferences but also on personal and individual responsibility for one’s health situation. In this way, national policy reforms are more piecemeal than paradigmatic and overall we can perhaps not claim that the elder care system in Denmark has undergone great transformation in regards to the principles of care provision. Nevertheless, with the attempts to improve governance and steering, there seem to have taken place an incremental change which is of importance not only for users of home help and their relatives, but also for present and future employees working in the care sector. The introduction of strict time control, standardisation of care tasks and the purchaser-provider split threatens to industrialize care work and care provision and to erode the sense of trust and the development of personal relations between care provider and care user. Also, when looking at the local adjustments of the service level, it is apparent that home care today reaches mainly the most frail, and covers mainly personal care while assistance with practical tasks in the home has been reduced.
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3. Home Care in England

Caroline Glendinning & Alison Wilde

3.1. Introduction

This chapter covers home care services in England only. In 1999 responsibility for health and social care policies and services was transferred from the UK Parliament to the Scottish Parliament and the Welsh and Northern Ireland Assemblies. Other functions, including social protection and social security, remain the responsibility of the UK Parliament. This devolution of statutory responsibilities, together with the distinctive institutional structures within each UK countries that shape policy implementation, have resulted in differences between the constituent countries of the UK. Many of these are relatively small, but they are particularly apparent in relation to social care (Bell, 2010).

Reforms to home care services in England have been driven by three factors: the long-term, structural underfunding of social care services in general (of which home care services constitute an important element); demographic trends common to all advanced welfare states; and a consistent policy trajectory over the past 20 years from successive governments to support more people at home, for longer, in order to avoid (or at least delay) entry to residential care. This latter policy affects both older people, who are now living at home with levels of support needs that, two decades earlier, would have led to residential care admission; and younger people with very severe disabilities who now increasingly live at home rather than in hospital or residential settings.

English home care services suffer from chronic structural under-funding. There is a substantial market for privately purchased care and heavy reliance on informal care. Eligibility thresholds for home care have risen and services are increasingly targeted at only those with the highest level needs. Publicly-funded home care services now provide largely personal care within the home, although this trend has been heavily criticised by older people (Clarke et al., 1998). Help with domestic tasks, psychological/emotional support and help to participate in social activities outside the home are rarely covered, particularly for older people, although this may change in future as more older people receive personal budgets.

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The main approach to reforms in English home care over the past two decades has been the creation and further development of quasi-markets. Initially this involved the creation of a ‘mixed economy’ of supply, with local authorities increasingly contracting with external, private (charitable and for-profit) providers rather than relying on their own, in-house services. More recently a potential ‘mixed economy’ of purchasing has been developing, through the introduction of personal budgets. Personal budgets have the potential to allow individuals to control the resources for their care and negotiate directly with home care providers and others in order to secure personalised support arrangements. In addition, there have been some developments in preventive and rehabilitation services, particularly for people discharged from hospital; these aim to reduce longer-term needs for publicly-funded home care services.

### 3.2. Background – the organisation of home care services in England

The funding and structures for English home care services originate in the post-war welfare state. Then, the newly established National Health Service (NHS) was responsible for ‘treatment’ and ‘cure’, with local authorities providing residential and domiciliary social care services for people in need of ‘care and attention’ (Means and Smith, 1998). This division of responsibilities was underpinned by different funding and accountability mechanisms, which have remained fundamentally unchanged since the late 1940s. NHS services, funded from general taxation, are largely free at the point of use and directly accountable to central government. NHS services for people living in their own homes include general and specialist nursing care and specific services for people with mental health problems, dementia, those at risk of falls or incontinence. These services are outside the scope of this chapter.

Local authority services are funded through a mixture of central and locally-raised taxation, plus significant contributions of means-tested charges levied on service users. While the accountability of local authority social care services to central government has increased over the past 50 years through an extensive range of financial controls and performance management mechanisms, there is nevertheless also some accountability to locally elected politicians. This means that local politicians can also make decisions about the proportions of their total budgets to be allocated to social care and, within that, to home care services.

The boundaries between NHS health and local authority social care services are fluid and have shifted considerably since the late 1940s. Many functions, particularly those affecting older
people and younger people with mental health problems or learning disabilities, have moved from the NHS to become the responsibility of local authority social services (Means et al., 2002; Glendinning et al., 2005). Home care services have remained a core responsibility of local authorities throughout this period. However, home-based support for people with mental illnesses or learning disabilities, and for people newly discharged from hospital is often jointly and delivered funded with NHS partners.

As well as home care services, people needing substantial, repeated or regular personal care and/or supervision can claim a social security cash benefit, the Attendance Allowance (or Disability Living Allowance for working age disabled people). These are paid at different levels, depending on the level of help that is needed, and were originally intended to meet extra disability-related expenses. However the benefits are increasingly assumed to be available to pay for care and are usually taken into account in means-tested calculations of user charges. People whose needs are not high enough to qualify for local authority funded home care services are likely to use the allowances to pay for a range of informal support and commercial services (Corden et al., 2010).

England also has a cash income-replacement benefit for family carers called Carers Allowance, although its level is very low; a national strategy setting out the responsibilities of local authority social services and NHS services to support carers (HM Government, 2010); and a highly effective carers’ lobbying organisation (www.carersuk.org). Questions about family and informal care are included in the UK’s ten-yearly population census; figures from the 2001 Census showed that around ten per cent of the total English population (12 per cent of the adult population) were carers, of whom about 20 per cent provided more than 50 hours a week care (Carers UK, 2009).

In 2004/5 gross public expenditure on all social care for older people in England was estimated to be £8 billion; charges paid by users recouped around one-fifth - £1.6 billion - of this. NHS services to older people living in their own homes were estimated to cost a further £450 million in 2002/3 (Wanless, 2006). It is difficult to estimate the exact numbers or proportions of older and disabled people who need help and support with personal care or household tasks who actually receive home care services, whether publicly funded or privately purchased.

Eligibility thresholds vary from one local authority to another. However, most local authorities restrict eligibility to those who have only minimal assets or savings (thus often excluding home owners whose house is included in estimates of assets); low incomes; and high levels of care needs. Indeed, because of the current very tight restrictions on public spending, most local authorities are raising their needs-related eligibility criteria to the highest levels. Any support
needs that are met by family or informal carers are not taken into account in assessments for publicly-funded home care.

Because of these very tight eligibility criteria, many people purchase some or all of their home care services from their own private resources. A recent analysis suggests that around 751,000 people aged 65-plus in England receive community based social care (which includes home care services but also some other community-based services such as day care). Of these, 19 per cent paid for all their own care and a further 21 per cent ‘topped up’ their local authority-funded services with additional private purchases. In other words, 40 per cent of all people aged 65-plus paid from their own resources for some or all of their community-based services (IPC, 2011). This is in addition to the means-tested charges that are levied by local authorities towards the costs of the services they do provide.

3.3. What have been the main driving forces for reforms in home care and what have been the reform strategies?

The context of under-funding

Overall, English social care services, including home care services, are widely acknowledged to be significantly under-funded, relative to levels of need. Reforms over the past two decades have been driven by rising demographic pressures, in the context of a continuing failure to achieve comprehensive and sustainable funding reforms. Political pressures to achieve a more sustainable funding basis for adult social care began to build during the 1990s. These pressures arose particularly from the need for older people to ‘spend down’ their assets (including the value of a home) before qualifying for local authority-funded care; and by the variations between local authorities in eligibility thresholds for home care services and levels of user charges. An official Commission of Enquiry was established in 1997 (Royal Commission, 1999) but its main recommendations were sidelined by the then Labour Government. An independent Commission re-examined the options for reform in 2006 (Wanless, 2006), but did not have sufficient political leverage to stimulate change. Further proposals for reform were introduced by the outgoing Labour government in 2009 (DH, 2009a) but progress was stopped by failure to achieve cross-party agreement before the 2010 General Election. The incoming Coalition Government has established a new Commission of Enquiry into funding options that is due to report in 2011. Meanwhile (autumn
major reductions in public spending have been announced that are expected to have particularly harsh impacts on funding for adult social care services.

The underfunding of social care has led to increasingly tight eligibility criteria being applied by most local authorities; these criteria include financial assets, income and levels of unmet need (any support needs met by informal and family carers are not counted). In 2006/7 in England, around 6,000 older people with high support needs, and 275,000 people with less intensive needs, were estimated to receive no social care services and also have no informal care. A further 1.5 million people were estimated to have some shortfalls in the care they did receive (CSCI, 2008).

Although there has been an overall increase in the volume of publicly-funded home care, this masks changes in the numbers and types of households who receive services. Over time, local authorities have deliberately targeted services towards those with higher levels of need, and reduced the provision of lower level support to the larger number of households with fewer, or less urgent, needs. Thus in 1992, over 500,000 households received local authority-funded home care services; by 2001 this had dropped to 381,700 households and again to 354,500 households by 2005. However, in 1992 an average of 3.2 hours per week of local authority-funded home care was provided to each household that received services; by 2005 this had increased to 10.1 per week. By 2005, 24 per cent of all households receiving local authority-funded home care received six or more visits, and more than ten hours of home care services, per week (CSCI, 2006). This trend reflects pressures to reduce admissions to residential care and the higher levels of support consequently needed by people in order to remain in their own homes. It has been encouraged by Government targets for local authorities to increase the proportions of people receiving home care who receive intensive services and to increase the numbers of older people able to live at home with intensive support, rather than entering residential care.

Reforms over the past two decades have reflected a consistent belief in the effectiveness of market-related competition in driving down costs, reducing the power of providers and improving choice, quality and responsiveness for users. This underlying reform trajectory has proved remarkably persistent, despite the changes in 1997 from Conservative to New Labour Governments and again in 2010 to a Conservative-Liberal Democrat Coalition. There have been two main phases to reforms: the initial introduction of quasi-markets in home care; and the introduction of personal budgets.
Quasi-markets and a ‘mixed economy’ of supply

The first phase of market reforms reflected the ambitions of the Thatcher Conservative governments of the 1980s to break down the public sector as a monopoly supplier of services and introduce market-style competition. It ‘was based on ideological commitments to market principles and the belief that only by introducing them into what was perceived as sluggish, unresponsive bureaucratic apparatuses of the welfare state could efficient services, responsive to consumers’ choices, be delivered’ (Bartlett et al., 1998: 1-2).

Following concerns about the growing use of residential care as the default service option for older people, and a series of reports highly critical of the lack of coherence in previous policies (Audit Commission, 1986; Griffiths, 1988), major reforms were implemented in 1993. These reforms assigned clear responsibility to local authorities for promoting the development of domiciliary, day and respite care services as alternatives to costly residential care; and also developing private sector services to compete with local authority provision (DH, 1989). The changes were far-reaching. Local authorities created separate structures for their commissioning/purchasing and service provision activities; and started to encourage private (non-profit and for-profit) provider organisations to develop and to compete for contracts with in-house home care services (Means et al., 2002). For any individual older or disabled person, a care manager would conduct an assessment and then purchase home care services from one (rarely more) of the provider organisations with which the local authority had contracts; this was expected to offer greater choice and flexibility for service users.

However, during the 1990s there were pressures for further reform from two sources. First, younger disabled people demanded to be given the cash equivalent of home care services in kind (‘direct payments’), so that they could employ their own personal assistants and exercise choice and control over the activities, timing and manner in which they received help. The right to receive direct payments instead of services in kind was introduced in 1997 for working age disabled people and extended to older people and parents of disabled children in 2000. The English government actively promoted take-up of the direct payments option, believing that this would facilitate the creation of support tailored to individual needs and circumstances. From 2001 English local authorities were required to offer direct payments to all those eligible for home care services and the numbers of direct payment holders became an indicator on which the local authority performance was measured. A £9 million fund was established in 2003 for local authorities to invest in new advice
and brokerage services, often delivered by voluntary and user-led organisations, to provide information and support to prospective direct payment holders. However, take-up of the direct payment option remained low; in 2007/08 direct payments still constituted only one to six per cent of local authorities’ gross expenditure on adult social care (DH, 2009, Appendix A). Take-up also varied widely between individual local authorities (Fernández et al., 2007) and between groups of service users – older people and people with mental health problems were consistently less likely to opt for direct payments than younger people with physical disabilities (Leece and Bornat, 2006).

Secondly, research carried out by academics, pressure groups representing older people and the English social care inspection and regulatory body drew attention to the inflexibility of home care services. Evidence grew of how tasks were rigidly prescribed by micro-purchaser care managers, regardless of individual preferences or changes in circumstances (Henwood et al., 1998; Qureshi et al., 1998; Raynes et al., 2001; Francis and Netten, 2004). Pressures to drive down costs and difficulties in recruiting and retaining home care staff led to widespread criticisms of home care visits being as short as 15 minutes; longer visits being cut short because staff were not paid for their travel time; and lack of continuity, with users typically receiving visits from a large number of different home care workers. One survey found a third of users ‘described having no choice over the support services they used’ (Coalition on Charging, 2008). Another study (Francis and Netten, 2004) found major problems in the reliability of home care visits, because financial and staffing pressures did not allow enough time for workers to travel between visits. In response, some local authorities began to ‘zone’ their home care provision, contracting with one provider to provide services to all users in a specific neighbourhood (Baxter et al., 2008). While this was not compatible with market principles of competition and choice, it did reduce travelling times for staff and create greater continuity for users. Other studies (Clark et al., 1998) found users deeply dissatisfied with the range of tasks home care workers were able to undertake – these restrictions reflected the fact that local authorities would fund only personal, and not domestic, care or help with activities outside the home.

**Personal budgets and a ‘mixed economy’ of purchasing**

In response to these pressures, a second phase of reform began from 2005, with the piloting of individual budgets (IBs). This was underpinned by an aggressive discourse of consumerism that the (then) Labour Government brought to many areas of public sector reform (Glendinning, 2008). It drew on the experiences of In Control – an initiative to give people with learning disabilities greater
choice and control over their social care support. IBs were piloted in 13 local authorities between 2006 and 2008 (Glendinning et al., 2008) and followed by a decision to extend the approach (termed personal budgets – PBs – in the roll-out) to all users of adult social care (DH, 2007). PBs involve a greater role for self-assessment and a transparent and potentially more equitable method for calculating the resources allocated to each person eligible for social care. These resources can be used flexibly, according to individual preferences and outcomes agreed with a care manager. Personal budgets can be held in different ways: as a cash payment held and managed by the service user; by the care manager and used to purchase home care and other services from local authority-contracted providers; or by a home care service provider, to be used to pay for care as and when desired. Personal budgets can be used to purchase a wider range of services and tasks than previously available through care manager-purchased home care or direct payments. The evaluation of the IB pilot projects found that IBs were used to fund help with domestic tasks, gardening, leisure activities and outings, although the low levels of IBs received by older people meant that high proportions of their budgets were typically used for essential personal care (Glendinning et al., 2008).

Provisional figures show that by 2009/10, 9.6 per cent of all people aged 65-plus in England in receipt of local authority community-based services were receiving personal budgets. In 89 per cent of local authorities, personal budgets were being provided to between 0 and 20 per cent of all eligible older people; 11 per cent of local authorities were providing personal budgets to between 20 and 67 per cent of all older people in receipt of community-based support (Age UK, 2010).

Personal budgets effectively devolve purchasing power - command over an individual’s resources for social care - closer to the service user; another way of describing this is that it encourages a ‘mixed economy of purchasing’ to complement the ‘mixed economy of provision’. This shift in purchasing power has potentially major implications for home care provider organisations. Early evidence suggested that less flexible provider organisations could have difficulties in responding to budget-holders’ requests and find their business threatened; others reported budget-holders requesting help with a much wider range of tasks besides personal care. Budget-holders were also beginning to use their resources to purchase home care more flexibly, for example, ‘banking’ hours to ‘save up’ for a special occasion or outing, or in case of a possible relapse in health. However home care provider organisations also reported new risks, including being exposed to non-payment by budget-holders; new transaction costs and invoicing systems; loss
of staff who were ‘poached’ by budget-holders to work as personal assistants; and new responsibilities for managing risk (Glendinning et al., 2008; Baxter et al., 2008).

**Intensive home care services and low level/preventive services**

The concentration of home care services on those with the highest levels of need has led to major concerns about the absence of support for people with moderate or lower levels of support needs. Robust research evidence on the cost-effectiveness of supporting people with lower level needs is still emerging. However, strong arguments have been put forward both by organisations representing older people and by local authorities themselves, that the absence of low level support is likely to increase the risk of needing more costly, intensive services in the long-term. Consequently, since around 2002, all local authorities have developed a range of rehabilitative and preventive services, often jointly with local NHS partners, aimed at reducing levels of need for home care services. Broadly, these services take three main forms; two of these help to bridge the gap between hospital treatment and home care:

- ‘Intermediate care’ – nursing, physical rehabilitation and therapy services to support early hospital discharge. These take a variety of forms but can involve intensive help at home following hospital discharge or to prevent admission (Institute of Health Sciences, 2005)

- Re-ablement home care services – intensive, short term home care interventions, typically for around six weeks following first referral for home care, to develop confidence and self-care skills. Re-ablement aims to improve clients’ psychological and physical functioning in the expectation that needs for long-term home care support will be reduced. Re-ablement has been shown to lead to immediate and longer-term reductions in assessed needs for home care (Newbronner et al., 2007; Glendinning et al., 2010); and has also been demonstrated to be cost-effective (Glendinning et al., 2010).

- Low level preventive services – shopping, visiting, support for social activities, often provided through charitable organisations and supported by grant funding from local authorities (Windle et al., 2009).

**3.4. What is home care/help?**

Traditionally, local authority home help services provided help with personal and domestic tasks, but during the 1990s resource pressures increasingly restricted the service to help with personal care
only. Nursing, psychological, physiotherapy and other health-related interventions are provided by the NHS, usually only after referral from a General Practitioner or other clinician. Both local authorities and the NHS provide equipment and assistive technology devices for use at home, often through occupational therapy services and equipment stores that are jointly funded and managed.

As a result of growing funding shortfalls and the tightening of eligibility criteria, home care services came increasingly during the 1990s to provide just help with personal care. It is rare for local authority-funded clients to receive help with domestic tasks, particularly if this is the only type of help that is required. In addition, home care services increasingly also provide help with some tasks that were previously considered an NHS responsibility, particularly managing incontinence and prompting users to take medication.

However, personal budgets allow users to have greater choice over the range of tasks they receive help with. Some home care service providers therefore anticipate receiving increased requests for help with a wider range of domestic activities, including housework, home decorating, looking after pets and companionship/support to undertake activities outside the home. Such flexibility is of course also available to people purchasing home care services privately from their own resources.

As well as providing support to people living in their own homes, home help/care services are also provided to older people living in specialist supported housing; and to younger disabled people with learning disabilities or mental health problems, again often in supported housing settings. For the latter groups, support to undertake training, employment or leisure activities, to manage money, and help with shopping and cooking are also likely to form part of home care.
3.5. How is home care/help organised?

Eligibility for publicly-funded home care is assessed by local authority care managers, and excludes people with any more than minimal savings or assets and the lowest incomes. Assessments take into account any help provided by informal carers – this usually does not count towards an individual’s assessed needs. Guidelines drawn up by the English government outline four levels of need: low, moderate, substantial and critical. Local authorities determine which levels of need they will fund services for in the light of their overall budgets. Most local authorities now fund services only for people with substantial and/or just critical levels of need.

In most local authorities, people eligible for publicly funded home care will be offered a period of re-ablement or extended assessment for up to six weeks, before referral on for longer term support (either in the form of a personal budget or in-kind service).

Long-term home care support is now provided predominantly by private organisations. Reflecting the development of a ‘mixed economy of supply’ outlined above, in 1992 98 per cent of home care hours were delivered by local authority in-house home care services; by 2005 over 73 per cent were provided by private organisations (CSCI, 2006). There has been a steady increase in the number of private home care organisations; in March 2009 there were 5,134 registered home care provider organisations in England, an increase of 237 over the previous year. Four out of five provide home care for adults and older people with physical disabilities and three quarters provide care for older people with dementia (CQC, 2009). This trend is mirrored by a marked decline in the number of home care services provided by local councils. Table 3.1 below shows the recent steady growth in the number of independent (private and voluntary) agencies, derived from registrations with the quality regulator body.
TABLE 3.1
Number of domiciliary care agencies registered with CSCI/CQC 2004-2009, by type of provider

<table>
<thead>
<tr>
<th>Domiciliary care agencies</th>
<th>end March 2004</th>
<th>end March 2005</th>
<th>end March 2006</th>
<th>end March 2007</th>
<th>end March 2008</th>
<th>end March 2009</th>
<th>August 2009</th>
<th>% change 2005*-2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private</td>
<td>1,320</td>
<td>2,910</td>
<td>3,286</td>
<td>3,473</td>
<td>3,687</td>
<td>3,845</td>
<td>4,033</td>
<td>39%</td>
</tr>
<tr>
<td>Voluntary + other</td>
<td>214</td>
<td>438</td>
<td>511</td>
<td>491</td>
<td>483</td>
<td>619</td>
<td>618</td>
<td>41%</td>
</tr>
<tr>
<td>Sub-total: independent</td>
<td>1,534</td>
<td>3,348</td>
<td>3,797</td>
<td>3,964</td>
<td>4,170</td>
<td>4,464</td>
<td>4,651</td>
<td>39%</td>
</tr>
<tr>
<td>Council</td>
<td>340</td>
<td>731</td>
<td>794</td>
<td>717</td>
<td>680</td>
<td>624</td>
<td>624</td>
<td>-15%</td>
</tr>
<tr>
<td>NHS</td>
<td>7</td>
<td>32</td>
<td>41</td>
<td>48</td>
<td>47</td>
<td>46</td>
<td>44</td>
<td>38%</td>
</tr>
<tr>
<td>Total</td>
<td>1,881</td>
<td>4,111</td>
<td>4,632</td>
<td>4,729</td>
<td>4,897</td>
<td>5,134</td>
<td>5,319</td>
<td>29%</td>
</tr>
</tbody>
</table>


Where local authorities still operate some home care services themselves, these increasingly provide specialised services, for example, extended assessments of people with rapidly changing needs; short-term rapid responses to crises that would otherwise risk hospital admission; or home care re-ablement (see above) (Glendinning et al., 2010).

There are also private nursing agencies that supply nurses to people purchasing their own care, although their main activity is to supply nursing staff to care homes.

Although the private home care provider market has developed mainly in response to the demands of local authority monopsony purchasing, it is both fragmented and unstable. The majority of home care agencies are medium (50-199 employee) and large (200+ employee) operations. They typically have a flat structure, with large numbers of care workers and small numbers of central managerial, supervisory and administrative jobs (Skills for Care, 2010). There is considerable diversity of ownership, including voluntary/charitable or not-for-profit organisations, social enterprises (businesses with primarily social objectives whose surplus revenue is reinvested for these purposes); sole proprietors, partnerships and franchises; and limited companies (ranging from single branches to large national organisations).

There is considerable turnover of providers, with high proportions of agencies being de-registered and newly registered each year. Some of this turnover may have been reduced as local authorities introduced ‘zoned’ contracts and reduced the number of providers they contracted with. Other providers, particularly smaller ones, may find it hard to withstand increases in financial risk.
and transaction costs as individual personal budget holders replace large local authority purchasers. On the other hand, the extension of personal budgets creates potential opportunities for new providers to enter the market and for existing providers to diversify into a wider range of services, such as help with recruiting and paying staff for people who want to use personal budgets to employ a personal assistant (Glendinning et al., 2008).

3.6. How is home care financed?

Home care services are funded from two sources. Local authorities, mainly through taxation-derived grants from central government, fund services for those who meet the local financial and need eligibility criteria. The proportion of total local authority resources allocated to adult social care – and within that the proportion spent on home care services – depends upon local priorities and politics. The proportion of total local authority expenditure on older people that is spent on day/domiciliary services varies between local authorities from just over 20 per cent to nearly 60 per cent (DH, 2009, Appendix A).

The second source of funding is from private individuals – service users and their families:

- the income-tested user charges paid by recipients of local authority-funded home care services;
- the fees paid by people who are ineligible for local authority-funded services and who purchase home care entirely from their own private resources;
- and the fees paid by those who receive some local authority-funded home care but who ‘top’ this up with additional privately purchased home care.

It is estimated that older private purchasers account for around 20 per cent of the total home care market in England, purchasing care worth around £417 million in 2004 (Poole, 2006; see also IPC, 2011). An estimated 3.96 per cent of those aged 65-plus report paying for private domestic help (which includes cleaning as well as personal care); the proportions show no clear patterns according to age or gender (IPC, 2011). Recent interviews with representatives of groups representing the care industry found that a majority expected the volume of self-funding to increase in the future, reflecting continuing demographic pressures and public spending constraints (IPC, 2011). Moreover, the extension of personal budgets is likely to reduce providers’ reliance on large volume
local authority contracts and this may encourage them to market their services directly to potential clients, including potential private purchasers.

3.7. Who are the carers – the home care workforce in England?

Home care workers employed by local authorities and private home care providers are predominantly low paid, part-time women. In 2006, out of an overall workforce of 47,970, 95 per cent of care assistants and home carers were women.

People from black and ethnic minority (BME) communities (including both UK-born and foreign-born workers) are over-represented in the home care workforce, although the numbers vary considerable according to sector and location. In total, 17 per cent of home carers and care assistants (some of whom will be working in residential settings) are from BME communities. A slightly lower proportion, 15.4 per cent of employees in private home care agencies are from BME communities (Skills for Care, 2010). The percentage of care workers from BME communities is much higher in London, at 47 per cent of front-line social services staff (this percentage also includes care assistants working in residential settings).

Migrant (i.e. foreign-born) care workers account for 18 per cent of all care workers (including care assistants in residential settings), a higher proportion than in the overall workforce (13 per cent). Like care workers from BME communities, migrant care workers are concentrated in London and the south of England. Recent migrant care workers have tended to come from Poland (especially since Poland joined the EU in 2004) and sub-Saharan Africa. Recent migrant care workers tend to be younger than both non-recent migrants and UK-born care workers and are also more likely to be male – men account for 31 per cent of care workers who migrated to the UK in the past decade, compared to 13 per cent of UK-born care workers. Recent migrants are also more strongly concentrated in the private than the public or charitable sectors, although evidence suggests that those who stay in the social care labour market may eventually move to the public sector, with its somewhat better pay and terms and conditions, when the opportunity arises (Cangiano et al., 2009).

Social care is one of the sectors of the UK economy where low pay is common (Low Pay Commission, 2005), notwithstanding the fact that direct care workers were one of the groups to benefit most from the introduction of the National Minimum Wage in 1999 and social care employers were amongst those most concerned about its impact (Grimshaw, 2002; Grimshaw and
Carroll, 2006). The median gross hourly rate for home care workers in 2009 was £6.80, which was slightly higher than that for care workers across all adult services. This is nevertheless only a little above the (then) National Minimum Wage (£5.73 for people aged 22 and over). This excludes senior care workers (all care sectors), whose estimated median gross hourly wage rate during the same period was £7.00. Recent analyses, however, show a gradual but significant increase in care workers’ pay rates and this has led to a widening gap between care workers and those in other low skilled occupations (Cangiano et al., 2009).

The skill levels of the homecare workforce are generally low. However, employing agencies are now required to have specified levels of qualified staff. National Care Standard 20, relating to the competency and training of staff, specified that by 1 April 2008 50 per cent of all personal care was to be delivered by workers with National Vocational Qualifications (NVQ) or equivalent. Skills and qualification levels are therefore slowly increasing, with most staff having or working towards NVQ qualifications acquired through on-the-job learning and assessment. Newly appointed home care workers without relevant qualifications must register for NVQ training within six months of starting employment. However, up to the end of March 2007, between a fifth and a quarter of registered home care agencies had not met this qualifications standard. In 2008, only 32 per cent of care assistants or home care workers had gained NVQ level 2 and a further 27 per cent level 3 (the two lowest levels) or above (Eborall and Griffiths, 2008). Perhaps influenced by the difficulty in implementing Care Standard 20, the Care Quality Commission (the English national health and social care regulatory body) has recommended that the 50 per cent target figure should be dropped and replaced by a requirement that employers ensure they have ‘sufficient’ numbers of suitably qualified, skilled and experienced staff. From January 2011, NVQs will be incorporated into a new Qualifications and Credit Framework (QCF) that will enable people to gain qualifications at their own pace along flexible routes and allow a 'mix and match' approach to meeting the different development needs of the workforce (www.skillsforcare.org.uk/qualifications_and-training).

There are few workers in domiciliary care with professional (e.g. nursing) qualifications. Three-quarters of the domiciliary care workforce work as care/senior care workers providing direct, hands-on personal care and only three per cent have professional roles (the rest being managerial or supervisory positions). Direct, ‘hands-on’ care is provided primarily by women – 79 per cent of all those working in private domiciliary care agencies are women, as are 94 per cent of those providing local authority domiciliary care (Skills for Care, 2010). Eighty-two per cent of women working in domiciliary care do so on a part-time basis (compared to 56 per cent of men).
Home care provider agencies report significant problems in recruiting and retaining staff and turnover is high. Turnover problems are not unrelated to levels of pay, which have remained relatively low because of the purchasing power of local authorities in keeping down the prices they pay for services. The vacancy rate in social care is nearly double that for all types of industrial, commercial and public employment (Eborall and Griffiths, 2008). Many of the vacancies are described as ‘hard to fill’ because of a shortage of suitably qualified candidates (rather than an overall shortage of applicants) (Moriarty, 2008). Patterns of demand for services, with peaks in the morning and evening, also reduce the attractiveness of work in the sector, particularly where there are alternative low skilled employment opportunities in the local retail and catering sectors.

The introduction of direct payments and the extension of cash-based personal budgets may gradually lead to a more diverse, flexible and less regulated workforce. In 2009-10, 9.6 per cent of people aged 65-plus receiving local authority funded community based services were receiving personal budgets (Age UK, 2010). Assuming an average of 2.3 personal assistants (PAs) employed per recipient (Skills for Care, 2010), this gives an estimate of over 200,000 people working as personal assistants for older people. As more people receive personal budgets instead of directly provided services, the numbers of people working directly for service users is likely to increase further.

A survey of personal budget-holders found they reported greater reliability and flexibility from their directly employed personal assistants and lower levels of psychological, financial and physical abuse than from agency home care staff. Personal assistants also reported high levels of satisfaction, with only one in five concerned about long hours and one in three about low pay. There are no requirements for personal budget holders to provide contracts or formal conditions of employment to the personal assistants they employ, or for such workers to have any minimum qualifications. Only 34 per cent of PAs had been given a job description; personal budget-holding employers gave low priority to previous experience or job training, and only a minority supported compulsory registration (Skills for Care, 2008). Local authorities are beginning to develop systems to help prevent abuse of people who direct their own support ‘but the evidence indicates that no council yet has a systematic approach in place. Information and support to people funding their own care was also variable between councils’ (CSCI, 2008).

By emphasising the benefits of working for an agency (for example, training opportunities, guaranteed hours of work, sickness and holiday entitlements), some managers of home care agencies hope to deter significant numbers of their employees from moving to work for individual
personal budget-holding employers (Baxter et al., 2008). The latter may, therefore, be more likely to recruit helpers from their own informal local networks, leading to an overall increase in the size of the home care workforce, albeit potentially under less formal or regulated arrangements. In addition, provider organisations may also begin recruiting unqualified staff to provide the ‘companionship’ and domestic help demanded by some personal budget holders (Glendinning et al., 2008; Baxter et al., forthcoming). However, any impacts on the overall volume and range of home care service options that result from users being able to purchase services directly instead of through a care manager are likely to take some time to become apparent. Moreover, any such changes may be of less significance than the increasing constraints on local authority funding and wider difficulties in recruiting and retaining home care staff and personal assistants.

3.8. Regulation and quality control

All home care provider organisations (including in-house local authority services) must be registered with the Care Quality Commission, a national, independent regulatory body that oversees the quality of all health and social care services in England.

In order to register, a home care service provider must complete an application form and provide appropriate financial references, a statement of purpose, a business plan, and a set of written policies and procedures making clear how the organisation intends to comply with the Domiciliary Care Regulations 2002 and the National Minimum Standards. Providers must also nominate a ‘responsible individual’, a senior member of the organisation responsible for supervising the management of the service. Although the responsible individual is not registered, they represent the organisation and must be able to show that both they and the organisation meet the fitness requirements for registration. In addition, upon registration, domiciliary care agencies are required to provide an outline of the training programme for the next six months for all staff, including managers.

The introduction of these registration requirements in 2003 led a small number of home care providers to cease operating. Enforcement actions can be issued by the CQC against organisations that fail to meet minimum registration requirements, leading to registration being cancelled if the failure persists, although this is rare (CSCI, 2006).

In addition, regular inspections (announced and unannounced) of each provider organisation encourage compliance with a set of National Minimum Standards (NMS). There are three types of
inspection: key inspection, and random and thematic inspections. A key inspection is a major assessment of the quality of the service and any risk it might present and is usually unannounced. Newly-established agencies have a key inspection in the first six months. Shorter inspections focus on specific issues and supplement the key inspection. They may follow up a previous concern or complaint, a change of manager, or a change in the service. Thematic inspections focus on a theme, for example how staff manage users’ medication.

The NMS cover all aspects of management and care practice, but have been criticised for having an undue focus on processes and paperwork, rather than on outcomes and practice. Recent inspections have therefore focused on standards relating to improving health and well-being; safeguarding dignity and respect; and leadership and management (CSCI, 2006). In 2005/6, around three-quarters of all home care provider organisations met or exceeded all 27 NMS.

From 1 October 2010, a new registration system is being introduced for adult social care providers under the Health and Social Care Act 2008.

3.9. Conclusion

It is widely acknowledged that public funding for long-term care in England falls well short of need. Publicly-funded home care services are increasingly restricted to those who have only minimal financial assets, low incomes and the highest levels of personal care needs. The focus of publicly funded home care services on those with high levels of need for personal care also reflects a longer term objective of developing domiciliary-based services in order to prevent – or at least delay – entry to residential care. Consequently, over the past decade although there has been an overall increase in the volume of publicly funded home care services, these are increasingly targeted on fewer households who receive relatively intensive services. Because of this increased selectivity and targeting, there is also a substantial private market, with older people and their families purchasing all their home care services from their own resources, or ‘topping up’ publicly funded home care with additional private purchase. Further consequences of the shortfalls in provision and the increased targeting of services are greater reliance on informal carers and significant levels of unmet need. Current deficit reduction-related restrictions on public spending are likely to increase these trends further.

Over the past two decades there has been a rapid and extensive shift from home care services being provided predominantly by local authorities, to the outsourcing of these services
from an extensive network of private (charitable and for-profit) providers. As the market has developed, so quality-related processes for registering and inspecting services have also been introduced. Home care provider organisations are usually relatively small and local. They have grown up in response to the demands of local authorities, which have negotiated large block contracts to provide home care services for eligible clients. These contracts have enabled local authorities to secure economies of scale and keep down prices. However, local provider markets are also relatively unstable, particularly in the context of a shortage of home care workers, and there is considerable turnover of both organisations and the home care staff within them.

With the introduction of direct payments and the extension of personal budgets across English adult social care, there are likely to be changes in local authority commissioning responsibilities; new demands on providers to offer a wider range of services; and possible threats to providers’ ability to recruit and retain staff from personal budget holders seeking to employ their own care workers. However, personal budget holders are also likely to recruit care workers from their own informal networks, leading to even greater fragmentation, diversity and lack of regulation within the overall home care workforce.
3.10. References


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4. Home Care in Finland

Teppo Kröger & Anu Leinonen

4.1. Introduction

During the last two decades, home-based care services for older and disabled people have experienced a radical change in Finland, following a rather surprising path. From the early 1990s, many other European countries have been expanding their home-based service provisions but in Finland the coverage rate of home help services has during the same period become halved. This change has taken place even though home care has the whole time remained as a national official policy emphasis. Actually, it is not just the coverage rate but the whole concept of home care that has experienced a profound change in Finland. Home help services that earlier were provided by social welfare agencies have in many cities become integrated with home nursing, forming together a new service under the heading ‘home care’. Home-based care has become more medicalised and started to provide service of such intensity that was earlier available only within institutional care. This change has been reflected in service statistics: a new category of ‘regular home care’ has been invented, referring to an intensified home-based service, and taken as one of the main indicators of service provisions for older people. What is striking is that such a full-scale transformation of an essential welfare state service has taken place without any real policy debate. The legislation governing the service has remained the same from 1982 to 2011. No one ever made the decision to thoroughly alternate the character of home care in Finland, the transformation process has instead happened ‘by stealth’. The main driving forces of the changes in Finland have been: concern about increasing care needs and their costs for the society, decentralisation, deinstitutionalisation and expansion of service housing, amalgamation of home-based social care and home nursing and integration of informal family care as a part within the publicly organised care system.

The aim of this paper is to describe and analyse this development. How and when did the transformation of Finnish home care services take place? What phases and elements did the process include? And how could such a dramatic shift be possible without any visible alterations in social and health care legislation or any distinctive decision to reform this welfare service? The paper will

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examine in detail the transformation of home care that mainly took place already in the early 1990s. The transformation is connected to two other recent processes that structure the current provisions: the amalgamation of home-based social and health care services and the integration of informal family care into the formal care system. Finally, a look will be taken on the most recent developments asking whether Finland is at the moment stepping back from some of the changes made during the 1990s. The paper will conclude with a discussion of the transformation. The special national focus of this paper is to look in detail at the intensification of home care as well as at the integration of informal care within the formal care system.

4.2. Legislative framework of home care in Finland

In Finland home-help services (kotipalvelut) have referred to assistance with functions and activities related to personal care and attendance and other activities of daily living. Since their inception in the 1950s, home-help services have been mostly organised by municipal social welfare authorities. There is no particular legislation on services for older people but home-help services are instead included in the general Social Welfare Act from 1982 (and Social Welfare Decree from 1983) which is a broad framework law that does not provide detailed regulations on home help. The legislation defines home-help this way:

"Home-help services mean performance of or assistance with functions and activities related to housing, personal care and attendance, child care and upbringing, and other conventional functions and activities in normal daily life."
(Social Welfare Act 710/1982, Section 20)

“Home-help services are organized in the following forms:
1) assistance, personal attendance and support provided at home by a trained home helper or house aid for an individual or a family; and
2) auxiliary services, such as meals on wheels, clothes maintenance, bathing, cleaning, transportation and escort services, and services promoting social interaction.”
(Social Welfare Decree 607/1983, Section 9)
In principle, these services cover all age and population groups but in practice, the service has become more and more seen as a part of service provisions primarily for older people though there are also a number of disabled people using it.

Although Social Welfare Act of 1982 was a framework law that did not provide detailed regulations, it was in the 1980s accompanied by a centrally-led planning system that obliged local authorities to follow national policy lines if they wished to receive central funding. This central regulation was nevertheless abandoned in 1993 and local authorities have enjoyed considerable local autonomy ever since. (Kröger, 1997 & 2011).

Local authorities are also in charge of need assessments in Finland. Usually they do not have any special profession of assessors but the assessments are instead performed by home-help managers as part of their work. Home help managers have a professionally oriented higher education (from 3.5 to 4 years full-time studies in Polytechnics) or a corresponding education according to the former education system. Local authorities are allowed to perform the assessments the way they wish, i.e. there are no nationwide eligibility criteria and the practices vary among municipalities.

Currently, there are ongoing preparations for the enactment of a new specific Act of Old Age Services. In March 2011 the Ministry of Social Affairs and Health published its outline that states, for example, that an older person would have a right to care and rehabilitation services when his/her needs are assessed and written into a care and service plan (see, www.stm.fi). As Finland is facing parliamentary elections in April 2011, it will be the task of the new government and the new parliament to decide whether this Act will be enacted.

According to the Services and Assistance for the Disabled Act, severely disabled people have a right to a number of different services, including service housing, and from September 2009, personal assistance. Personal assistance is a social service free of charge for persons with severe disabilities. A municipality cannot refuse to provide this service if the applicant fulfils the criteria under the law for access to the service. Personal assistance is provided for everyday activities as well as for work and studies. Support for other purposes should be given, as well, at least for 30 hours per month (from 2011). However, the municipalities can use several alternative ways of organising the service: 1) compensating a person with a severe disability for the costs of employing an assistant (in the same way which was the system also before the 2009 reform), in which the assistant has a contractual employment relationship with the person he or she assists, 2) giving the disabled person a service voucher for purchasing assistance service, or 3) organising the service
through its own service production (e.g., as home care service), in the form of a purchased service, or in cooperation with other municipalities.


4.3. Transformation of home help into ‘regular home care’

By the turn of the 1990s home-help services had already become remarkably developed in Finland. To cover 18.6 per cent of the +65 population or 31.4 per cent of the +75 population (Table 4.1) was at that time internationally exceptional, even within the Nordic region.

But things were to be changed soon. In 1991, Finland was hit by a major economic recession that led to severe cuts in public expenditures, also in central grants to municipal social and health care services. Furthermore, right in the middle of the recession in 1993 another major change took place: a radical decentralisation that made local authorities considerably more independent from central government. On the other hand, the reform delegated the financial and other responsibility for social and health care from the national level to the local level. (Kröger, 2011.)

TABLE 4.1
Users of home help services in Finland 1990–2005, number of households and % of +65 age groups

<table>
<thead>
<tr>
<th>Year</th>
<th>65-74 (number)</th>
<th>65-74 (% of age group)</th>
<th>75-84 (number)</th>
<th>75-84 (% of age group)</th>
<th>85+ (number)</th>
<th>85+ (% of age group)</th>
<th>65+ (number)</th>
<th>65+ (% of age group)</th>
<th>75+ (number)</th>
<th>75+ (% of age group)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1990</td>
<td>36,451</td>
<td>9.3 %</td>
<td>67,018</td>
<td>29.0 %</td>
<td>21,995</td>
<td>42.3 %</td>
<td>125,464</td>
<td>18.6 %</td>
<td>89,013</td>
<td>31.4 %</td>
</tr>
<tr>
<td>1995</td>
<td>20,087</td>
<td>4.6 %</td>
<td>42,484</td>
<td>18.2 %</td>
<td>23,895</td>
<td>35.7 %</td>
<td>86,748</td>
<td>11.8 %</td>
<td>66,379</td>
<td>22.1 %</td>
</tr>
<tr>
<td>2000</td>
<td>15,938</td>
<td>3.6 %</td>
<td>39,930</td>
<td>15.2 %</td>
<td>27,280</td>
<td>34.8 %</td>
<td>83,148</td>
<td>10.7 %</td>
<td>67,210</td>
<td>19.7 %</td>
</tr>
<tr>
<td>2005</td>
<td>13,754</td>
<td>3.1 %</td>
<td>41,361</td>
<td>13.6 %</td>
<td>30,489</td>
<td>34.4 %</td>
<td>85,604</td>
<td>10.2 %</td>
<td>71,850</td>
<td>18.3 %</td>
</tr>
<tr>
<td>Change</td>
<td>-62.3 %</td>
<td>-66.7 %</td>
<td>-38.3 %</td>
<td>-53.1 %</td>
<td>-18.7 %</td>
<td>-31.8 %</td>
<td>-45.2 %</td>
<td>-19.3 %</td>
<td>-41.7 %</td>
<td></td>
</tr>
</tbody>
</table>

Source: SOTKAnet data base (www.sotkanet.fi)

By 1995 when the recession started to be over, it could be seen that a substantial transformation had happened in home care. In only 5 years, the coverage rate had almost become halved (Table 4.1). The number of older people receiving home help had become radically cut – and such a development had hit exactly the service that had for a long time been marketed as the bedrock of care policy (Vaarama & Lehto, 1996). It was particularly the age group 65-74 that were affected most seriously but also many people between 75 and 84 became excluded from the service. Only in
the oldest old +85 age group did the number of service users continue on an upward trend but even there the coverage did not keep up with the pace of the ageing, causing a declining coverage rate.

The end of the recession did not bring back a coverage rate close to 20 per cent of the 65+ population. On the contrary, the policy line that had been adopted during the early 1990s continued in the late 1990s and the early 2000s. The way down from the level of 1990 had been steep. Overall, the coverage rate of home help for older people decreased by as much as 45.2 per cent between 1990 and 2005. This is in sharp contrast with the developments in many other countries that during the same period continued to expand their home-based service provisions (Huber et al., 2009).

Alongside the radical drop in coverage rates, a major change has taken place concerning the intensity of home-based provisions. In 1995 a new statistical concept was introduced in Finnish welfare statistics: ‘regular home care’. This was a brand new category that came to include users who receive home care ‘as part of a valid care and service plan’, that is, who are defined as permanent users of services by the system, or who otherwise receive home care visits at least once a week (Count of Regular Home-Care Clients on 30 November of 2009, 12). Statistics-making reflects the interests of policy-makers and whereas earlier the interest had covered all users without any discrimination, now the attention was to be focused primarily on heavy users of home care. Since 1995, particular counts on ‘regular home care users’ have been performed every other year, from 2007 every year. The increased attention shows clearly the growing importance of this ‘regular home care’ for policy-makers. By now, it is most often only ‘regular home care’ that is reported when the indicators on home care services are presented in official documents in Finland.

Results from these counts show a very linear development: from count to count there have been smaller and smaller shares of users who receive the service rather infrequently (Table 4.2). The median value of monthly visits has risen rapidly, having almost doubled since 1995. The share of those ‘regular home care users’ who receive more than 40 monthly care visits, that is, at least 10 visits per week has more than doubled (see also, Vaarama et al., 2004, 47). These users receive a very intensive service and the latest report from November 2009 tells that as many as 9.0 per cent actually receive at least 90 visits per month, that is, three or more home care visits per day (Count…, 2009, Appendix table 2). However, these visits can be extremely short. According to a recent study, the actual total work time of home care workers per client has decreased on average by half an hour from 2007 to 2009 (Heinola et al., 2010, 38).
Home care in Finland is serving more and more solely the oldest of the old and the frailest of the frail. The main focus in home care policy has since the mid-1990s been directed to those users who are using an intensive service, not just receiving home services occasionally (Heinola et al., 2010; Vaarama, 2009). The other side of the coin is that younger groups of senior citizens and those whose care needs are not yet very extensive, have less and less access to home care services.

4.4. Integration of home help and home nursing

Care work is almost an entirely female profession in Finland, the share of men among care workers is under two per cent. On the other hand, recruiting migrants as care workers is still a very new and limited phenomenon in Finland. Overall, Finnish home care workers are well-educated (over half of them have over two-year basic education) and most work full-time. Within residential settings, temporary work contracts are very usual within home care, non-permanent contracts are rare. (Kröger & Vuorensyrjä, 2008; Kröger et al., 2009; NORDCARE data.)

Besides the reallocation of resources to the oldest old with highest needs, another characteristic feature of the transformation of home-based care services in Finland has been the simultaneous integration process between home help and home nursing. Home nursing (kotisairaanhoito), referring to nursing services that are provided by health care authorities at homes of people with diagnosed illnesses, were earlier administratively and professionally separate from home help provided by social welfare. Home help was offered by a semi-profession called home helpers with a couple of years of occupational education or by less trained home help
assistants. On the other hand, home nursing was performed by trained nurses or assistant nurses and included tasks like portioning medicines, wound care and giving injections. (Kröger et al., 2009.)

As a response to widespread criticism about the separateness of home-help services and home nursing, and as a method to increase cost-effectiveness, several local authorities have integrated these two services, creating a new service form under the title of ‘home care’ (kotihoito). This development has in many local authorities been connected to administrative reforms that have integrated local social and health care administrations. Earlier it was criticised that home-help and home nursing are not genuinely co-operating, which left their operation fragmented and forced users to mediate between the two systems. The new integrated model promised to take away this fragmentation and provide a coherent service, offered by the one and same care worker. A corresponding change has occurred within occupational training for care workers. In 1993 training programmes for home helpers and assistant nurses were merged, creating a new 3-year (for secondary school graduates: a 2-year) programme and a new occupational title ‘practical nurse’ (lähihoitaja) that was expected to function as the basic care worker occupation in the integrated social and health care of the near future. Within institutional care, the anticipated integration never occurred but in home-based care it did in large parts of the country and ‘practical nurses’ were soon to become its largest occupational group. (Henriksson & Wrede, 2008; Kröger et al., 2009.)

4.5. Towards personalisation and marketisation of care

The tasks that are in practice included in publicly provided home-based services have also undergone a major change. Originally these services were mostly focused on household tasks but gradually, particularly during the 1990s, personal care has become the most central task and a large number of local authorities do not anymore offer household services like cleaning. A shift from taking care of the home to taking care of the body has been identified by research (e.g. Andersson et al., 2004; Voutilainen et al., 2007a).

On the other hand there are also a growing number of for-profit private providers of home-help services that people may purchase directly. It is in particular cleaning services that are increasing purchased from for-profit providers by older people. Direct purchased has since 2001 been supported by a new ‘tax deduction for household work’ (kotitalousvähenys). Currently it is possible to receive a tax deduction up to 3000 € per year per person to cover 60 percent of the costs of using home care services from a registered for-profit provider. In addition to the taxpayer’s own
home, services provided at the homes of parents, grandparents and certain other relatives are also supported by the tax credit. Because service fees for municipal home care services are income-related, that is, those with higher incomes pay a higher fee, private alternatives may be less expensive than public care services for people with a good or a modest pension. During the 2000s, several municipalities have also started to offer service vouchers to home care recipients and informal carers, which also strengthens the use of private home care providers. When using a voucher, the user can select the service provider from a list of providers approved by the municipality. (Kröger, 2004.)

Furthermore, a number of municipalities have outsourced at least a part of their own service provisions (especially the so-called auxiliary services, i.e. meals on wheels, transportation, safety alarms) so that publicly funded home-help services are in practice provided by non-profit or for-profit providers. In some municipalities, some specific forms of services, e.g. respite care at home, are provided almost entirely by non-profit organisations. On the other hand, for-profit provision, that until mid-1990s was non-existent within home care services in Finland, has been growing very fast ever since. In 2004, already a quarter of home care recipients received their home care services from private providers (Kähkönen & Volk, 2008). According to the revised Delivery Act municipalities are actually expected to put all purchases which overrun 100 000 € into competitive tendering. The variety of both non-profit and for-profit providers is more extensive in larger municipalities that have larger and more heterogeneous populations, whereas in a number of rural municipalities, municipal provision is still the only source of home care (Kröger, 2009a).

4.6. Integration of informal care into home care

There is one more major change in Finnish care politics that is clearly connected to the transformation of home care. Informal family carers have become closely integrated within the formal care system and this development has occurred simultaneously with the transition into ‘integrated regular home care’. There has existed a statutory home care allowance scheme for older and disabled people in Finland since the early 1980s, being originally included in the Social Welfare Act of 1982. In particular since the early 1990s difficulties of family carers have become widely highlighted in public discussion and at the same time the support system for carers has become firmly established. In 1993 this scheme received a piece of legislation of its own, reflecting extension and firmer institutionalisation of the programme as an essential part of care policies.
concerning older people. The special law was further reformed in 2005 and is now titled the Act on Support for Informal Care.

Recent surveys have showed that family members are the most general and often the only source of help among people +60 and that the number of those adult children who regularly provide help with domestic tasks, transportation and errands to their parent(s) is substantial (Vaarama & Moisio, 2009; Vaarama, 2009). Even among those older and disabled people who receive home care services, a recent study shows that the amount of informal care is over twofold the care time that is provided by formal care (Heinola et al., 2010, 38). Only a small part of these carers receive formal support because the support depends on local professionals and on the policy and the economic condition of the municipality (Kröger, 2009a). On the other hand, there are also many care-giving family members who do not wish to apply for the support and become formally labelled as carers (Mikkola, 2009).

It is the task of the municipal home care service to decide upon the formal support offered to informal carers. There are national guidelines concerning the sums to be paid to carers as well as respite care and other services that should be on offer. However, their implementation has been left to the discretion of local authorities, which has brought large variations between individual municipalities. (Voutilainen et al., 2007b; Kröger, 2009a.)

Statistics and official reports in Finland have focused their attention mostly to those carers who are officially recognised and categorised as family carers and who receive the home care allowance/informal carer support from local authorities. Actually the concept of a carer (omaishoitaja, ‘kin carer’ or ‘kin nurse’) did not exist earlier in the Finnish language; it was created only by the 1993 Informal Care Act. Consequently, the term has in Finland come to mean primarily those family carers who are receiving formal support. However, this group is only the tip of the iceberg, as the absolute majority of carers do not receive support from the formal system.
In any case, this support to carers is one of the very few forms of social support that have been expanding recently: in absolute terms, the number of carers of older people who received informal care allowance increased by 78.2 per cent between 1990 and 2009 (Table 4.3). Even in relative age group terms, when looking at how many older people are supported via informal care support received by their carers, the growth rate has been 30 per cent. This time there can be seen an increase of provision also – and, in particular – within the 65–74 and 75–84 age groups (see also, Heinola et al., 2010).

A government report describing the situation in 2006 shows that three quarters of supported carers were women and every second carer was caring for a spouse. A third (37 %) of supported carers was caring for a person under the age of 65. Every fifth supported carer was either an adult child or a parent of the care receiver and ten per cent were other relatives or close persons. More than a half of the supported carers had already retired from their work and about one fifth was still in fulltime employment. In 2006, the average monthly amount of the home care allowance was 416.32 €. In 2011, the national minimum amount is defined at 353.62 € per month. The allowance is taxable income for the carer. Since 1993, supported carers have also had a legislated right to have days off from caring and in 2007 this right was extended to three days off per month. On the other hand, using these days is often complicated in practice. Respite care is mainly offered within residential settings; receiving municipal home-help services as respite care has actually become more unusual since 1998. (Voutilainen et al., 2007a.)

### Table 4.3

<table>
<thead>
<tr>
<th></th>
<th>65-74 (number)</th>
<th>65-74 (% of age group)</th>
<th>75-84 (number)</th>
<th>75-84 (% of age group)</th>
<th>85+ (number)</th>
<th>85+ (% of age group)</th>
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<th>65+ (% of age group)</th>
<th>75+ (number)</th>
<th>75+ (% of age group)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1990</td>
<td>3,869</td>
<td>1.0 %</td>
<td>5,866</td>
<td>2.5 %</td>
<td>3,441</td>
<td>6.6 %</td>
<td>13,176</td>
<td>2.0 %</td>
<td>9,307</td>
<td>3.3 %</td>
</tr>
<tr>
<td>1995</td>
<td>3,253</td>
<td>0.8 %</td>
<td>4,672</td>
<td>2.0 %</td>
<td>3,369</td>
<td>5.0 %</td>
<td>11,294</td>
<td>1.5 %</td>
<td>8,041</td>
<td>2.7 %</td>
</tr>
<tr>
<td>2000</td>
<td>4,055</td>
<td>0.9 %</td>
<td>6,142</td>
<td>2.3 %</td>
<td>4,158</td>
<td>5.3 %</td>
<td>14,355</td>
<td>1.8 %</td>
<td>10,300</td>
<td>3.0 %</td>
</tr>
<tr>
<td>2005</td>
<td>5,279</td>
<td>1.2 %</td>
<td>9,231</td>
<td>3.0 %</td>
<td>5,286</td>
<td>6.0 %</td>
<td>19,796</td>
<td>2.4 %</td>
<td>14,517</td>
<td>3.7 %</td>
</tr>
<tr>
<td>2009</td>
<td>6,032</td>
<td>1.2 %</td>
<td>11,071</td>
<td>3.5 %</td>
<td>6,371</td>
<td>5.9 %</td>
<td>23,474</td>
<td>2.6 %</td>
<td>17,442</td>
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</tr>
<tr>
<td>Change</td>
<td></td>
<td>55.9 %</td>
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<td>20.0 %</td>
<td></td>
<td>88.7 %</td>
<td></td>
<td>40.0 %</td>
<td></td>
<td>85.1 %</td>
</tr>
</tbody>
</table>

Source: SOTKAnet data base (www.sotkanet.fi).
Overall, formal support for carers of older people has in Finland become significantly broadened at the same time when formal care services have become very strictly targeted. One part of the transformation of the home care system in Finland has been the growing role of informal family care. Many more older people receive care nowadays only from their families whereas the model of ‘shared care’, where both the state and the family are providing help for the same persons, has become less usual. At the same time, support for carers has been on the increase but it needs to be remembered that this support still covers only a small minority of all carers.

4.7. Come-back of non-regular home care?

The most recent figures on home care provisions in Finland are once again somewhat surprising. The downward trend that had continued ever since 1990 seems to have hit rock-bottom in 2005. In the whole +65 population, the coverage rate of home help has raised from 10.2 per cent in 2005 to 11.4 per cent in 2009 (Table 4.4). This might not look like a major change but the rate of the change has been almost 12 per cent in a short period of only five years. This is not an insignificant change while at the same time the ageing process has been going on with full force. In absolute terms, the number of older users of home help has actually increased in five years by over 20 per cent. The growth has taken place especially within ‘non-regular’ home care, not within ‘regular home care’ (SOTKAnet data). It is also remarkable that this time it has not been solely the oldest of the old who have received more resources as the coverage rate has increased also within the 65-74 and the 75-84 age groups. This time even an economic recession does not seem to have disrupted the growth: the figures for 2008 and – especially – 2009 keep following the upward track.
TABLE 4.4
Users of home help services in Finland 2005–2009, number of households and % of +65 age groups

<table>
<thead>
<tr>
<th></th>
<th>65-74 (number)</th>
<th>65-74 (% of age group)</th>
<th>75-84 (number)</th>
<th>75-84 (% of age group)</th>
<th>85+ (number)</th>
<th>85+ (% of age group)</th>
<th>65+ (number)</th>
<th>65+ (% of age group)</th>
<th>75+ (number)</th>
<th>75+ (% of age group)</th>
<th>85+ (number)</th>
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<tbody>
<tr>
<td>1990</td>
<td>13,754</td>
<td>3.1 %</td>
<td>41,361</td>
<td>13.6 %</td>
<td>30,489</td>
<td>34.4 %</td>
<td>85,604</td>
<td>10.2 %</td>
<td>71,850</td>
<td>18.3 %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1995</td>
<td>14,853</td>
<td>3.2 %</td>
<td>42,312</td>
<td>13.7 %</td>
<td>32,960</td>
<td>35.2 %</td>
<td>90,125</td>
<td>10.4 %</td>
<td>75,272</td>
<td>18.6 %</td>
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</tr>
<tr>
<td>2000</td>
<td>14,837</td>
<td>3.2 %</td>
<td>42,770</td>
<td>13.6 %</td>
<td>35,191</td>
<td>35.8 %</td>
<td>92,798</td>
<td>10.6 %</td>
<td>77,961</td>
<td>18.9 %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td>15,581</td>
<td>3.3 %</td>
<td>43,763</td>
<td>13.9 %</td>
<td>36,875</td>
<td>35.5 %</td>
<td>96,219</td>
<td>10.8 %</td>
<td>80,638</td>
<td>19.2 %</td>
<td></td>
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</tr>
<tr>
<td>2009</td>
<td>16,632</td>
<td>3.4 %</td>
<td>46,572</td>
<td>14.6 %</td>
<td>40,452</td>
<td>37.2 %</td>
<td>103,656</td>
<td>11.4 %</td>
<td>87,024</td>
<td>20.4 %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Change</td>
<td>20.9 %</td>
<td>9.7 %</td>
<td>12.6 %</td>
<td>7.4 %</td>
<td>32.7 %</td>
<td>8.1 %</td>
<td>21.1 %</td>
<td>11.8 %</td>
<td>21.1 %</td>
<td>11.5 %</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: SOTKAnet data base (www.sotkanet.fi).

Based on the available data, it seems that Finland has come to second thoughts concerning the transformation of home care. Whereas in the 1990s and early 2000s ordinary home help came under threat and attention was focused solely on the oldest old, now also people in their late 60s and in their 70s are once more included to an increasing extent. Certainly, the coverage rates have not yet reached the level of 1990 and neither has ‘regular home care’ vanished as a term or as a focus. However, in the latter part of the first decade of the new century, older people with non-continuous care needs seem nevertheless to have become once more addressed by the formal home care system in Finland.

One feature in this most current change is identical with the earlier transformation: once again, the policy turn has not been openly discussed in Finland: it has again happened ‘by stealth’. In the current decentralised system, major policy changes are not determined nor even widely discussed at the national policy-making level. Local authorities in Finland are free to act as they wish to a large extent. In the early 1990s they halved the coverage of home care, in the latter part of the first decade of the 21st century they started again to increase it. Why? No one knows as it has not been studied. In the early 1990s the cuts in central funding and in local tax revenues seemed obvious explanations but, however, economic reasons can not explain why local authorities kept on decreasing coverage levels still in the late 1990s and early 2000s when the recession was already over. Neither do economic explanations count for the recent turn; in particular as local authorities have continued to scale their provisions up under the current recession.
There is at least one possible explanation for the latest development. Due to an amendment of the Social Welfare Act, all people aged 80+ have since 2006 had a legal right to have their needs assessed within a week and in 2009 this right was extended to all people aged 75+. The same right was given also to younger people with high care needs (to those who receive the highest rate of a benefit called Care Allowance for Pensioners because their ‘illness or injury results in an around the clock assistance and guidance by another person’). This right to needs assessment does not as such constitute any right to receive home care services as local authorities are still free to decide to whom they offer services. However, the long-term downward trend of the coverage rate did experience an upward turn exactly in the same year when older people obtained the right to needs assessment. Furthermore, the introduction of service vouchers in the early 2000s may have had some effect on the increasing use of non-regular home care services.

4.8. Conclusion

Summary of the general development in home care in Finland

The transformation from a service that covered a large part of the older population and a large scale of tasks to a service that focuses strictly on the oldest old and the frailest frail and only on personal care took place in Finland in the early 1990s and the development followed until 2005 the same track: home care becoming more and more selective and more and more targeted to the oldest of the old and the frailest of the frail. A large of part people under 85 became excluded from the service as it has become more and more intensified. A brand new category of ‘regular home care’ was launched and taken into use to reflect this new orientation of home care services in Finland. Intensified home care has become a method in keeping institutional provision as low as possible, substituting for the need for institutional care for the rapidly increasing part of older people who need large amounts of daily care.

It has not been only the coverage levels and the targeting of services that have experienced a profound change during the last two decades in Finland. The whole concept of home-based care has gone through a radical transformation, changing from a separate system of home help from social welfare and home nursing from health care to an integrated service provided by a brand new occupation. This process of integration has not been easy and even within the country but integrated home care has nevertheless become the mainstream, adopted by the majority of largest cities.
Furthermore, home care has moved away from a focus on household tasks to a concentration on personal bodily care. At the same time, local authorities are also outsourcing their care service provisions at accelerating speed to for-profit providers and direct purchase of for-profit services is increasingly supported by tax deductions and vouchers from local authorities.

Despite of this thorough transformation, the legislative framework regulating home care has stayed almost fully unchanged since the early 1980s. The integration between home help and home nursing did require small additions to both the Social Welfare Act and Primary Health Care Act but no major revisions of either law have been made. This means that the changes have not been driven by national policy-making but more by reaction of local authorities to current and anticipated pressures from service demands and expenditures.

There is one major exception from this lack of national policy-making: the expansion of support for family carers has been widely discussed in publicity and also written into a new piece of special legislation. Overall, the emphasis given to informal family care has been one characteristic part of the transformation of care policy in Finland. Referring to Saraceno’s (2010) concepts, it could be claimed that in Finland ‘supported familialism’ (or in Leitner’s (2003) terms: ‘optional familialism’) has become emphasised for the frailest older people and ‘familialism by default’ (or ‘implicit familialism’, according to Leitner) has become the prevailing model for those older people who need less intensive help. This development is based on the ‘intensification’ and ‘personalisation’ of care. Those frail persons who receive home care services receive personal care to a large extent and those whose needs are more practical have to depend on informal help and private purchase of services. Furthermore, also the ‘marketisation’ and ‘personalisation’ of care can be viewed as a route to promote a kind of ‘familialism’: when users and their families are offered service vouchers and tax deductions, they come to play a major role as customers within the care market and usually need to pay a large part of the total cost in the end.

**Summary of the development from the main perspectives of the project**

**Meeting high quality and diversified and individualized needs** The process of intensification of home care has meant that more extensive and continuous needs can now be covered within home care. On the other hand, needs for less intensive care or for household tasks are not anymore covered by the public system, people need to use their own money (if they have that) to purchase such support from the market.
Stronger user orientation User influence has been rather weak in Finland, which is also seen in that the transformation was realised even though it was to a large extent against the preferences of users (exclusion of household tasks, exclusion of many older people). Finally in 2006 the introduction of the right to needs assessment has strengthened the user orientation of the Finnish home care system.

Optimal balance of division of work The overarching long-term care policy goal has since the 1970s been to reduce institutional care and to make it possible for older people to live in their homes as long as possible. However, in practice, cutting down traditional forms of institutional care has not become followed by increasing resources in home care. Actually the coverage of home care experienced a dramatic decrease when the resources became focused on those with highest needs. This on the one hand means that now it is possible to have intensive care needs covered by home care. On the other hand this also means that the responsibility for older people without intensive needs has been pushed to family members.

Best way to attract and retain care workers Most care workers in Finland have at least a two-year professional education and are in full-day work. The motivation and skills of care workers are high but working conditions are problematic and often do not make it possible for workers to deliver quality care. While the main source of motivation for care workers is still the opportunity to help other people, and the high level of professional education strengthens the commitment of care workers to their occupation, the problems in working conditions form a threat for attracting and retaining care workers in the future.

Qualification structures Qualifications are regulated by the Act and Decree on the Qualification Requirements for Social Services Professionals (272/2005). Overall, qualifications within home care services in Finland are on a high level. Home care managers have a three-and-half-year or a four-year social or health care degree from a Polytechnic or an older three-year degree. Home care workers have a new integrated three-year practical nurse degree (Vocational Qualification in Social and Health Care) or an older two-/three-year degree from either social care or health care (STM, 2007).

Quality assurance and regulation (a priori) According to the Social Welfare Act and the Local Government Act (365/1995), local authorities need to inform local residents about ongoing plans and provide opportunities for participation and user influence. Many municipalities have organised Councils of Older People as well as Councils of Disabled People with the particular purpose to support participation of these groups in municipal decision-making. Most municipalities
have a old age care policy strategy that has been approved by the local council (Voutilainen, 2007). A number of local authorities perform preventive home visits among older people in order to assess existing service needs but also to inform about available services. Municipalities are required to have a Social Ombudsman to advice and inform users of social services but also to evaluate the realisation of rights of users within the municipality. Municipalities also conduct local user satisfaction surveys. The national quality recommendation on care and services for older people provides general recommendations regarding staff in home care (Ikäähmisten …, 2001 & 2008). The outline (published on March 9, 2011) regarding the planned new Act of Old Age Services includes new means to monitor old age care services: personnel working within social and health care would have an obligation to report of defects within old age care to their work unit and to the municipality, a serious defect should be reported directly to the Regional State Administrative Agency. (See, e.g., www.stm.fi; Kananoja et al., 2007.)

Quality assurance and regulation (a posteriori) Regional State Administrative Agencies monitor regularly the implementation of social and health care legislation. The right to good service is enacted in the Act on the Status and Rights of Social Welfare Clients (812/2000). It says that the user has a right to make a complaint concerning the way s/he has been treated to the responsible manager within the unit or department of social care. Furthermore, concerning a decision made by a municipal employee, the user can make a ‘demand for rectification’, addressed to social welfare board of the municipality. If this does not bring a change, it is further possible for the user to make an ‘administrative appeal’ to an administrative court. Any person who is not satisfied with her/his treatment by – or generally with the function of – the local authority can also make a ‘municipal appeal’ to Regional State Administrative Agency, the Parliamentary Ombudsman in Finland or the Chancellor of Justice in Finland. (See, e.g., Kananoja et al., 2007.)

Funding system of home care service provisions 1) Public home care services are funded primarily by local tax revenues and secondarily by central grants for social and health care and, finally, by user fees. 2) Private (non-profit or for-profit) home care services outsourced by local authorities are funded in the same way: by local taxation, central grants, and user fees. Earlier NGOs could receive semi-public extra funding from the Slot Machine Association but this funding for non-profit home care services is now prohibited because it was claimed to distort free competition between non-profit and for-profit providers. 3) Private (non-profit or for-profit) home care services purchased directly by users are funded primarily by user fees that can be partly covered by tax deductions and/or vouchers from local authorities. Overall, the distinction between
non-profit and for-profit services has become blurred to a high extent as nowadays they need to compete on equal terms for both outsourced provisions from local authorities and direct purchases from families.

**Summary of outcomes for older people, their families and home care workers**

As an outcome of the changes, older people have been reported to experience shortages in municipal care service provisions and these shortages have grown wider during the 2000s. According to a nationwide survey made in 2006, a third of people aged 70–74 feel that they do not receive enough external help. Furthermore, 20 per cent of even those who do receive home care services say that the help they receive is not adequate, especially concerning household tasks. (Vaarama et al., 2006; Vaarama, 2009; Voutilainen et al., 2007a.)

It has been claimed that the intensification of municipal services increases equality among older people as cutting support from those who do not have intensive care needs and from those who have enough resources to purchase their services by themselves actually leaves resources to those who are in the weakest position (National Audit Office, 2010). Nevertheless, older people whose needs are not met by municipal services, and particularly those older people who do not have enough informal resources or financial possibilities to pay for services, also end up in a difficult situation. Many of them have been noticed to stay indoors at their homes alone without possibilities to go out and meet other people (see, Heinola et al., 2010). As a consequence of the changes, practices that enhance participation in social life and bring everyday joy have become marginalized within the system. However, preventive social care practices would be essential in breaking emotional and social isolation of older people that threatens to grow into a serious societal problem in Finland.

There is also information coming from some local authorities that public home care services are offered primarily to less well-off people while those with good economic resources are advised to purchase private services themselves (see also Vaarama, 2009) – a policy of ‘creeping selectivisation’ which is in contradiction with the principle of universalism that is often seen as the cornerstone of the Nordic welfare model. There is evidence about significant in access and quality of publicly organised home care services. As a consequence from these problems, we can see growing inequalities between low-income older people who need to depend on their families and high-income older people who purchase more and more private home care services from the market.
Family members of older and disabled people face a continuous concern over the well-being of their kin. In particular, if adult children take or are forced to take responsibility over the daily or weekly care of their parents, this may affect their ability to concentrate on their own work and limit the time available to hobbies, friends and own children and partner (Leinonen, 2011). General trust in public home help has also decreased in Finland amidst criticism of social welfare services (Muuri, 2010).

From the point of family carers, the extension of ‘supported familialism’ is a mostly positive development. More carers than earlier now receive formal support in Finland. However, the support system for carers is far from ready. The coverage of the allowance is very limited, the amount of the benefit is low and many carers have found it difficult to organise appropriate respite care during their statutory free days (Salanko-Vuorela et al., 2006). Statutory days off are meant for rest and recreation but often these are impossible due to lack of appropriate respite care. Often respite care is offered only within residential settings, which is unacceptable for many carers and older and disabled people (e.g., Mikkola, 2009).

There are some studies on the integrated home care that show that the earlier fragmentation between home-based social and health care services has become reduced as it is now most often the same personnel that performs both the home-help and the home nursing tasks (e.g. Andersson et al., 2004). On the other hand, professional groups from both health care and social care have been critical towards the reform (Wrede & Henriksson, 2004). Health care professionals criticise that the current staff (who are for the most part not anymore trained nurses) does not have adequate medical expertise to perform home nursing tasks. For their part, social care professionals criticise that the integrated home care reminds rather closely earlier home nursing and is focused on medical treatments. According to this criticism, an approach that aims more broadly to promote the quality of life of older and disabled people – including social interaction with the users, co-operation with family and other networks, going out for a walk – has become marginalised within the new integrated home care (see, e.g., Henriksson & Wrede, 2008; Wrede & Henriksson, 2004).

Intensification of home care has changed the work of care workers. Care work at home is nowadays perceived as too hectic and many workers feel that they are not anymore able to fill users’ needs and wishes. Consequently, many home care workers do not feel well at their work and are dissatisfied with their work conditions. This anxiety of home care workers is indicated in reports produced by trade unions (e.g., Super, 2010) and in academic research (e.g. Kröger et al., 2009). For example, according to the NORDCARE study, a quarter (24.9 percent) of Finnish home care
workers thinks that they ‘usually have too much to do’ and almost as many (21.9 percent) say that s/he is ‘unable to respond to the needs of the users’. In addition, over a fifth has ‘considered seriously leaving their work’ (Kröger, 2009b). When home care workers were asked to report their hopes for change, many wished ‘more helping hands’ and ‘more individualised care’, that is, ‘work without time pressure’ and ‘ability to focus not only on basic needs’ (Leinonen, 2009).
4.9. References


STM (2007), *Qualification Requirements for Social Services Professionals in the State, Municipal and Private Sectors in Finland*, Helsinki, Ministry of Social Affairs and Health.


www.stm.fi The web site of The Ministry of Social Affairs and Health.

5. Home Care in Germany

Hildegard Theobald, Sarah Hampel & Therese Mansfeld\textsuperscript{11}

5.1. Introduction

In Germany, home-care provision is publicly supported in a complex interplay of several policy schemes, with the Long-term Care Insurance (LTCI) as the most significant. Until the introduction of the LTCI in 1995/96, caring responsibilities for frail family members—mainly elderly adults—lay with the family, based on the principle of subsidiarity. Only where family members were unable to provide sufficient care at home did welfare organisations step in; since 1962 funds were granted at local authority levels on the basis of the Federal Law on Social Assistance following a means-test. Since the end of the 1970s, the lack of universal public support for long-term care-needs fostered a social-policy oriented debate on the difficult situation of frail (elderly) adults. Furthermore, during the 1980s the increasing social assistance costs for residential care services challenged the financial sustainability of the available funding scheme. In the end, the high costs of the social assistance scheme provided the main incentive for the introduction of the Long-term Care Insurance.

Following the social insurance tradition of the German welfare state a social insurance scheme was introduced by federal law. The nationwide valid law precisely defined social rights, the mode and principles of funding, and the implementation of the scheme in the interplay of federal, regional and local policy levels. The law also included the interaction of all these aspects with semi-public organisations, like the insurance funds, as well as the principles of re-organisation of formal care provision. The introduction of this law thus meant a considerable restructuring of public long-term care support and care provision valid for the country as a whole to secure regional equality. The insurance scheme was designed to combine ideas on a sound and sustainable funding of care needs with social policy goals. Following intense negotiations a universal policy scheme within a strict framework of cost containment policies was established, which granted support for the whole population based on social rights on a medium level. Furthermore, the law aimed to promote family and home-based care provision as opposed to residential care, and formal care provision was to be guided by a market-oriented restructuring and expansion.

In this report we examine the development, design and consequences of the Long-term Care Insurance.

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Insurance (Social Statutes, SGB XI) and its interrelationship to further policy schemes that grant support in situations of home-care needs. Related to the policy designs the report analyses significant dimensions and their interplay, i.e. how social rights, mode and principles of funding are defined, and how, particularly within the framework of the LTCI, the mix of home-based and family care provision have been reorganised towards the familialisation and marketisation of care provision. It reveals the country-specific content of the processes, which can be summed up as: a strong regulatory state on the federal level; a strictly defined funding scheme; the establishment of a regulated market of home-based care provision with private for-profit and non-profit providers on equal terms; and public support of care-giving within the family framework.

At the beginning of the report an overview is provided on the distinct policy schemes granting public support in a situation of home-based care-needs (section 2). Following this, we show the way the institutional design of the policy schemes are embedded in a distinct mode and outline the principles of funding and the corresponding interplay of public and private funding responsibilities (section 3). The law on LTCI is based on the idea of a welfare mix of care provision, i.e. different societal sectors are to contribute to care provision. How the law aims to deliberately re-organise the interplay of different societal sectors is discussed in following section (section 4). The definition of social rights, private and public funding responsibilities and the idea of a welfare mix has brought about certain outcomes from the perspective of the (potential) beneficiaries, the families and family carers, as well as formal carers are examined with regard to the regulations in the different sections. Finally, the drivers of change and main reform strategies, as well as the main characteristics of long-term care support and its consequences, are summarised in the conclusion (section 5).

5.2. Social policy schemes, social rights and assessment procedures

In Germany, a mix of social-policy schemes introduced on a central level, i.e. Social Statutes (SGB), define distinct social rights with regard to home care. The Social Statutes (SGB V, IX, XI, XII) differ widely with regard to their aim, target groups, institutional designs, the central-regional-local interplay as well as their quantitative significance. The quantitatively most significant social statute, the Long-term Care Insurance (LTCI) (SGB XI) aimed to provide universal support embedded in cost containment policies. The federal law is based on clearly defined, centralised regulations to secure regional equality; i.e. equal access to benefits dependent on the level of care
needs valid in the entire country. In the process of policy development several institutional dimensions such as the threshold to benefits, the range of risks covered as well as types and levels of benefits were used to combine universalism and cost containment policies (Deutscher Bundestag, 2002; Theobald forthcoming, 2011).

**Levels of care dependency**

LTCI provides universal support on three clearly defined levels of care dependency, i.e. levels of needs related to personal care and household assistance, which are expected to last for at least six months.\(^{12}\) The law defines different types of benefits related to the three levels of care dependency – cash payment, home-based care services, residential and semi-residential care services (see appendix table 5.2). The beneficiaries may choose between the use of cash payments to organise care provision privately or home-based, or for semi-residential/residential care provision. The level of benefits is adapted to the different cost structures of care provision. Independent of the type of care provision, the benefits are only meant to partially cover care needs and thus leave a considerable level of private responsibility – to be covered either with private economic means or informal, family care provision.

At the time of introduction of LTCI, care needs were strictly oriented towards functional disability in order to contain costs. The neglect of cognitive impairments during the assessment of care dependency and the following lack of public support for applicants with dementia illness resulted in intense public debates on their care situation (Deutscher Bundestag, 2002). Gradually, the law has been changed to cover care needs related to cognitive impairment or psychological difficulties, in particular, certain dementia conditions were considered. Since 2002, after the introduction of the Complementary Nursing Act, a new benefit has been established, granting further €460 per annum to beneficiaries suffering from dementia illness, to improve care provision or to unburden informal carers. The granted level of support was heavily criticised, and was increased in the 2008 reform to a maximum of €2400 p.a. and opened up for applicants who do not meet the threshold of care dependency level 1 (MDK Bayern, 2008). The benefit is service-oriented; i.e. it can only be used to purchase either semi-residential-, or low-threshold services, such as e.g. different forms of respite care or services related to leisure respectively group activities (see section 4.3). The introduction of the new benefits is only meant as a first step to adjust the definition of care dependency to the situation of older adults with dementia illness. At the moment there is an on-

\(^{12}\) In the following, the term care dependency will used based on the definition of care and household needs within the LTCI.
going reform process, which aims at establishing a new definition of care-dependency, which should include cognitive and mental impairments. To date, an expert group has already recommended a new definition of care dependency, while cost calculations revealed that higher expenditures could be expected (Wingenfeld et al., 2008a, 2008b; Rothgang et al., 2008). It is still unclear, whether, when or how reform will take place.

**Social assistance coverage**

Before the introduction of the LTCI, long-term care needs were covered mainly by the regulation on Help to Long-term Care (Hilfe zur Pflege) within the Social Assistance Scheme (now SGB XII). With the establishment of the LTCI regulations on the Help to Long-term Care scheme were restructured and provide now support after a means-test when care needs are below the threshold of the LTCI or supplement benefits of the LTCI to secure a needs-oriented support. The introduction of the LTCI was based on the principle of universalism and led to a significant increase in the number of people in all ages receiving benefits from approx. 563,000 in 1994 (within the Help to Long-term Care scheme SGB XII) to 2.34 million care dependent beneficiaries under the LTCI in 2009, a proportion of 11.5 percent of adults 65 years and older (Eisen/Mager, 1999; Federal Statistical Office, 2011). 5 percent of beneficiaries of all ages using home-based care and 25 percent using residential care services received additional social assistance benefits based on the Help to Long-term care Scheme (Federal Ministry of Health, 2007). According to a representative survey, approx. 3 million citizens aged 70 years or older stand in need of some form of assistance with housekeeping, of which approx. 2 percent receive social assistance benefits (Schneekloth, 2006).

**Additional services**

A further scheme “Elder Assistance System” (Altenhilfesystem SGB XII) obliges local authorities to promote the development of services to foster the independence and participation in society of older adults. Local services are generally defined as universal by national law, while the type of support and related eligibility criteria—for instance the type of care needs—are decided at local levels. In contrast to the LTCI and the Help to Long-term Care within the Federal Social Assistance Law, it is not related to individual social rights. The development of certain local level offers is defined as optional for local authorities, which may adapt the mode of implementation to suit local level needs and circumstances. Typical service offers are e.g. meals-on-wheels, transport services, advisory services but also senior clubs or communication centres. The considerable room for discretion has
resulted in a widely differing local service structure, which has even been reduced since the introduction of the LTCI (Bönker et al., 2009).

**Home nursing**

Finally, within the framework of the Social Health Insurance scheme (SGB V) home nursing is provided for all members of the insurance (approx. 90 percent of the population) based on needs in three defined situations and prescribed by the medical doctors. It is a comprehensive support, which may be related to user charges. Home-nursing can be granted on a short-time period to reduce or avoid hospital treatments, when it is necessary for the success of a medical treatment or to maintain living in the own flat for people in need of psychiatric nursing services. Related to time-periods up to 6 months (below the threshold of the LTCI) it can even include personal care or household services.

**Support for people with disability**

The benefits of the different schemes discussed above are also available in case of disability and can be combined to create a comprehensive care arrangement. The Federal Law on Rehabilitation and Participation of Disabled People (SGB IX), which came into effect in 2001, stipulates in detail the mode of integration of the different schemes related to home-based care. The following eligibility criteria are defined as precondition to use SGB IX “Physical, cognitive impairment or mental health problems, which last (or can be expected to last) more than six months and which do not correspond to age-related behaviour.”

The law describes that the eligibility criteria, regulations etc. defined within the different policy schemes are also generally valid for beneficiaries of SGB IX, with the exception of the Social Assistance scheme (Help to Long-term Care) that provides universal benefits without means-testing. The local authorities are responsible for case/care management services. In 2008, a personal budget – a regulated cash benefit – was permanently introduced as a individual social rights. Here, the beneficiaries may choose between different types of services or/and to employ a personal assistant up to the granted lump sum. Evaluations on model projects introduced in 2004 found that the level of support differs widely with an average level of support of €1000 per month (Metzler et al., 2007).

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13 The further 10 percent of the population receive home-nursing services funded by private health care insurances.
**Needs assessment**

Needs assessments are organised differently within the several legal frameworks. Within the elder assistance system and the Help to Long-term Care scheme (SGB XII) needs assessment are defined by local authorities. Related to the personal budget (SGB IX) different forms of needs assessments have been established at regional levels (Metzler et al., 2007). Within the framework of the Long-term Care Insurance (SGB XI) the organisation of assessments is defined in a great detail on a central level. Eligibility criteria are defined on a central level within the law; the regional level medical services of the Health Insurance Funds are responsible for carrying out assessments and, in co-operation with the central level medical services of the Health Insurance Funds, for the development of the instruments or procedures. Country-wide instruments or procedures are used to reduce regional inequality, while the assessment is not oriented towards the development of a care plan. While the introduction of central-level assessment procedures has reduced regional inequalities, adherence to certain socio-economic and ethnic groups, still impacts significantly on the results of the assessment procedures. Applications of adherences of lower socio-economic groups and some migrant groups, e.g. Turkish migrants, are more often rejected and are more often assigned to lower levels of care dependency (Federal Ministry of Health, 2007; Okken et al., 2008).

### 5.3. Funding: Mode of funding, private and public responsibilities

Modes and principles of funding as well as related regulations on the central-local interplay also differ considerably between the schemes. While the Elder Assistance System and the Help to Long-term Care schemes are tax-funded, the LTCI is funded either by social or mandatory private insurance contributions. In the process of policy-making related to the LTCI, social insurance was compared to a mandatory private insurance scheme. The introduction of both social and private long-term health care insurance schemes is the result of a compromise negotiated during the process of policy-making. The Christian Democratic Party as a partner in a conservative-liberal coalition on the federal level, the Social Democratic Party related to the social democratic dominated Council of the Federal States (Bundesrat) and the unions opted for a social insurance solution, which offers more scope for redistribution between different societal groups. The liberal party advocated for a private insurance scheme that emphasised individual responsibilities. In the end the liberal party agreed to a social insurance scheme under the premise that a (mandatory) private insurance scheme should be introduced for the members of the private health care insurances (Meyer, 1996).
establishment of a division between social and private long-term care insurances resulted in a contrasted economic situation of the insurances. Insuring the healthier, more affluent members, the economic situation of the private insurances are characterised by a surplus while the social Long-term Care Insurances have experienced deficits in some years. This led to public demand for an introduction of a “Bürgerversicherung”, advocated in particular by the left-wing parties and unions, where all citizens contribute to one insurance scheme (Theobald, 2004; Häcker et al., 2007).

In addition, the principles of funding – above all the definition of private-public responsibility and the political level of regulations - differ between the schemes. For services within the framework of the Elder Assistance systems, local levels decide on the mix of private and public funding. Within the Help to Long-term Care schemes, cash benefits and needs-oriented services are granted following a means-test. However, offspring can be made economically responsible for the costs. Statistics on beneficiaries of the Help to Long-term Care scheme show that in 2008 397 110 people of all ages received the benefit, which can be compared with 2.34 Million people granted supported within the framework of LTCI in 2009 (Federal Statistical Office, 2010, 2011). There are no statistics on the Elder Assistance system available. Within the LTCI scheme, care risks are only partially covered, resulting in a certain mix of private and public funding, as well as delivery of family care. As the most significant scheme, the interplay of public and private funding will be discussed in greater detail in the following.

Different research findings on the situation of domestic care show that beneficiaries only rarely use private means to purchase professional care services as it was intended by the law. In addition, the use of private means is strongly related to the income level of the beneficiaries. In a representative inquiry, on average 8 percent of the beneficiaries said they purchased professional home-based services with private means, a proportion that increases to 18.6 percent for beneficiaries with a monthly income of € 2,500 or more. The beneficiaries mainly supplement the services covered by insurance benefits by informal, family care, reduce the level of support, or vote for cash benefits only (see Runde et al., 2003). The high private costs have also been put forward as one reason for the low level use of semi-residential services. In 2009 only 0.8 percent of beneficiaries were using short-term care and 1.4 percent attended a day-care centre (Federal Statistical Office, 2011). In order to facilitate the use of semi-residential services since the reform in 2008 costs for day- or night care services can be granted up to a certain level in addition to the home-based respectively cash payment benefit (SGB XI, § 41; MDK Bayern, 2008).
With the introduction of the insurance the benefit levels were fixed by law and were not increased until the reform in 2008, which turned out to be a major dilemma for the private-public mix of funding (on benefits levels see table 5.2 appendix). It represented a loss in purchasing power of 18.8 percent relative to the Consumer Price Index, which in turn led not only to an increase of private costs but also to an increase in the number of those resorting to social assistance (Schneider/Reyes, 2007). The fixed benefit level is related to a cost ceiling introduced within the law on LTCI (SGB XI); i.e. the income of the insurance based on the contributions of the members – 1.7 percent of gross earnings - defines the expenditure. In order to enable an increase of the benefits and to improve the economic situation of the social long-term care insurances in general, in 2008 the Grand Coalition introduced an increase of the contribution rate to 1.95 percent of gross-earnings—the first general increase since the introduction of the insurance. Before, in 2005, based on a judgement of the Federal Constitutional Court the contribution was raised by 0.25 percent for childless adherents. The judgement was motivated by the “double contribution” of families with children to care provision; via insurance contributions and the raising of “potential cares”.

5.4. Home-based care provision in a welfare mix

Besides the introduction of social rights and mode and principle of funding, the law on LTCI also provided the starting-point for a restructuring of care provision. Characteristic of the German system is its emphasis on a welfare mix of care provision by different societal sectors – family, welfare associations, market – and the cooperation between different groups among care workers, i.e. formal, informal family carers and voluntary workers. The state is assumed to adopt a regulatory role by defining the mode of the interplay of different societal sectors, as well as qualification and occupational training programmes related to certain types of care work. The regulations of the LTCI introduced in 1995/96 are still valid, but have since been further developed. In the following development and characteristics of the welfare mix of care provision in Germany will be discussed.

**Mix of informal and formal care provision**

Within the framework of the LTCI, a largely family-oriented care strategy has emerged. Based on the principle of free choice between the different types of benefits, the majority of beneficiaries are cared for at home supported by cash payments only (see table 5.1). The use of home-based and
residential services has - only slightly - increased since the introduction of the insurance (Federal Statistical Office, 1999 - 2011).

**TABLE 5.1**
**Benefit use in 2009**

<table>
<thead>
<tr>
<th>Benefits</th>
<th>in % of beneficiaries</th>
<th>in % of population 65+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Residential services</td>
<td>30.7</td>
<td>3.8</td>
</tr>
<tr>
<td>Home-based services/combination</td>
<td></td>
<td></td>
</tr>
<tr>
<td>cash/services</td>
<td>23.7</td>
<td>3.0</td>
</tr>
<tr>
<td>Service use: beneficiaries living at home only</td>
<td>34.3</td>
<td></td>
</tr>
<tr>
<td>Cash payments only</td>
<td>45.6</td>
<td>4.6</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>11.5</td>
</tr>
<tr>
<td>Day care services/additional</td>
<td>1.4</td>
<td>0.2</td>
</tr>
</tbody>
</table>


A representative inquiry of 2002 analysed in a greater detail the mix of care provision in home-based care arrangements. In 2002 36% of beneficiaries living at home used professional care services within the framework of LTCI (comparable with the figures of 2009 see table 5.1). In addition, 23 percent of the beneficiaries privately purchased services, which is related to a dual structure of care use. The beneficiaries with cash payments only were mainly cared for by family members, friends or neighbours who received a nominal sum, and only 9% drew on paid private support. In contrast, the users of professional care services purchased additional private assistance, often household assistance. Home-based service users typically received a mix of informal and home-based care services (Schneekloth, 2006). In several representative inquiries informal carers reported to be (very) burdened by informal care provision, and about 60 percent demanded more comprehensive support (Runde et al., 2003; Schneekloth, 2006).

Within the largely family-oriented strategy widely different care arrangement patterns have emerged for men and women, beneficiaries of different socio-economic classes and ethnical background. Representative statistics on family care-giving indicate changing gender patterns in care provision. The female share of 73 percent among main informal carers in 2002 already represented a reduction of the proportion of women carers following the introduction of LTCI (Schneekloth, 2006). The increasing share of male informal carers is mainly based on an increase of spousal care. However, the number of sons acting as a main informal carer also increased, albeit at
a low level. The mode of care provision differs significantly between male and female main informal carers. Male carers can be found sharing care arrangements with other informal and formal carers, in particular care services who usually deliver personal care (Schneekloth/Wahl, 2006).

The use of cash payments or professional services provides a first indicator on the impact of the living situation, socio-economic status and ethnicity on the patterns of care arrangements. Generally within the framework of LTCI, home-based care services are more often used by beneficiaries who live alone with precarious social and family support, or older adults on higher socio-economic strata and are more likely to be German nationals than certain migrant populations (Blinkert/Klie, 1999; Klie/Blinkert, 2002; Heusinger/Klünder, 2005; Okken et al., 2008). The distinct care arrangements may indicate an overburdening situation for some groups of informal carers, but also a lack of care services; for instance, in the 2002 representative study 14 percent of care recipients reported a lack of care provision (Schneekloth, 2006). In Germany several research projects have been conducted to explain the emerging unequal care arrangement patterns. Projects into the impact of socio-economic class reveal a complex pattern of class-related economic and cultural factors that influence the construction of care arrangements (see Klie/Blinkert, 2002; Heusinger/Klünder, 2005). Economic factors are related firstly to the (private) costs for the purchase of care services, which are unfolding within the design of LTCI. Within this framework, the level of care-dependency and the type of care provision determine the amount of public support, while the care recipient's economic situation is not considered. Only below a certain income threshold are beneficiaries eligible for additional social support within the framework of social assistance. The economic burden related to the purchase of services differs depending on the income situation and impedes service use for beneficiaries with more limited private means.

Secondly, economic factors are related to opportunity costs when informal carers interrupt or reduce their employment. In 2002, 10 percent of informal carers had interrupted employment and a further 11 percent had reduced their working hours in order to meet their caring responsibilities. Previous to this, fully 51 percent of the main informal carers in employment age had not been gainfully employed (Schneekloth, 2006). The combination of informal care-giving and employment is strongly influenced by socio-economic class, i.e., women on the lower socio-economic strata are significantly less often employed at the advent of care dependency – as it is defined within the framework of the LTCI - and, if employed, more often reduce or interrupt their employment (Runde et al., 2003). The pattern of labour market participation may be furthered by pension credit points related to informal care provision. For informal care activities of at least 14 hours a week (and up to
an employment of 30 hours a week) pension credit points are available, which are generally on a low or medium level and in fact oriented towards women with lower qualification levels (Schneider/Reyes, 2007).

The class differences are also related to cultural factors, which, in turn, are related to parental care (see Heusinger/Klünder, 2005). The role of the family members in care provision is emphasised in all socio-economic classes in Germany. Despite an emphasis on the responsibility of the family, the upper middle-classes involve professional home-based services or use residential care services dependent on the care needs. The (lower) middle-classes might also call upon paid assistance – mainly on the grey market - to lighten the burden of informal carers. Families at the lower end of the socio-economic scale expect free provision of care and are more unwilling to accept a move to residential care. Moreover, migrant background may influence patterns of care arrangements. In an analysis of assessment reports in one German region the Turkish migrant group voted more often for cash benefits than the German group (91 percent to 42 percent) and less often for home-based services (9 percent to 29 percent), and hardly ever for institutionalised services (0-1 percent to 29 percent) (Okken et al., 2008).

More recently embedded in the European Employment strategy support, strategies have been created to reduce employment breaks due to care provision and to promote the combination of long-term care provision and employment. With the LTCI reform in 2008, two leave schemes were established to improve the combination of informal care work and employment. One scheme grants a ten-day unpaid leave to organise or adapt a care arrangement. A second scheme enables carers to interrupt their employment or to take up part-time work on an unpaid basis for up to 6 months. In addition, day care or night care services can be granted, if the services enable participation on the labour-market (MDK Bayern, 2008).

**Formal care provision: Regulation, market, and quality assurance**

The Long-term Care Insurance Law already defined principles related to the regulation and expansion of the professional care infrastructure. Since then, regulations on quality assurance measures have been introduced. According to the LTCI, the care infrastructure should be developed in a combination with certain market principles, such as competition between providers and cost-efficiency, and measures to secure high quality standards and user-orientation. Before the introduction of LTCI, primarily non-profit care providers and, to a lesser extent, private for-profit providers delivered home-based care. Municipalities were allowed to subsidise non-profit providers
to secure formal care provision, which afforded them a privileged position in care service delivery. Related to freedom of choice for users, the LTCI law opened up the care market on equal terms for for-profit and non-profit providers. With the new care market it was intended that the costs for service provision be covered by insurance benefits and complementary private means of the beneficiaries, and public subsidisation only allowed to supporting investments related to equal conditions for for-profit and non-profit providers (Meyer, 1996).

In Germany, access to the insurance funded care market requires a contract with the long-term care insurance funds. To strengthen competition on the care market these insurance funds are obliged to negotiate a contract with every care provider that fulfils the defined preconditions—qualification levels of the care workers and cost-efficient care provision—without regard to the offers of already existing care providers. The negotiated contract defines care offers, quality standards, quality assurance measures of the individual provider and related prices. With the contract the providers are obliged to introduce or further develop a quality management system and to accept external controls. The providers calculate cost-effective prices, which have to be paid by the beneficiaries independent of their income situation. Based on the level of the benefit, the care providers are directly reimbursed by the insurance funds. Additionally, the providers are free to offer further types of services which can be purchased privately by the users. Until the introduction of the LTCI, private non-profit providers quantitatively dominated home-based care service provision, while for-profit providers were found above all in big cities. Since the introduction of the LTCI the proportion of private for-profit organisations has steadily increased to 61.5 percent in 2009 (Federal Statistical Office, 2011).

The LTCI law in 1995/96 already defined the orientation on quality standards developed within nursing science as a precondition for care provision. In 2002 (reformed in 2008), with the law on Quality Assurance and Consumer Protection, existing regulations on quality assurance measures were summarised and organised within a single framework. According to the law, providers are obliged to establish a quality management system adapted to their individual situation, to carry out continuous quality assurance measures and to comply with expert standards established on the national level. Furthermore, the Medical Services of the Health Insurance funds carry out the external quality control according to predefined standards—from 2011 at least once a year. The reform of the law in 2008 emphasised transparency of the control results and enabled spot-check quality controls. Moreover, the results of these external controls are to be published in a way that users can understand.
The system of long-term care provision in Germany impedes but also supports the development of an adequate or integrated service support for the beneficiaries and/or their families. Care services are funded within the framework of different social statutes, but may be delivered by the same provider. In 2009, 97.2 percent of care service providers hold a contract with both the LTCI funds and the Health Insurance funds and are therefore able to provide an integrated long-term care and home-nursing service (Federal Statistical Office, 2011). On the other hand, market orientation with the range of service providers within one area and the separate system of municipal service provision within the Elder Assistance system, impede an adequate and integrated service use. Moreover, until the 2008 reform, uncoordinated case/care management services at local levels were organised by a wide range of different actors, such as care insurance funds, public services and service providers. The 2008 LTCI reform required the development of care bases—so-called “Pflegestützpunkte”, in co-operation with different actors to provide adequate and reachable care/case management services at one locality. Since 2009, an individual right ranging from information to case management services exists, free of charge for all (potential) beneficiaries of the LTCI (MDK Bayern, 2008).

**Formal Carers: Qualification levels and working-situations**

According to the law on LTCI, long-term care has to be provided under the guidance of a nurse or elder carer with a three year occupational training and further training measures who is in charge and further carers, such as nurse assistants, volunteers and family carers carrying out daily care activities. In care arrangements based on cash payments only mandatory biannual visits of a nurse or elder carer were introduced to ensure high quality care. Moreover, informal family carers can—voluntarily—attend free courses on care provision. The regulations aim to maintain and support informal care provision as well as reduce costs of formal care provision, e.g. through the definition of low qualification levels.

Since then, laws and regulations have been launched to further develop the LTCI's basic principles. Related to professional care provision, the new laws or regulations aim to secure high-quality care and the availability of a care infrastructure within a cost containment framework. The development related to care workers can be characterised by the key words expansion, efforts to improve professional training programmes, the restructuring of co-operation between different types of carers and the promotion of a more cost-efficient care provision with the introduction of a care market as the following exemplifies:
- In 2002, the occupational training programmes of elder carers already established at federal state levels became standardised on a comparatively high, central level. The introduction was welcomed by most of the actors in the field and motivated either by the changing and more difficult caring tasks, e.g. related to multi-morbidity or chronic illnesses, or the necessity of establishing a more attractive profile to attract or retain qualified care workers (Oelke/Menke, 2002).

- In 2002, within the framework of the Complementary Nursing Act, a new type of (“low threshold”) services was created to be provided by voluntary workers under the guidance of a professional carer. The cooperation of professional carers and voluntary workers was intended to ensure care quality within a framework of cost containment. The inclusion of this hybrid type of service was welcomed by social and political actors alike, because it was meant to contribute to an unburdening of the highly burdened informal carers. Research findings since then have revealed that the establishment of low threshold services may lead to precarious employment conditions at the margins of the formal care infrastructure (Sauer/Wissmann, 2007).

Laws and regulations interact with the overall conditions within the employment area – such as existing qualification requirements, and market orientation – and create a certain profile and working situation of formal care workers. The introduction of the LTCI led to an expansion of the formal care labour market in Germany. The workforce increased from approx. 65,300 home-based care workers in 1995 to approx. 268,891 in 2009 (Schölkopf, 1998; Federal Statistical Office, 2011). From an international perspective, home-based carers are comparatively well trained; in 2009 33.4 percent of home care workers were registered nurses and a further 19.7 percent were trained elder carers. 18.8 percent had completed an occupational training course as a nurse or elder care assistant or a further care-related training, and 24.8 percent had no care-related training or no training whatsoever. Only 1.0 percent of care workers had completed a BA-degree in nursing or for social work (Federal Statistical Office, 2011).

This statistic also reflects the low proportion of nurses with a BA-degree in the health care sector as a whole. The comparatively high qualification levels, which are not required by the LTCI can be explained by the fact that integrated care provision by one provider includes basic nursing care as well as home nursing with its higher qualification requirements. In summary, 22.4 percent of
all care workers in general band 12.5 percent of all nurses carry out their work within the framework of the LTCI only (Federal Statistical Office, 2011).

With 87.5 percent of all care workers being women home-based care work is a female-dominated occupation. The expansion of employment is reflected in a rise in part-time work from 54.2 percent in 1995 to 73.2 percent in 2009, which is also related to an increase of employment contracts with lower social security standards (22.5 percent among the care workers) (Schölkopf, 1998; Oschminanski, 2010; Federal Statistical Office, 2011). The development of non-standard employment was selected as one strategy to increase flexibility and lower costs in the sector (Theobald, 2004; Oschmianski, 2010).

Economic constraints related to cost containment policies within the LTCI framework and the increasing competition due to the entrance of private for-profit care providers resulted in a lowering of wages and an increase of wage differentials between trained staff, i.e. nurses elder carers, and assistants (Theobald, 2004). In a representative questionnaire in 2007/08 addressed to elder carers, low wages are the most cited problems with workplaces. 72 percent of full-time employed elder carers earned less than € 2,000, which is defined as a threshold to precarious wages in Germany. Among part-time elder care workers, only 20 percent earn more than € 1,500 (Fuchs, 2008). In order to secure a minimum wage, a temporary minimum wage scheme was introduced by law in August 2010 (to run until December 2014). It defines wages for care workers who provide basic nursing care employed by a formal care provider. The minimum hourly wage amounts to € 8.50 for 2010 (rising to € 9.00 in 2013) in the old federal states and € 7.50 in 2010 (rising to € 8.00 in 2013) in the new federal states.

Due to the difficult employment conditions but also in order to enable more culturally-sensitive home-based care service provision, carers with a migrant background are increasingly employed, with an estimated share of 18% in elder care provision. Typically, the migrant care workers – mainly from Eastern European countries and Russia or Ukraine – live already in Germany as citizens or as residents with permanent work permits. There is only limited research available on their employment situation (Steffen, 2009). The employment of migrant carers can be classed as one strategy to attract and retain care staff. Other strategies include the introduction of the new elder carer occupational training programme in 2002 aimed at increasing the attractiveness of the area, the employment of older re-trainees related to labour market policies, as well as efforts to promote a continuous employment career despite family responsibilities, and to increase the retirement age of care workers embedded in the European Employment strategy (see above).
**Care arrangements within the grey economy**

Care gaps related to the definition of the public support within the framework of the LTCI have triggered the emergence of a mainly grey economy related to further service provision. The care gap concerns the support with household assistance. Moreover, the delivery of home-based care services in Germany is still based on the idea of an available family or social network to take over the more comprehensive care tasks, which is no longer always the case. Related to these situations, two different care arrangements in the grey economy can be distinguished. In the first, assistance with household tasks is provided by older German women, housewives or recently-arrived migrant workers, who may serve a number of households on an hourly basis (Gather et al., 2002). Tax deductions have been introduced to create a regular market for household services. Since 2009, tax deductions are available for 20 percent of the costs up to 4,000 € per year in case of regular, standard employment and up to 510 € per year related to employment with lower social security standards.

Increased demand for more comprehensive care services in some households has resulted in the emergence of 24-hour care arrangements provided by a live-in migrant carer as a second pattern. According to estimates, about 120,000 migrant carers provide 24-hour care in about 60,000 households in Germany on a rotational basis, which means they cover the needs of about 5 percent of long-term care beneficiaries living at home (Own calculations based on Steffen, 2009; Federal Statistical Office, 2011). Mainly severe care-dependent older adults on higher income levels use such care arrangements (Neuhaus et al., 2009; Lutz, 2009). Families with migrant carers in Germany cite the lower costs for care compared to 24-hour formal care provision or residential care, the wishes to avoid nursing-home admission and to relieve the burden on family carers. Migrant workers typically provide both domestic services and care activities (Neuhaus et al., 2009).

Many of these workers come from the new EU-member states in Eastern Europe on the basis of a short-term or tourist visa and offer their services on a rotational pattern (Finotelli, 2008). In 2002, on a temporary basis (that became permanent in 2005) a legal care worker recruitment scheme was implemented to hire domestic workers to families with care dependent members from eastern European countries (Poland, Hungary, the Czech Republic, Slovakia, Slovenia, Romania and Bulgaria). The regulations correspond to regular working-conditions in Germany, labour laws and social security standards must be adhered to and up to 2009 the activities concerned domestic work only. Since then these domestic workers are allowed to carry out basic care activities, such as bodily care etc. According to the authority responsible for the placement 3,032 domestic workers
were employed on this basis in 2007. The monthly costs are between € 1,500 and € 2,000. Empirical research reveals that users view the regulations as too bureaucratic and as not corresponding to their own needs (Lutz, 2009).

Regulations related to the single market project are often used to legitimise this type of care provision. The right of free movement for services within the single market project, which allows the temporarily provision of services on a self-employed basis, has often been brought forward. However, in November 2008, the local court in Munich defined the practice as illegal due to the non self-employment character of the activity, such as service provision to one customer only, and imposed a fine on the broker (a ruling confirmed by the higher regional court in Bamberg in 2009). As a consequence the agencies in question attempt to establish a new model, where one migrant carer subsequently serves three users. The Posting of Workers Directive of the EU is also put forward as a legal basis. According to the directive, it is possible for companies to offer temporary services in other EU-countries. This type of arrangements is often organised by agencies. According to the law, customers in Germany are obliged to follow Germany's labour laws, such as those relating to working-hours, but these do not fit well with 24-hour care arrangements (Caritas, 2006; Neuhaus et al., 2009; Steffen, 2009). The largely illegal situation in Germany is an open secret but it is also – covertly – accepted (Lutz, 2009). A majority of actors demand that an affordable service offer may be introduced. More recently, welfare associations start projects to improve the situation of migrant carers respectively demand a strategy for a regularisation (Neuhaus et al., 2009)

5.5. Conclusion

In Germany, home-based care provision is still a largely family-oriented activity, particularly when related to care for elderly adults, and one that is underpinned by existing laws and regulations. Despite the family-orientation, several social statutes have been introduced to grant social rights, and to regulate and organise care provision and funding. The social statutes differ with regard to target groups, aims, risks covered, benefits and their central-regional-local interplay.

LTCI (SGB XI) introduced in 1995/96 is the most significant social-policy scheme. The law was triggered by a combination of social-policy concerns—lack of public support in situations of long-term care dependency and financial concerns, and the then existing lack of a sound and sustainable funding scheme. Following the German social insurance tradition, LTCI is stipulated by a federal law. The federal law on LTCI defines social rights, mode and principles of funding and
implementation of the scheme, as well as the organisation of formal and informal, family care provision.

The LTCI grants universal public support on a medium level embedded in a framework of cost containment policies. The federal law strictly defines levels of care dependency, related benefits and assessment procedures valid in the entire country in order to secure regional equality. Three further Social Statutes (SGB V, IX, XII) that govern the sector either complement public support or define the interplay of different Social Statutes, e.g. with regard to comprehensive support in cases of disability.

The federal law on Long-term Care Insurance has also restructured care provision based on the idea of a welfare mix throughout the whole country. The emphasis is placed on publicly-supported family care-giving combined with a publicly-regulated but market-oriented care infrastructure. Characteristic here are the deliberate efforts to include different types of care provision, i.e. informal, family care, voluntary work, as well as formal and, recently, even paid care provision within the family framework. In representative German and European inquiries the German respondents appreciate the basic assumptions on care provision within the framework of the LTCI. Freedom of choice for users and their families related to formal or informal care provision, choice of providers, control of care quality and the unburdening of the informal, family carers are clearly welcomed (Runde et al., 2003).

Despite strict regulation on a federal level, a wide range of inequalities has emerged within the framework of LTCI with regard to socio-economic status, gender, ethnicity (migrant groups) and type of frailty. Inequalities in care provision are related to access to different types of benefits, as well as to the interplay of family care-giving and formal care provision. These inequalities can be explained by cultural factors, such as ideas on the role of family within care provision, but also by economic factors, e.g. the private costs of care provision and opportunities on the labour market for (mainly female) family carers. The expansion of the formal care infrastructure combines public regulations and funding with market-orientation embedded in cost containment policies. The principles are reflected in the goals to secure high-quality and cost-efficient care provision. Despite the comparatively high qualification levels of the care workers, the female-dominated field is characterised by part-time work, low wages and, increasingly, by the involvement of care workers with a migrant background. Simultaneously, a grey care market has emerged to fill the care gaps manifesting themselves within the framework of the Long-term Care Insurance.
5.6. References


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SGB V, IX, XI, XII


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## 5.7. Appendix

### TABLE 5.2
Care dependency levels: Long-term care insurance and corresponding benefits

<table>
<thead>
<tr>
<th>Care dependency levels</th>
<th>I Considerable</th>
<th>II Substantial</th>
<th>III Most substantial</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need of care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within the range of personal care</td>
<td>Two daily activities</td>
<td>Daily activity</td>
<td>Daily activity</td>
</tr>
<tr>
<td>Frequency</td>
<td>Once per day</td>
<td>Three times/day</td>
<td>Round the clock</td>
</tr>
<tr>
<td>Housekeeping</td>
<td></td>
<td>Several times a week</td>
<td></td>
</tr>
<tr>
<td>Time</td>
<td>90 min/day</td>
<td>3 hours/day</td>
<td>5 hours/day</td>
</tr>
<tr>
<td>Within share of personal care</td>
<td>45 min.</td>
<td>2 hours</td>
<td>4 hours</td>
</tr>
</tbody>
</table>

### Benefits

<table>
<thead>
<tr>
<th>Need of care</th>
<th>I Considerable</th>
<th>II Substantial</th>
<th>III Most substantial</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash payments: (per month, p.m.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>July 2008</td>
<td>215.00 €</td>
<td>420.00 €</td>
<td>675.00 €</td>
</tr>
<tr>
<td>January 2010</td>
<td>225.00 €</td>
<td>430.00 €</td>
<td>685.00 €</td>
</tr>
<tr>
<td>January 2012</td>
<td>235.00 €</td>
<td>440.00 €</td>
<td>700.00 €</td>
</tr>
<tr>
<td>Care services (home based): (p. m.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>July 2008</td>
<td>420.00 €</td>
<td>980.00 €</td>
<td>1470.00 €</td>
</tr>
<tr>
<td>January 2010</td>
<td>440.00 €</td>
<td>1040.00 €</td>
<td>1510.00 €</td>
</tr>
<tr>
<td>January 2012</td>
<td>450.00 €</td>
<td>1100.00 €</td>
<td>1550.00 €</td>
</tr>
<tr>
<td>(extraordinary high need of care 2008-2012)</td>
<td></td>
<td></td>
<td>(1918.00 €)</td>
</tr>
<tr>
<td>Care services (institutionalised): (p.m.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>July 2008</td>
<td>1023.00 €</td>
<td>1279.00 €</td>
<td>1470.00 €</td>
</tr>
<tr>
<td>(extraordinary high need of care)</td>
<td></td>
<td></td>
<td>(1750.00 €)</td>
</tr>
<tr>
<td>January 2010</td>
<td>No increase</td>
<td>No increase</td>
<td>1510.00 €</td>
</tr>
<tr>
<td>(extraordinary high need of care)</td>
<td></td>
<td></td>
<td>(1825.00 €)</td>
</tr>
<tr>
<td>January 2012</td>
<td>No increase</td>
<td>No increase</td>
<td>1550.00 €</td>
</tr>
<tr>
<td>(extraordinary high need of care)</td>
<td></td>
<td></td>
<td>(1918.00 €)</td>
</tr>
</tbody>
</table>

Sources: SGB XI; MDK Bayern (2008)
<table>
<thead>
<tr>
<th>Benefits</th>
<th>I</th>
<th>II</th>
<th>III</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Need of care</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Respite care (informal care)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Up to four weeks a year</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>July 2008</td>
<td>215.00 €</td>
<td>420.00 €</td>
<td>675.00 €</td>
</tr>
<tr>
<td>January 2010</td>
<td>225.00 €</td>
<td>430.00 €</td>
<td>685.00 €</td>
</tr>
<tr>
<td>January 2012</td>
<td>235.00 €</td>
<td>440.00 €</td>
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<td><strong>Short-term care or Respite care (institutions)</strong></td>
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<td>Up to four weeks a year</td>
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<td>July 2008</td>
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<td>January 2012</td>
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<td><strong>Semi-residential:</strong> Day/night care: (p.m.)</td>
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<td>July 2008</td>
<td>420.00 €</td>
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<td>January 2012</td>
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<td><strong>Complementary benefits (p.m.)</strong></td>
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<td>High need of supervision, e.g. due to dementia illness</td>
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<td>July 2008: basic rate</td>
<td>100.00 €</td>
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<td>July 2008: extraordinary rate</td>
<td>200.00 €</td>
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Sources: SGB XI; MDK Bayern (2008)
6. Home Care in Ireland

Virpi Timonen, Martha Doyle & Ciara O’Dwyer

6.1. Introduction

The number of older people in Ireland has increased significantly. However, care services for older people, particularly home and community care services, have failed to keep pace with the changing demographic profile. This has resulted in increased pressure on acute hospital care services, which have also risen in cost; this has arguably been the single most significant driver of expansion in home care. In response, the government increased spending on community care services and introduced a Home Care Support Scheme, which provides older people with individually tailored packages to enable them to live in their own homes. The scheme allows for a mix of nursing care, domestic assistance, personal care attendance and a range of therapeutic services. While the Home Care Support Scheme has been the main tenet of reform in home care services for older people in Ireland, it has an “administrative” status, and so older people are not automatically entitled to receive it. Neither is there a guaranteed right to other home care services in Ireland. As a result, the provision of home care is uneven throughout the country and standards of care also vary due to the lack of national standards or guidelines. The private sector has grown significantly over the last decade, though the absence of licensing laws means that the total number of private care providers in operation is unclear. It has been suggested that the variance in provision of home care services and in standards may be due to the costs of a more standardised system which are perceived to be excessive. Indeed, much of the funding for home care services relies on the care recipient contributing at least some of the overall fee. However, reform of home care services in Ireland is still on-going. Consideration is currently being given to the regulation of home care services although it is anticipated that much work is still required before national standards will emerge. An important very recent reform is the rolling out, in 2011, of the National Guidelines for the Standardised Implementation of the Home Care Packages, which for the first time specified nationally applicable eligibility criteria and thereby seeks to ensure that those with greatest care needs will benefit from the scheme.

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6.2. What have been the main driving forces for reforms in home care/help and what have been the reform strategies?

What have been the main driving forces for reform?

Since 1968, policy makers and advocacy organizations in Ireland have consistently called for improvements to home care services. However, investment in this area was only increased significantly after 2000, and has more recently stabilised or even reduced as a result of cutbacks in funding. A number of developments have contributed to the recent emphasis on home care.

The number of older persons in Ireland is growing, and the growth is particularly fast in the 80+ category. The number of older people living alone is projected to increase dramatically in the next two decades with a doubling of the numbers between 2002 and 2021 for both males and females (Pringle and Connell, 2004). The rapid increase in women’s labour market participation is often argued to restrict the supply of informal (family) care, the cornerstone of the Irish care regime (Timonen and McMenamin, 2002).

The recent focus on home care was brought about by concerns about the escalating costs of hospital and other forms of institutional care. Formal domiciliary care services have rapidly come to be perceived as a ‘solution’ to the challenges in providing care to the ageing population of Ireland. Notwithstanding this concern, lack of adequate community care is still leading to the use of acute hospital facilities to care for many older people who are unable to move back home after hospital discharge, a practice that has negative implications for the health service as a whole and is also expensive to the exchequer (Health Service Executive, 2005, Houston, 2003).

What have been the main reform strategies?

Home Care Packages: A key development in the provision of domiciliary care services in Ireland came about in 2001 when the Department of Health and Children acknowledged that the existing arrangements were not sufficient to successfully support home care. A new national health strategy document, Quality and Fairness - A Health System for You (Department of Health and Children, 2001), outlined plans to invest in community-based health services, including home care, which would help to alleviate pressure on acute health care services and which would also be cheaper than residential care. Thus, the Department of Health and Children encouraged the Health Boards to pilot home care grant schemes (Timonen, 2004). Following the pilot of the home care grant scheme, the Interdepartmental Working Group on Long-term care called in 2005 for the delivery of home care.
packages to persons at risk of admission to residential care, but who were capable of living at home with the provision of sufficient supports. Within Ireland’s National Development Plan 2007-2013, *Transforming Ireland – A Better Quality of Life for All*, €4.7 billion was allocated to a range of measures to allow older people to live independently in their own homes for as long as possible. The largest part of the programme was the Home Care Support Scheme. This scheme allows for individually tailored packages to be developed for each recipient (mainly for older people who are at risk of admission to long-term care, but also to other groups needing care in the community, including people with disabilities). Services available within these packages are a case-appropriate mix of care provided by nurses, home care attendants, home helps and various therapies including physiotherapy and occupational therapy. As the scheme is not a right based on legislation, there is no automatic entitlement for it and its provision varies throughout the country. The scheme was rolled out in 2006 after pilots of the scheme between 2004 and 2006. In 2006, the scheme was allocated €55 million. By 2008, this had increased to €120 million and approximately 8,000 people were using the scheme.

Overall, home care services were significantly expanded during the decade or so since 2000: In 2009, approximately 65,000 older people received home help or a home care package (HSE, 2009a), compared to approximately 16,000 in 2000 (Mercer, 2002). However, the average number of home help hours provided in Ireland fell over the course of the last decade, from eight hours per week (Mercer, 2002) down to five (Gannon and Davin, 2010), signalling that more people are getting formal home care but in smaller amounts than in the past – a trend that diverges from the trend observable in other EU countries, where more care is provided to a declining percentage share of the older population.

Reform of home care services for older people is still on-going in Ireland. Consideration is currently being given to the regulation of home care services. According to the 2009 report by the National Economic and Social Forum (2009), national quality guidelines for home care support services (HSE, 2009b) were drafted by the Health Services Executive’s (HSE) Advisory Group on Services for the Older People Expert in October 2008. However, it is anticipated that much work is still required before these standards will be implemented (NESF, 2009).

**Emergence of private providers:** In addition to the increased allocation of public funds to home care packages, a number of changes have also taken place in the delivery of domiciliary services in the past decade (Doyle and Timonen, 2008). The most recent development in the Irish care mix is the
emergence of private sector agencies and the (part-) financing of their service delivery by the State. The private sector has expanded significantly in the past decade. Research carried out in 2009 suggested that approximately 126 private home care providers operated in Ireland (PA Consulting, 2009a), although, as such companies are not required to have a licence, the total number actually in operation in Ireland is unclear.\textsuperscript{15} The private sector in 2009 received €13.9 million via the state-funded Home Care Packages, which constituted the majority of private sector operators’ revenue (approximately €9.7 million was received via fully privately-funded payments).\textsuperscript{16} The rise of the private home care sector can be attributed both to the fact that funding made available to the public and especially the non-profit sectors has been largely based on retrospective model (i.e. based on what was provided in the previous year), and to the increased emphasis on cash-for-care where public funds are used to purchase home care services from private companies and non-profit providers (Timonen et al., 2006).

\textit{Continuing role of the non-profit sector:} In addition to the recent allocation of funding to care packages, the State has provided financial assistance (since 1970) to the non-profit domiciliary care sector, referred to as the home help service. The non-profit sector remains larger continues to receive significantly more State funding than the private sector, approximately €79.15 million. While this (at times sporadic) funding stream has in most instances not been sufficient to cover all of the organisations’ overhead costs, the majority of the non-profit home care organisations are heavily reliant on this money for their continued survival. Non-profit providers remain the main providers of domiciliary care services (Department of Health and Children, 2006a). However, the introduction of cash-for-care packages and changes in employment laws in 2000 have led to significant changes in the organisation and management of the non-profit sector and the formalisation of the relationship between the state and non-profit providers (Timonen et al., 2006). Thus, the non-profit sector’s total “share” of the market has declined as a result of the growth of the private sector (PA Consulting, 2009a).

\textsuperscript{15} A trawl through the Golden Pages website (www.goldenpages.ie) in 2005 revealed 43 voluntary and private home care organisations in the Dublin area (Timonen et al., 2006); a similar search in 2010 revealed over 1,000 ‘hits’ of organisations that are involved in some form of home care provision within Ireland.

\textsuperscript{16} It is important to note that this figure was extrapolated from survey data for just 25 private providers carried out by PA Consulting in 2009 (PA Consulting, 2009) and may therefore not fully reflect the number of private clients (i.e. those paying the full market price for care) of such companies.
6.3. What is home care/help?

Which services and cash benefits are included under the term ‘home care/help’?

Domiciliary services in the Irish context can be divided into three categories, 1) home help services, 2) home care packages and 3) public health nursing services.

1) Home Help: Home help service is the delivery of domestic support, such as cleaning, cooking and shopping. The delivery of home help is legislated under Section 65 of the Health Act 1953 which states that the HSE is empowered, but not obliged, to provide home help service directly or indirectly through a non-profit organisation. Section 65 has been replaced by Section 39 of the Health Act 2004 which according to the NESF (2005) allows the HSE to give financial assistance to any person or body that provides a service ancillary to the HSE. In effect, it allows for the continued funding of home help services, but also potentially allows for cash transfers to informal carers.

2) Home care packages: As detailed above, home care packages are a new development in the home care context in Ireland. According to the Department of Health (2006a: 28), home care packages ‘should comprise services such as public health nurse, day care, occupational therapy, physiotherapy, home help services and respite care whether drawn from the existing pool of services or any additional resources which might be put in place’. According to a Department of Health and Children funded study conducted by PA Consulting (2009b:15) there are four types of Home Care Package, namely:

- HSE Direct Provision: Services provided directly by HSE (public sector) staff
- HSE Indirect Provision: Services paid for and managed by the HSE, but delivered by non-profit and/or private providers.
- Cash Grant: Payment of cash grants to facilitate the client or their representative to purchase a range of services/supports (not available nationally)
- Respite Home Care Package: Access to short-term residential respite, primarily to support carers, organised and paid for by the HSE.

Recipients of home care packages can receive a combination of the above four services.

3) Public health nursing services: Public health nursing services to older people are typically delivered by health care assistants (HCAs). HCAs provide personal care services, such as washing,
dressing and help with exercises if care plans are devised by an occupational therapist of physiotherapist (Timonen et al., 2006).

**What are the distinctions between home help and other services such as home nursing?**

Formally there is a clear distinction (as outlined above). In practice, however, researchers have been able to identify situations where home support workers also perform medical or para-medical procedures (Timonen et al., 2006). Due to lack of regulation of the sector and inadequate investment, the practice of combining medical/nursing and non-medical care tasks by unqualified personnel continues.

**Which user groups are encompassed and which care tasks and activities are included?**

The provision of *Home Help*, according to the Citizen’s Advice Bureau: 17 ‘is not limited in the categories of people they can assist at home. However, the priorities are normally to provide a service to people with Hepatitis C who have Health Amendment Act Cards18, older people, families with small children where the mother is dead or seriously ill and people with disabilities’.

The *Home Care Package Scheme* allows for individually tailored packages to mainly older people who are at risk of admission to long-term care, but also to other groups needing care in the community, including people with disabilities. An official evaluation of the scheme revealed that 77% of recipients were over 75 years of age, 38% were over 85 and 6.8% were aged 65 years or under (PA Consulting, 2009b). 63% of the home care package recipients were female.

The work of *Health Care Assistants* falls under the remit of the public health nurse and is available to a wide spectrum of people in the community, including older people, people with disabilities and expectant mothers.

See above for classification of care tasks provided under the different categories.

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18 People who contracted HCV through the administration within the State of blood or blood products are entitled to a Health Amendment Act Card (HAA card).
6.4. How is home care/help organized?

What is the overall organisational long-term care approach, i.e. what is the role of home care/help within long-term care policies and provisions?

Despite successive governments’ stated policy of encouraging older people to remain living in their own homes for as long as possible, the majority of recent policy changes in relation to long-term care have been in the area of residential care as opposed to domiciliary care. Public expenditure on home care in Ireland has historically been low and remains lower than in most other EU countries (Huber et al., 2009). As a result, home care in Ireland at the beginning of the twenty-first century was both under-developed and under-resourced. In 2000, public expenditure on home care in Ireland was 0.19 per cent of GDP, and public expenditure on residential care amounted to 0.33 per cent (OECD, 2005). Thus, home care services have been traditionally under-resourced. This under-resourcing, coupled with the haphazard delivery of community care services, has acted as unintended, but powerful incentives for older people to enter residential care (O'Shea, 2002). There is no definition in Irish legislation of what constitutes ‘community care’ and a lack of clarity on eligibility criteria persists (NESF, 2005). There has been a significant bias for investment in residential care over home and community care services. For example, estimated expenditure on residential care in 2005 was €428,826,000 compared with €112,236 spent on home help services (NESF, 2005).

In spite of this, formal domiciliary care services have rapidly come to be perceived as a ‘solution’ to the challenges of providing care to the ageing population of Ireland (Timonen and Doyle, 2008). Approximately one-third of community-dwelling older people receive support from other people, either formally or informally (O'Hanlon et al., 2005). Much of the support provided is by family and friends or by voluntary organisations. This implies a strong (implicit) reliance by the State on informal care, rather than through the adequate provision and funding of formal care services that would facilitate older people to continue living at home (O'Shea, 2006, Gallagher, 2008). While funding for formal home and community care services has increased in recent years, it is possible that a new system for the payment of residential care (the Nursing Home Support Scheme, 2009) may yet again channel funding away from home care services, leaving domiciliary care as the poor relation in terms of policy-making and quality assurance for older people’s care services (Ahern et al., 2007).
Does home care/help include both health and social welfare aspects, and is care for disabled and elderly organized similarly?

Home Care/Help: Social and/or Health Aspects: Services to support people in need of long-term care to remain living in their own homes include both social and health aspects. As noted above, home and community care services include home help (domestic support, such as cleaning, cooking and shopping), home care packages (which includes domestic support as well as healthcare services such as visits from a public health nurse, day care, occupational therapy and physiotherapy) and public health nursing services (washing, dressing and help with passive exercises if care plans are devised by an occupational therapist or physiotherapist).

Home help services and other social welfare services are not integrally linked but home care packages tend to include a wider package of services such as day care, respite, meals-on-wheels and domestic support. Approximately 5% of older people receive meals-on-wheels (O'Dwyer and Timonen, 2008); formal provision of other services is more limited (Haslett, 2003, NESF, 2005).

Organisation of Care for (Younger) People with Disabilities and Older People: In theory, services for people in need of long-term care do not usually require applicants to meet an age criteria, but in practice, the manner in which services are delivered tends to differ. Home-care services for older people tend to focus on maintenance rather than rehabilitation or improvement, whereas younger people with disabilities are more commonly offered services with a rehabilitative or independence-promoting approach, such as supported employment schemes, independent living or day services. This is largely because of a drive for the deinstitutionalization of care for (younger) people with disabilities (Quin and Redmond, 1999).

However, for younger people with disabilities, the provision of care is arguably more haphazard. While some (younger) people with disabilities can avail of home care services (e.g. home helps), overall provision for the two groups is treated differently. The Disability Act 2005 provides for an assessment for all people with a disability, but does not guarantee any provision of services. However, older people in Ireland do not automatically have a right to a needs assessment. Similar to the heavy reliance on institutional care for older people, in the past there was a long tradition of institutional care for people with disabilities. Almost one-third of people with disabilities in Ireland live in full-time residential services, almost 70 per cent live in a home setting with their parents or foster parents and only 3.5 per cent live independently or semi-independently (Kelly et al., 2007). Sixty per cent of people with intellectual disabilities using residential services
in Ireland still live in ‘special living’ settings which are generally larger and congregate in nature and include 7% in hospital accommodation (Mulvaney et al., 2007). However, this number is falling rapidly (Kelly et al., 2009).

What is the role of central, regional and local authorities in the organisation of home care?

Policy is formulated at the central level by the Department of Health and Children and also to some extent by its executive arm, the HSE. To the extent that it exists at all, policy is implemented, in a very inconsistent manner, by the HSE’s Local Health Offices (LHOs). The lack of firm, clear national guidelines on assessment and eligibility to services, and the inability to drive their implementation are the main reasons for this inconsistency. In the absence of clear guidance from the central level, LHO-level actors are forced to devise their own operational systems, resulting in a significant amount of variance throughout the country. There is also an absence of other factors that might bring about more consistent practices e.g. lack of electoral accountability and incentives at the local level. Service delivery funded through the public purse is orchestrated by the LHOs that hire staff (public health nurses, health care assistants) or pay for service delivery by private or non-profit providers. Service level agreements (between the Local Health Office that funds the services and the various providers) that govern the standards of care and training and supervision of staff are not in place throughout the country, and monitoring by the HSE is erratic. This means that service provision takes place in the absence of uniform external standards and rules.

6.5. How is home care financed?

What is the funding system?

Long-term care services in Ireland are funded from general taxation (OECD, 2005), with annual budget allocations towards home and community care challenged by the Department of Health and Children to the LHOs.

How are costs divided between the public and private purse?

The OECD (2005) details the public and private expenditure on long-term care as a percentage of GPD in the year 2000. According to their data, public expenditure on home care in Ireland was 0.19 per cent of GDP and institutional care 0.33 per cent of GPD. Information pertaining to 2005
indicates that total expenditure on (institutional and home) long-term care in Ireland increased slightly, to approximately 0.6 % of GDP (Huber et al., 2009). This more recent research suggests that public expenditure on residential care continues to exceed spending on home care services (Huber et al., 2009). Research carried out on behalf of the Irish Private Home Care Association of Ireland has suggested that the State contributes over 97% of the cost of home care services in Ireland (PA Consulting, 2009a).

**How are user fees calculated?**

*Community nursing services* are free of charge. In principle, *home help services* are free for persons with a medical card19. However, in practice, an informal means (financial) assessment is conducted. Commenting on this issue the Department of Health (2006a) states:

*The [home help] service is generally free to Medical Card holders although recipients may be asked to make a contribution. Other people are asked to contribute to the cost of the service. The service is provided as a matter of priority to people who have Health Amendment Cards, older people, families with small children where a parent is dead or seriously ill and people with disabilities. Each application for home help services is considered on its own merits. The HSE may take a number of factors into account, including income, other family support available, remoteness from services and availability of suitable people to provide the service. Persons who need a home help will normally apply to the local public health nurse who assesses the need for the service and then processes the application to the HSE.*

Therefore, it is not usual for older people to make a payment towards the costs of home-help services. Research indicates that requiring these financial contributions for services can be a barrier for uptake in Ireland (O'Hanlon et al., 2005).

At present, there is no standard means-test for qualifying for the Home Care Support Scheme (Home Care Packages), although many local areas carry out means-assessments (NESF,

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19 Between 2001 and 2008, everyone over aged 70 was entitled to a medical card without a means test. From January 2009 there are gross income limits of €700 per week for a single person and €1,400 per week for a married couple.
Obtaining data on user fees for home care packages is difficult. According to a Department of Health funded report completed by Prospectus (2003), the HSE does not currently report on key financial data such as:

- Overall budget or expenditure on home care packages at area or LHO level
- Cost per home care package recipient
- Relative spend on private providers or voluntary providers
- Whole Time Equivalents (WTE) spent on home care package delivery.

6.6. How is home care/help provided?

What is the role of and take-up of care from the cash vs services and public, private and voluntary sector?

The main provider of home care services in the Irish context is the voluntary sector which for the most part specialises in home help (domestic work) services (see above for categorisation) (Department of Health and Children, 2006a). Home help recipients receive an average of 5 hours per week (PA Consulting, 2009b). At present there is a greater concentration of private providers in urban areas, and at this point in time there is little evidence that they are crowding out the non-profit sector (Timonen et al., 2006). A national analysis of the Home Care Package Scheme by PA Consulting (2009b: 19) found that:

The most common type of Home Care Package was HSE Indirect Provision (37.1%) followed by HSE Direct Provision (21.1%), Cash Grant (18.7%) and Respite (8.8%). The remaining Home Care Packages (14.3%) were a combination of types. Supplementary analysis of this figure shows that 87.1% involving HSE Direct Provision; 50.3% involving Cash Grants; 25.8% involved HSE Indirect Provision and 23.9% involved Respite.

There is some evidence of significant differences in the profiles of the public, private and non-profit sectors in the care tasks that they undertake. Research carried out by Timonen and Doyle (2007) found that the non-profit sector specialises in providing domestic help during the daytime (although in practice this often veers in the direction of personal care if the client develops personal care needs) and the public sector focuses on personal care (also during daytime, in short bursts of
typically 30–60 min per client per day). The private sector appears to be carving a niche in more flexible, night-time, round-the-clock service, as well as companionship-type services.

**What is the complementarity between formal and informal help?**

The comparatively modest level of expenditure on formal care services for older people in the past can be attributed to both ‘objective’ demographic factors and societal norms and expectations, namely the comparatively low ratio of older people to younger people in the overall population of Ireland and the assumption that care in the home is predominantly a private matter and the responsibility of family members or the non-profit sector (Timonen and Doyle, 2008). This reliance on informal care from friends and relatives was explicitly acknowledged within government health and social care strategy documents between 1968 and 1988. However, documents written in the 1990s and 2000s have dropped this policy of relying on informal carers, while suggesting that the state would endeavour to support informal carers. The bulk of community care continues to be provided by informal caregivers (Citizens Information Board, 2002). In fact, over two-thirds of home care package recipients rely on their families and partners for informal care (PA Consulting, 2009b). Despite this reliance on informal care, Mangan (2002: 29) argues that carers in Ireland have virtually no rights and there is no legal right to respite care. In addition, there is little financial incentive for family members to provide informal care. Often, caregiving means giving up paid employment, and state support for informal care is “partial and conditional” (O'Shea, 2003a). The Carer’s Allowance is only available to those who pass a means test (i.e. are deemed low-income) and the Carer’s Benefit, legislated in The Carer's Leave Act, 2001, allows carers to avail of leave for 15 months and retain their employment rights and return to their job or job of similar status once finished caring. Payments are low and the Department of Social and Family Affairs, which administers both schemes, have acknowledged their restrictive nature (Department of Social and Family Affairs, 1998). The Carer’s Benefit scheme has an exceedingly low take-up rate (Timonen and Doyle, 2008).

There is a strong reliance on informal care in the home and community. This reliance, coupled with inadequate funding for the domiciliary care sector and greater support for providers and users of residential care (O'Dwyer and Timonen, 2008, Timonen *et al.*, 2006, Haslett *et al.*, 1998, Haslett, 2003) mean that home and community care services are poorly co-ordinated and older people are expected to fit themselves into the services rather than the other way around (O'Shea, 2006). It has been suggested that, if Ireland is to continue to rely on a model of family care, there is a need for
better conditions and higher payments for family carers (Citizens Information Board, 2002). Recent research suggests that carers (for people with dementia) are happy to care for their relative with dementia, though many suggested that they would benefit from greater practical and financial support to continue their caring responsibilities (O'Shea, 2003a).

6.7. Who are the carers?

Who are the formal care workers (migrant/domestic and gender) and what are their employment situation and qualifications?

Ireland experienced a shortage of care workers during the years of strong economic growth that came to an end around 2008. While this problem is likely to be reduced due to the economic downturn, an increased demand for long-term care services coupled with decreased availability of informal (family) carers led to the employment of growing numbers of migrant care workers in the Irish long term care sector. Walsh and O'Shea (2009) estimate that approximately 16 per cent of the long-term care workforce are foreign nationals. Along with the United Kingdom and Sweden, Ireland offered unrestricted access to its labour market to the citizens of the ten new EU member states in 2004. Many of these migrants, particularly those employed in the private or ‘grey’ care labour market are afforded weak social protections and employment benefits (Timonen and Doyle, 2009). Certain groups within the long-term care workforce are more likely to confront obstacles and discrimination than others (Timonen and Doyle, 2009). The experiences of European, South Asian and African carers are significantly different and a relationship appears to exist between carers’ region of origin, and their experience of care work, employment mobility and long-term plans for remaining within the sector.

Many migrant care workers are employed within the private sector. As the tasks carried out in the private sector focus on more flexible, round-the-clock care, there is more risk of mistreatment of such workers. Timonen, Doyle and Prendergast (2006) suggest that more flexibility is required from private sector care workers than from their public/non-profit sector counterparts in terms of the range and combination of care duties. Workers in the private sector tended to have lower levels of remuneration and weaker social rights than non-profit or public sector workers. Indeed, a recent
television programme, *Prime Time Investigates – The Home Care Scandal*,\(^\text{20}\) highlighted the poor pay and conditions received by some carers working in the private sector, including one carer who received just €300 for carrying out over 300 hours of caring work in one month, including care provided over 24 hour periods with no breaks or relief or training. In the absence of a joining-up of migration, labour market and long-term care policies, this segregation of care workers within the care sector is likely to worsen, as the private sector continues to grow (Doyle and Timonen, 2010).

There are no mandatory training requirements for home care staff in Ireland but non-profit and private sector providers generally demand that applicants for home care worker vacancies have at a minimum some basic prior training (first aid, manual handling) or provide training in-house (for which some providers are seeking formal accreditation). However, anecdotal evidence has suggested that workers within the private sector often have little or no training, in spite of claims by companies that all care staff have received formal training; some evidence that this is the case in at least some private companies was given in the *Prime Time Investigates Programme* mentioned above. In the public sector (health care attendants) qualifications are required and additional training is more readily available than in the non-profit and private sectors (Timonen and Doyle, 2007).\(^\text{21}\) Recent research found that homecare workers have expressed concerns about the limited training opportunities available to them (NESF, 2009).

*Who are the informal care workers (age and gender)?*

A national survey has found 8% of people aged 65 and over were informal carers in 2008; people aged 65 and over were 1 in 7 of all those who said that they provided informal care (Wren, 2010). The majority of informal Irish carers are female, accounting for 100,214 (or 62%) of all carers, with the remaining 60,703 (or 38%) accounted for by male Carers. The key age cohort for carers is the 45 to 64 year group, with 10% of women and 6% of men in this cohort providing unpaid care, suggesting that adult children continue to play a strong role as informal carers in Ireland. These rates are significantly higher than the proportion of persons aged 65 and over that are female carers (4%) and male carers (3%), and double the rate in the 25 to 44 years cohort also for both genders, at 5% and 3% respectively (Carers Association, 2009). A review conducted by the Joint Committee on

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\(^{20}\) Broadcast on 13\textsuperscript{th} December 2010. Available to download and watch on http://www.rte.ie/news/av/2010/1213/primetimeinvestigates.html#

\(^{21}\) There are a number of relevant courses available (some equivalent to secondary school diplomas, others equivalent to a Bachelor’s degree) in vocational colleges and technical colleges across Ireland on “Healthcare Support”, “Care for the Older Person”, “Care Practice in Community Care” and “Care Support” (Walsh and O’Shea 2009). However, lack of support from employers may act as a barrier to workers enrolling on such courses until it becomes a mandatory requirement.
Women’s Rights (1996), concluded that the majority of carers were female and many were older. Similarly, Cullen et al. (2004) state that all studies of carers in Ireland have found that women are more likely to be carers than men. They state that intra-familial and highly gendered factors come into play in determining which family member will become a care-giver; evidence suggests that there may be a tendency for the role to be assigned to the most ‘available’ person, based on factors such as physical proximity and presumed availability.

According to Eurobarometer data, the percentage of Irish people (21.5 per cent) providing help within the family is the fourth highest across 15 European countries (Alber and Kohler, 2004). Ireland also comes in at fourth highest (11 per cent) for delivery of care outside the family. Delivery of care to people over 60 was reported by 20.7 per cent of Irish participants.

6.8. How is home care/help governed and regulated?

_What are the rules regarding eligibility criteria, needs assessment, and user payment?_

Until 2011, there were no national guidelines detailing who is eligible to either a home care package or home help service. The Citizen’s Advice Bureau pointed out that, since the home care package scheme is an administrative scheme, older people do not have an automatic right to services under the Scheme. Numerous reports have recommended the development of appropriate assessment tools and clarification of eligibility criteria (Mercer, 2002). The HSE drafted National Guidelines for the Standardised Implementation of Home Care Packages. According to the official evaluation of the scheme, ‘the draft guidelines included reference to co-payment by HCP recipients, but were amended following advice that there was no legal basis for such charging’ (PA Consulting, 2009b). Local Health Areas drafted their own eligibility guidelines and service level agreements with service providers. User fees for home help services tended to be at the discretion of the home care manager (Timonen et al., 2006).

The lack of regulation of domiciliary care and absence of stipulations on user payments stands in stark contrast to the regulation of institutional care. Efforts to reform the regulation of institutional care culminated in the enactment of the _Health Act 2007_ which provides for the establishment of the Health Information and Quality Authority (HIQA), an independent statutory body whose functions include the inspection and regulation of residential settings for older people. In addition, new legislation on payment for nursing homes, ‘_A Fair Deal_’, resulted in new payment
schemes for nursing home residents and stipulated that prospective and current nursing home residents undergo a care assessment and means test. The immediate contribution towards the cost of care is based on 80% of each individual’s assessable income, with deferred contribution of up to 5% of an individual’s assets, collectible after the person’s death (Department of Health and Children, 2006b). The Health Act 2007 which would have provided an ideal framework to improve the regulation of domiciliary care services did not make explicit reference to the domiciliary care sector (Ahern et al., 2007).

Progress was made in late 2010, when the HSE finally approved the National Guidelines for the Standardised Implementation of the Home Care Packages Scheme. Following approval by the Department of Health in November 2010, implementation of the Guidelines commenced on 1st of December 2010 and full implementation is taking place gradually throughout 2011. The main changes included in the Guidelines are (1) a national standard application which will be used for all new applicants to the scheme; (2) client information booklets; (3) a standard format for reporting outcomes of the client care needs assessment; (4) standard access criteria based on care needs; (5) nationally applicable definition of what constitutes a Home Care Package; and (6) standard approaches regarding frequency of reviews and management of complaints. The implementation of these Guidelines is intended to ensure that applicants for Home Care Packages are treated in a similar way regardless of their geographical location and that those with the greatest care needs will benefit from the scheme. However, there are still no regulations governing home care, although it is anticipated that Quality Guidelines for Home Care Services will be submitted to the Department of Health by the HSE in April or May 2011.²²

**What are the financial control mechanisms for regulating and coordinating services from public and private providers, e.g. purchaser-provider split?**

There are no explicit financial control mechanisms; the HSE’s LHOs work within the budgets that are allocated to them and are, in principle, free to use these towards direct (public) service provision, or to purchase services from the private and non-profit sectors.

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²² Information received via a personal email communication from Geraldine Rigney, National Specialist on Services for Older People at the HSE, dated 14 March 2011.
6.9. How is quality of home care/help assessed?

Is there emphasis on participation or empowerment of the users and what procedures are installed to achieve this?

The introduction of home care packages marks a shift in policy in relation to consultation and inclusion of older people in making decisions about their own care. Users can choose either to purchase the care and support they need (typically from a list of private and/or non-profit providers within the area) or to use care services provided by the HSE (PA Consulting, 2009b). However, it has been noted that duplication of means and care assessments in some local areas, coupled with variation in the services available, can limit the choices and autonomy of users (NESF, 2009).

Separate to the home care package programmes, user participation, choice and empowerment in taking up home care services is limited. As noted earlier, community care services often work on the basis that recipients must fit themselves into the service rather than the other way around.

Otherwise, attempts to increase the participation of older people in organising their own care have remained at a pilot stage. O’Shea (2003b) provides information on a three-year government demonstration programme which allowed older care recipients to decide what services to purchase and when and where they be delivered. Eligibility to the programme was based on functional status rather than means, with older people assigned to three categories of dependency (moderate, high and continuous). Recipients received a weekly cash payment to a maximum of €250 based on the level of dependency. The money could be used to purchase services or pay a family carer. The findings of the evaluation are not documented and so it is unclear if the initiative has terminated or whether there are plans to roll out the programme.

The need to capture health care recipients’ feedback and to routinely collate and analyze complaints was identified as an essential policy prerogative in the national health strategy, *Quality and Fairness: A Health System for You* (Department of Health and Children, 2001). To date, however, it seems that little or no emphasis has been placed on systematically reviewing and analyzing the complaints made against the domiciliary care sector. Users have few opportunities to have an input into the running and quality of many community services (O'Dwyer and Timonen, 2008, Haslett, 2003). Hodgins and Greve (2004: 89) who comment on ageism inherent in Irish policy health care documents since the publication of the first care document of older people in 1968 state:
Consultation with older people, when mentioned, is very much about services they see as necessary rather than what would promote their health, what way they would like to be involved in promoting their health and what contribution they would like to make to policy development.

There have been calls for greater user involvement for example in the Mercer report (2002: 9):

_A choice of provider, whether arranged directly with the funding body, or facilitated by the use of vouchers, direct payment mechanisms or cash benefits, would increase consumer choice. Consumers would be able to select the mix of services that best suit their preferences._

**What is the scope, procedures and tools of quality assessment of home care?**

As noted earlier, home care services in Ireland are currently not regulated in terms of quality. However, consideration is being given to the regulation of home care services. According to the 2009 report on Home Care Packages (National Economic and Social Forum, 2009), national quality guidelines for home care support services were drafted by the HSE Advisory Group on Services for the Older People Expert Group in October 2008 (HSE, 2009b). However, these guidelines remain unpublished. Many commentators have called for a mechanism, such as mandatory regulations, for ensuring a minimum standard within home care services. For example, The Law Reform Commission (2009) is calling for an amendment of the Health Act 2007 which provided for the establishment of the independent Health Information and Quality Authority (HIQA) on a statutory basis. The recent television programme mentioned above, _Prime Time Investigates – The Home Care Scandal_, documented the impact of the lack of a regulatory framework for the home care sector. Footage from hidden cameras showed older care recipients being force-fed and threatened. The implications of home care workers not turning up for work was also highlighted, namely, care recipients not being able to get out bed for days at a time, resulting in hunger, incontinence as well as posing a number of other health risks. The programme (shown only recently) has caused public outcry, which is broadly reflective of the aftermath of a similar programme shown on national television in 2005 (_Prime Time Investigates: Home Truths_), which contained hidden footage of abuse of residents in one private residential care setting. The 2005 programme led to reform of regulation of the residential care sector. Therefore, it is possible that the more recent programme
may also have a similar impact for the home care sector. However, there has been a high level of dissatisfaction expressed in recent days that government policy on care for older people is now “reactive”, and led by the media, rather than fore-planned.

What are the national preferences for home based care?
Since the 1960s, successive Irish governments have stated a commitment to pursuing policies with the intended effect of enabling as many older people as feasible to continue to live at home. However, as Hodgins and Greve (2004) note, many of these policy recommendations have been aspirational, a bias towards institutional care still persists and policies and funding have traditionally focused on expanding residential care (NESF, 2005). As noted above, the National Development Plan 2007-2013, *Transforming Ireland – A Better Quality of Life for All*, announced the ring-fencing of €4.7 billion to fund a range of measures to allow older people to live independently in their own homes for as long as possible, highlighting a clear shift away from almost 50 years of prioritizing the provision of residential care services for older people.

The vast majority of older people who live in their own homes indicate a preference for home-based care (O'Hanlon *et al.*, 2005). This study revealed that stigma was attached to some services (Garavan *et al.*, 2001). Living in a rural area and having a lower income seemed to be associated with perceived stigma of services. Eleven per cent of respondents, the majority of whom had little informal assistance, said they would like to have meals-on-wheels. However, 29 per cent of the overall sample rated meals-on-wheels as ‘highly embarrassing’. Receiving counselling, home help, visits from social workers and personal care attendants was also rated by one-fifth of the sample as being ‘highly embarrassing’.

What are the methods for handling complex cases?
One of the shortcomings of the Home Care package scheme highlighted by an assessment conducted by a government advisory body is that the scheme has not been implemented uniformly throughout the country (NESF, 2009). Instead, there is a significant amount of variation at local level in how the scheme operates. The report highlighted that different medical assessments are used to determine whether an individual is in need of home care support and outcomes of needs assessments are often linked with the funding available. As a result, those with complex care needs may not always receive the care they require to enable them to remain living in their own home.
6.10. How are the policy changes overall related to outcomes for the users?

Do the users appreciate certain policy changes?
Overall, older people in receipt of home care packages and their families are very positive about them (NESF, 2009). Many recipients value the service as the alternative would be to move into a residential care home. In addition, recipients and their families have some autonomy in designing a care package that best suits their needs. However, the assessment of the scheme by the NESF (2009) suggested that it was too heavily focused on inputs and failed to adequately measure outcomes for users. When introduced, policy-makers did not agree what the expected outcomes of the scheme would be and links between budget and performance, and clear accountability mechanisms were not outlined in the policy development. As a result, there has been significant variation at local level in how the scheme is implemented (NESF, 2009).

Are the policies contributing to changing patterns of care provision?
Yes, the introduction of the Home Care Packages has changed the care landscape considerably, first and foremost through aiding the rise of the private providers but also, more positively, by enhancing availability of formal care services, albeit in a manner that is inconsistent across the country.

Do the policies contribute to an increasing inequality among different groups of users?
The 2009 NESF report suggests that this may be the case, although a definitive answer to this question would call for further research.

6.11. Conclusion

The delivery of domiciliary care services in Ireland is fragmented and uneven, with enormous variations around the country. The lack of national guidelines on needs assessment, eligibility and quality assurance leads to inconsistency of provision of home care services. Access to services is more closely related to the area of residence and availability of supports within that area than to care needs. These problems are symptomatic of the lack of implementation of national guidelines on the delivery of home care services. The NESF (2009) suggests that the reason for the government’s tardiness in implementing national eligibility criteria may relate to the fiscal
implications that a more standardised system would incur and that the introduction of a means-based system is likely to be politically unpopular.

The ‘theme’ that Ireland encapsulates and exemplifies in the arena of home care, is the transition from a system that is heavily reliant on family care towards a more diverse, more formalised system, within the context of a liberal welfare state and the associated ‘low tax, low spending’ policy. The last decade has seen a piecemeal shift from a reliance on families and the non-profit sector towards a greater welfare mix where the private sector has expanded, but the State is still struggling to shed its subsidiary role and to adopt a stronger, more directive role in financing, co-ordinating and regulating home care.
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Active Participants in the Community and in Long-term Care Settings, 16th-17th November, 2010,
7. Home Care in Italy

Cristiano Gori23

7.1. Introduction

The changes occurred in home care in Italy over the last ten years or so are of particular interest at a comparative level. This Mediterranean country, in fact, has experienced a deep process of change without reform and this process has mostly concerned home care. A long-awaited national long-term care reform, under public and political discussion since the mid 90s, has not been enacted. The several proposals made public since the mid 90s pursued the same aims: to increase the state public expenditure devoted to long-term care, to increase the provision of in-kind services, mostly in the community, and to reduce the huge inter-regional differences in the amount of public-care provision.

The state expenditure devoted to Long-term care (LTC) has actually gone up, but not as an outcome of a change of direction in policy. In fact, the percentage of older people receiving the companion payment - a payment available to severely disabled people, regardless of their age, based solely on an assessment of their needs - rose from 6,0 percent (2002) to 9,5 (2008), ie by 58 percent in sevene years. The increase in the size of the users’ group was not due to any change in the policy design - as there was actually no modification in the features of the companion payments at all - instead it was due a bulk of reasons discussed below. The huge growth of the expenditure devoted to companion payment, without any political choice in that direction, has been the most important change in LTC in Italy in the last decade: the national focus – in the final part of the paper – will analyse it in details.

On the other hand, some Regions have introduced their own long-term care reforms, all aiming to give priority to care in the community. Usually, the reforms have been set up in those Regions – in the North and the Centre of the Country – where the provision of services in kind was already higher. In the country, the supply of services in kind has increased and also the degree of regional variations has further increased over the last decade.

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The overall outcome of the decade is that the unbalance between cash and care in the LTC public policy is even bigger than it was ten years ago. In fact, the provision of companion payments has growth more than the services in kind actually did. This feature strikes because since the beginning of the 90s all the experts have underlined the negative consequences of a welfare system too focused on the cash provision.

Consistently with the Livindhome Research Questions, the paper presents the situation of home care in Italy, its main features, the key changes over the last decade and the most important causes.

7.2. What are the drivers of change?

In order to develop home care services in kind, a national reform was actually needed. In fact, until now services in kind have been responsibilities of Municipalities and Regions, that cannot bear anymore the pressure due to the increasing demand of services. The State, instead, has never been involved in funding services in kind and there is huge consensus among experts that it should promote the development of services in kind (mostly in the community).

A national long-term care reform has been debated since the mid-nineties but no no government – either right-wing or left-wing – has seriously worked to introduce it. The public debate began in 1997, when the centre-left government led by Romano Prodi set up a commission of experts, named “Commissione Onofri” after its chair, the economist Paolo Onofri, to design an overall reform of the Italian welfare system, including long-term care. The Commission made several proposals, including one for a national long-term care reform, but these proposals were never implemented. Since then various politicians and experts have made proposals for a national reform, all of which share the same goals. They aim to increase public expenditure devoted to long-term care, to increase the provision of in-kind services, mostly in the community, and to reduce the huge inter-regional differences in the amount of public-care provision.

In Italy national governments are usually quite weak in political terms and the influence of pressure groups and lobbies is stronger than in most European countries. For the success of any political reforms, thus, the existence of powerful pressure group is essential. In welfare policies there are strong pressure groups regarding pensions, but not on long-term care for the elderly. Pressure groups for people with disabilities are quite strong but the people they fight for are too few, in comparison with the older citizens, to raise a substantial interest in the political arena.
In the highly decentralized Italian institutional setting, furthermore, the political relationship between the 20 Regional governments and the State is crucial. Actually, the Regions did never had the development of long-term care services as key aim in their bargaining with the State. Instead, the representatives of the 20 regions were quite effective in forcing the government to increase funding for health care and in preventing it from cutting expenditure it when it planned to do so.

7.3. What is home care?

The Italian public LTC system includes those services or cash benefits which are, at least partly, publicly-financed, and for which the public actor holds the responsibilities in defining the eligibility criteria and/or the quality standards. These services can be supplied also by private providers, mostly non-profit organisations, in agreement with public authorities. Table 7.1 presents the public LTC care inputs for dependent older people. Responsibilities for managing the different care inputs are divided among the State, the Regions and the Municipalities. In particular, the State is in charge of the companion payment and of the tax benefits; the Regions coordinate and fund the Local Health Care Authorities (“Aziende Sanitarie Locali”: ASL), i.e. the organisations that manage and provide (directly or through other institutions) health care to the resident population. Finally, the municipalities are in charge of personal social services.

The paper focuses on the different home care inputs, consistently with the overall aims of the Livindhome project. They are:

Integrated Domiciliary Care (Assistenza domiciliare integrata, ADI). It should at least in theory, provide both home help – described below - and home health care inputs (home nursing, physiotherapy and visits by specialists and the GP). In most of the cases the care packages consists only of health care related inputs (home nursing mostly, and physio as well). Health care related inputs are responsibility of the 20 Italia Regional Authorities and each Region has different eligibility criteria and care models. There are, nevertheless some common traits: the health-related inputs are provided only according to health-related needs (ie are not means-tested) and are free of charge.

Home help (Servizio di assistenza domiciliare, Sad). Municipalities are in charge of this service. Rules change among Municipalities but there some common traits: home help is both

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24 In Italy there are 20 Regions and some 8000 Municipalities. Some 30 percent of the Municipalities manage personal social services together with other municipalities in the same area.
needs-tested, according to need of continuing care, and means-tested, according to both income and assets; a user charge can be required.

**Companion payment (Indennità di accompagnamento).** This is a payment available to severely disabled people, regardless of their age, based on an assessment of their needs and paid irrespectively of the claimant’s financial conditions. It amounts to 487 Euros a month. There is no control over its actual use and no care plan is made. *The indennità* is completely detached from the provision of in-kind services. It is funded by the State and the eligibility criteria are the same for the whole country.

**Local care allowances (Assegni di cura).** They are financed and managed both by Regions and Municipalities through their health and/or social funds. They are both needs-tested and means-tested, made available to highly dependent older people with limited economic resources. Organisational arrangements vary, depending on the area.

### TABLE 7.1
Public LTC inputs for dependent older people

<table>
<thead>
<tr>
<th>Type of input</th>
<th>Service typology</th>
<th>Responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Home care: Services in kind</strong></td>
<td>Integrated domiciliary care (ADI)</td>
<td>Regions</td>
</tr>
<tr>
<td></td>
<td>Home help</td>
<td>Municipalities</td>
</tr>
<tr>
<td><strong>Home care: Cash benefits</strong></td>
<td>Companion payment</td>
<td>State</td>
</tr>
<tr>
<td></td>
<td>Local care allowances</td>
<td>Regions/ Municipalities</td>
</tr>
<tr>
<td><strong>Residential Care</strong></td>
<td>Nursing homes</td>
<td>Regions</td>
</tr>
<tr>
<td></td>
<td>Care homes</td>
<td>Municipalities</td>
</tr>
<tr>
<td><strong>Day-care services</strong></td>
<td>Day-care centres</td>
<td>Regions / Municipalities</td>
</tr>
<tr>
<td><strong>Support to informal and private care</strong></td>
<td>Tax benefits$^{25}$</td>
<td>State</td>
</tr>
<tr>
<td></td>
<td>Training courses</td>
<td>Municipalities</td>
</tr>
</tbody>
</table>

Source: Author’s own adaptation on Chiatti et al, 2010

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$^{25}$ There is a tax benefit between 400 and 800 Euros a year, for those hiring a care worker privately. There are not data available on the take-up rate and on the public expenditure involved, and it will be not considered further here.
Table 7.2 shows the percentage of people aged 65 and over receiving public care and of those receiving privately paid care (almost entirely from migrant workers) from the early 90s onwards; please note that the users of companion payments and those receiving private care often overlap as the former is commonly used to pay for the latter. According to the most recent official data available - concerning 2007 or 2008 - home care users are the 5.1 percent of older people 65+, of whom 3.3 percent receive ADI and 1.8 percent home help. Similarly, residential care includes a huge variety of institutions that vary widely between regions, both in name and characteristics. Overall about 3 percent of the older people live in them, and this percentage has not changed much in the last decade. The recipients of the companion payment increased to 9.5 percent in 2009 and today this allowance represents the main public LTC inputs in Italy. This amount of money is often used – as previously stated – to employ migrant care workers, who work in 7 percent of households with older people 65+. This shows that – in the European context – the provision of publicly funded home care is quite low in Italy. Within this scenario, the key changes of the last decade in home care have been the increase in the percentage of older people receiving home care and, above all, the quick growth of the companion’s payment recipients.26

TABLE 7.2
Older people users of long-term care, % of people aged 65 and over, Italy

<table>
<thead>
<tr>
<th></th>
<th>Early 90s</th>
<th>Early 2000s</th>
<th>Late 2000s</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Residential care</td>
<td>2.9</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Home care (services in kind)</td>
<td>2</td>
<td>3.8</td>
<td>5.1</td>
</tr>
<tr>
<td>Companion payment</td>
<td>5.0</td>
<td>5.5</td>
<td>9.5</td>
</tr>
<tr>
<td>Elderly receiving privately paid care at home</td>
<td>NA</td>
<td>7 %</td>
<td>7 %</td>
</tr>
</tbody>
</table>

Source: official data available, summarised in NNA Report 2010

Overall, the public expenditure on LTC in Italy remains very low. According to the official estimates, in 2008 the LTC expenditure for persons aged over 65 amounted to only 1.12% of GDP. Table 7.3 – based upon the official data provided by the National Economic Bureau - allows us to look at the public expenditure from two different points of view. One concerns the layer of Government in charge. The State spends 0.56 percent of the GDP (companion payment), the Regions 0.43 (health related care inputs: nursing homes, ADI, day care) and the Municipalities 0.13

26 There are no data available at national level concerning the local care allowances.
(social care inputs: care homes and home help). Another point of view concerns the main typologies of care inputs. Cash benefits amount to 0.56 percent, residential care 31 percent and home care 25 percent.

In comparative terms, some points are needed to underline: a) the percentage of public expenditure for cash benefits (0.56 percent of GDP) is the same as the sum of the expenditure on home (0.25 percent of GDP) and residential care services (0.31 percent) (Figure 2), b) 0.81 percent of the GDP out of the total of 1.12 goes to care provided in the community (services in kind + companion payment), c) the private family expenditure for employing migrant care workers (0.59 percent) is more than double as high as the total public resources allocated for home care (0.25 percent)\textsuperscript{27}. These data describes a country where the public effort is low and it is mostly devoted to provide a cash benefit used to hire migrant workers and/or to stay within the family.

**TABLE 7.3**
Public and private expenditure for LTC inputs for over 65 year old people (as percent of GDP), 2008

<table>
<thead>
<tr>
<th>Component</th>
<th>% GDP</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total public expenditure by layer of government in charge</strong></td>
<td></td>
</tr>
<tr>
<td>of which:</td>
<td></td>
</tr>
<tr>
<td>- State (companion payment)</td>
<td>0.56</td>
</tr>
<tr>
<td>- Regions (health related inputs)</td>
<td>0.43</td>
</tr>
<tr>
<td>- Municipalities (personal social services)</td>
<td>0.13</td>
</tr>
<tr>
<td><strong>Total public expenditure by main typologies of care inputs</strong></td>
<td></td>
</tr>
<tr>
<td>of which:</td>
<td></td>
</tr>
<tr>
<td>- home care in kind</td>
<td>0.25</td>
</tr>
<tr>
<td>- cash benefits (companion payment)</td>
<td>0.56</td>
</tr>
<tr>
<td>- residential care</td>
<td>0.31</td>
</tr>
<tr>
<td>Family expenditure for hiring migrant care workers (2008)</td>
<td>0.59</td>
</tr>
</tbody>
</table>


It is also interesting to locate the LTC public expenditure in the context of the overall public budget. It is 1.13 percent of GDP, while the public expenditure for social protection is 25.8 percent of GDP and the overall public expenditure 49.1 percent of GDP. Another way to capture the situation is to

\textsuperscript{27} Many families deploy the companion payment in their own private expenditure.
ask: “How much of the welfare expenditure is used for LTC?” a question whose answer is “0,4 percent of the GDP”, or even 0,2 percent considering only in-kind services (Table 7.4). The little public effort in this field is confirmed by the comparison with the situation in other European countries.

**TABLE 7.4**
Components of public expenditure, Italy, 2007

<table>
<thead>
<tr>
<th>Expenditure items</th>
<th>% GDP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long term care (of which services)</td>
<td>1.12 (0.56)</td>
</tr>
<tr>
<td>Health care</td>
<td>6.7</td>
</tr>
<tr>
<td>Pensions</td>
<td>14.0</td>
</tr>
<tr>
<td>Social protection</td>
<td>25.8</td>
</tr>
<tr>
<td>Total Public expenditure</td>
<td>49.1</td>
</tr>
<tr>
<td>Long term care as welfare % (services only)</td>
<td>0.4 (0.2)</td>
</tr>
</tbody>
</table>

Source: Author’s own elaborations on Ragioneria Generale dello Stato, 2009.

### 7.4. How is home care organised?

The role of home care inputs in kind in long-term care policies is increasing but still limited. Different payments for care are of growing relevance: The companion payment – a national measure - is the main policy to support elderly in the community and in most of the country local health authorities and Municipalities deliver also their own – locally arranged – care allowances. Furthermore, many families rely on the privately paid care provided by migrants, often deploying the payments for care to pay for (part of) their salaries.

Looking at the provision of services in kind, home care includes both health and social welfare aspects but most of the inputs provided are health ones. With respect to the various levels of government, central government is in charge of the companion payment and does not have responsibilities for services in kind. It is to stress that the central government does not have any kind of role concerning the quality, provision and organisation of home care. It means that the central government does not provide any kind of rule and guideline regarding the eligibility criteria, the quality of care and the amount of care provided, nor it has any role in monitoring them. In home nursing and in all the other health related care, eligibility criteria, quality and amount of care provided are responsibilities of the 20 regional governments and are delivered by the Local Health
Authorities. In home help, they are responsibility of the more than 8,000 Municipalities (Da Roit, 2007).

Currently, in Italy some 60 percent of the users of publicly funded long-term home care services receive it from the contracted-out providers. Most of the contracted-out providers are non-profit, but the percentage of for-profit ones is increasing. This is a gross estimation but there are not more precise data available. The features and rules of the contracting out - i.e. how the contracting out works, what the criteria to select private providers are and how is the quality of care actually provided monitored - vary substantially between regions and between municipalities.

The introduction of vouchers and “quasi-markets” in publicly funded home-care has been widely discussed over the last 15 years, both at political and academic level. The idea is to have several providers that compete with each other in order to be chosen by users and families. “Quasi markets”, nevertheless has been introduced only in a few areas. Among the regional governments, only Lombardia has introduced, in 2003, a voucher system in Adi. Users can choose one among different providers. The interest in “quasi markets” has now decreased and they are not likely to spread in the incoming future.

7.5. How is home care financed?

Health care inputs consumed by ADI are covered by the Local Health Authorities’ budgets based on capitation formula. This means that ADI services are free for users and delivered only according to the claimants’ needs, no co-payments are requested from users. All health care provided within the Italian National Health Service is free of charge for people aged 65 years and over. Health care is funded by the Regions, through both the funds they receive from the National Health Service and their own regional taxes.

Home help provided by social services has been characterised by a widespread introduction of charges and, increasingly, means-testing over the last decade. Social services are funded by the Municipalities, through the funds they receive from the State and their own local taxes.

The indennità di accompagnamento (companion payment) is financed by the national government and addressed to all severely disabled people, regardless of age. It is neither linked to contributions nor means-tested. It is provided locally (by Local Health Authorities) according to claimants’ needs and financed out of general taxation. Older people who are assessed as non self-sufficient (i.e. find themselves unable to walk without the permanent help of a companion or are not
able to carry out the activities of daily living life, need continuous assistance and are not in residential care) are entitled to the care allowance on the sole basis of their disability.

Figure 7.1 provides an overview of the funding and payment system of the Italian long-term care system, concerning both care in the community and residential care.

FIGURE 7.1
The funding and payment system of the Italian long-term care system

Source: Agenas, 2009.

7.6. How is home care provided?
Some 82 percent of the overall public expenditure devoted to care in the community (cash and services in kind) go to the indennita’ di accompagnamento. Most of the elderly – official data on it are not available – use the indennità in order to pay migrant workers that provide care. As previously stated most of the Municipalities and of the Local Authorities provide their own care
allowances. Of the 5.1 percent of users of services in kind 3.3 percent receive home nursing and/or others health related inputs; they receive on average 24 hours of care per year.

Up to now, the paper has referred to Italy has one territorial entity. Actually there is a high degree of regional and local variations with respect to the percentage of older people receiving LTC. Not only is there a greater provision of services in the Centre-North than in the South, but even within each Region the provision of care differs substantially between Municipalities and between Local Health Authorities. With respect to services in kind, not only the percentage of elderly recipients varies but also the organisational arrangements change a lot among the Regions and among the Municipalities. Figure 7.2 shows the overall home care coverage (integrated home care, Adi + home help) as users per population 65 and older in the different Italian regions (Longo and Tanzi, 2010).

FIGURE 7.2
Home care coverage (users per population 65+), Italy and Regions, 2008

![Home care coverage graph](image)

Source: Costa-Font, 2010.

Figure 7.3 looks at the balance between home care and residential care. The definition of a balance between the two service categories is one of the first LTC policy options to be decided about. Figure 7.3 graphically describes the current situation in Italy in this respect, by crossing the share of
older people receiving home care services (the sum of integrated home care and home help users) with the one of users in residential care. As the Italian situation does not seem to fully reflect the international context (as reported for example in Huber et al, 2009), according to which the increase of one type of care usually corresponds to an increase in the other one (and the other way around), Italian regions can be distributed in four models:

- regions with a “balanced development”: both home and residential care are above national average (top quadrant on the right), in particular Emilia-Romagna and Veneto;
- regions with a “home care prevalence”: reporting above average home care and below average residential care (top quadrant on the left), e.g. Umbria and Molise;
- regions with a “residential prevalence”: reporting the opposite situation (bottom quadrant on the right), in particular Piedmont;
- regions with a “weak supply”: both shares are below average (bottom quadrant on the left), most southern regions.

FIGURE 7.3
Share of older people in home and residential care in Italian regions, 2007-2008

Source: Author’s elaboration on NNA, 2009.
All previously analysed regional data have so far referred exclusively to in-kind services. In the following analysis data on in-kind users is crossed with data on older recipients of the national care allowance, the companion payment (figure 7.4). Most regions are in two quadrants. The first, on the top left side, shows a low number of service users combined with a high number of care allowance recipients: this quadrant contains most Southern regions, where the care regime is mainly monetary-based and care allowances often are used to compensate for the lack of policies against poverty and unemployment. The other quadrant, at the bottom on the right, shows those regions with a low number of care allowance recipients and above average service users, thus reflecting a situation of a mainly service-based welfare system.

### 7.7. Who are the carers?

In Italy, the families supply the bulk of the care for the dependent elderly, as informal caregiving is mostly provided by wives and daughters. Only to a minor extent, older people can rely on formal private and public services. Informal care is provided mainly for housekeeping tasks, for organising
care and for ensuring psychological and health support. The latter area of health care is also the one in which public and private services are most present (figure 7.5).

In this context, the care provided by migrant workers has become crucial. They are mostly women privately hired by families to care for and support their dependent older members. Indeed, in all activities except for the provision of health care, their contribution is more important than the one granted by “formal” services of public and/or private organisations.

FIGURE 7.5
Severely dependent over 65 years\(^{28}\), according to the type of care received, Italy, 2007 (%)

The reasons why in Italy it has become so popular to privately employ a migrant care worker are many (Lamura et al., 2010). First of all, this has happened because the increasing demand for elder care has been sustained by an ever decreasing availability of family carers, who in Italy still

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\(^{28}\) This term refers to those who, in order to satisfy the different mentioned needs, has to completely rely on someone else. The figure shows the number of totally dependent older people who are helped by close family members (pale grey bars), by other members of the wider familiar and friends network (squared bars), by private migrant care workers (vertical bars) and by public or private “formal” care providers (dark grey) (EUROFAMCARE data as reviewed by Lamura et al. 2008).
maintain however strong “familistic” attitudes. Moreover, the analysis of the rates of coverage of LTC services in Italy reveals the prevalent role played by the public cash benefits in comparison with the provision of services in-kind (see above). The share of recipients of the national care allowance (companion payment) is indeed much higher than that using home care or residential care. Summing all cash benefits granted at national, regional and municipal level, many dependent older Italians can count today on a supplementary amount of up to 1,000 Euros per month (which is close to the average income of an older Italian living alone). These allowances are not, or only partly, means-tested and can normally be used freely, and represent a clear public incentive to the private employment of migrant care workers (Bettio, Simonazzi and Villa, 2006, Ranci and Pavolini, 2008).

With respect to formal care, it is to distinguish between home help (Sad) and health-related home care (Adi). In home help, a social worker is in charge of the the assessment and of the care plan, and the actual care is provided by Asa (Assistenti socio-assistenziali, Care workers). Social workers attend a 3 year training and Asa a 1 year training. In health-related home care (Adi), a nurse and a social worker are in charge of the the assessment and of the care plan. The actual care is provided mostly by OSS (Operatori socio-sanitari, Care and health workers) and partially by nurses and physiotherapists. Both nurses and physiotherapists attend a 3-year-training and Oss attends a 1-year-training.

7.8. How is home care governed and regulated?

Home nursing and the other health related inputs are provided according to needs, irrespective of the financial conditions of the claimants. The eligibility criteria and rules concerning quality are set at Regional level. Home help is both means-tested and needs-tested, with in most of the cases a fee to pay. Eligibility criteria and fees are set by the municipalities.

Most home help provision is currently contracted out, and the externalisation is taking increasingly place in domiciliary health care as well. The majority of private providers are non-profit organisations, but the number of for-profit providers has constantly increased in recent years. Currently, in Italy more than 50 percent of the users of publicly funded long-term care services receive care from the contracted-out providers, both in residential care and home care. There are no national data available and the regional data are not comparable.
A much debated issue of the last 15 years has been the possibility to introduce a “quasi-market” system in home care. Both the Italian political debate and the academic literature have widely discussed the pros and cons of the introduction of a publicly funded system with several providers in competition and users that can use a voucher in order to choose the one they prefer. This system, nevertheless, has been actually introduced only in a few areas. Among the regional governments, only Lombardia has introduced, in 2003, a voucher system for most of the domiciliary health related inputs (ADI). An evaluation has showed that this system has faced a number of problems in working with respect to the real freedom of choice for the users, the actual interest of the users in it, the quality of the care provided and the rise of the public expenditure (Gori, 2010). In fact, since 2006 the regional government of Lombardy has progressively introduced a number of changes that has brought the system partially back to a contracting-out model.

With regards to the private service providers, the non-profit providers still dominate the market, as previously stated. Over the recent years, however, there has been an increase of the number of for-profit providers. There are no data regarding the number of the for-profit providers since for-profit sector still has a small share of the market. Most experts agree that it will increase further.

7.9. How is the quality of home care assessed?

The debate and the research on the quality in long-term care services have advanced substantially over the last decade in Italy. As in most European countries, the focus has been mostly on the quality in residential care, even though quality in home care has been increasingly discussed in recent years. With respect to the regulations and policy, the situation is quite different across the country. The central government is not responsible for setting up rules regarding quality in home care. With respect to residential care, the central government set in 2001 guidelines concerning the minimum level of quality to ensure across the country and some regional governments in the South, where the welfare system is less developed, have used it over the years as a point of reference. The responsibility for setting quality frameworks in home care is entirely in the hands of the regional governments. Overall, the level of quality assured varies extremely, both in residential care and home care, among the 20 Italia Regions.
7.10. How are the policy changes overall related to outcomes for the users?

There is no evidence available at national level looking at whether, and to which degree, users appreciate the companion payment and have appreciated the huge growth in its provision over the last decade. More in general, the companion payment is utterly under-researched in Italy.

There is, instead, some evidence at national level regarding home care services in kind and their role in the overall long-term care system. Some Eurobarometer data, in fact, allow us an insight view of it. Some three adult Italians out of four reckon that care of the frail older people requires their relatives a too high commitment. Also in most of the other European country the majority of people share this view, but not to the degree of their Italian fellows (table 7.5). Consistently with these latter evidence, Italy is one of the European country with the lower percentage of people thinking that the public provision of home care services for frail older people is adequate (table 7.6).

On the other hand, most of the Italian adults think that children should pay for the care of their frail older parents if the economic resources of the latter are not enough, a view shared only, in Europe, by the other Southern European countries (table 7.7). This is an indicator of a wider feeling – shared by the majority of the Italian population – that care of the frail elderly is first of all, and predominantly, a responsibility of the family. We notice here that in the attitude of the Italian population towards home care and long-term care more in general two different views coexist, that are not entirely consistent one with the other. In fact, most of the Italians think that a much public provision of home care is needed and most of the Italian also think that care of the frail elderly is a responsibility of their children.
TABLE 7.5
Do you think that care of the frail older people requires their relatives a too high commitment? EU Countries, 2007

<table>
<thead>
<tr>
<th>Country</th>
<th>% of adult citizens that agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denmark</td>
<td>42</td>
</tr>
<tr>
<td>The Netherlands</td>
<td>58</td>
</tr>
<tr>
<td>France</td>
<td>61</td>
</tr>
<tr>
<td>Ireland</td>
<td>62</td>
</tr>
<tr>
<td>Germany</td>
<td>63</td>
</tr>
<tr>
<td><strong>Italy</strong></td>
<td><strong>75</strong></td>
</tr>
<tr>
<td>Portugal</td>
<td>82</td>
</tr>
<tr>
<td>Bulgaria</td>
<td>95</td>
</tr>
</tbody>
</table>


TABLE 7.6
In your country the supply of public home care for the frail older people is adequate? EU Countries, 2007

<table>
<thead>
<tr>
<th>Country</th>
<th>% of adult citizens that agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belgium</td>
<td>58</td>
</tr>
<tr>
<td>Germany</td>
<td>53</td>
</tr>
<tr>
<td>The Netherlands</td>
<td>53</td>
</tr>
<tr>
<td>France</td>
<td>32</td>
</tr>
<tr>
<td>Sweden</td>
<td>42</td>
</tr>
<tr>
<td>Spain</td>
<td>24</td>
</tr>
<tr>
<td><strong>Italy</strong></td>
<td><strong>23</strong></td>
</tr>
<tr>
<td>Ireland</td>
<td>16</td>
</tr>
</tbody>
</table>


TABLE 7.7
Do you think that children should pay for the care of their frail older parents if the economic resources of the latter are not enough? EU Countries, 2007

<table>
<thead>
<tr>
<th>Country</th>
<th>% of adult citizens that agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spain</td>
<td>69</td>
</tr>
<tr>
<td><strong>Italy</strong></td>
<td><strong>68</strong></td>
</tr>
<tr>
<td>Portugal</td>
<td>55</td>
</tr>
<tr>
<td>France</td>
<td>48</td>
</tr>
<tr>
<td>Belgium</td>
<td>43</td>
</tr>
<tr>
<td>Germany</td>
<td>31</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>24</td>
</tr>
<tr>
<td>Sweden</td>
<td>15</td>
</tr>
</tbody>
</table>

7.11. National focus - The main policy change of the decade 2000-2010: the growth of the companion payment

The biggest policy change of the last decade has concerned the ‘companion payment’ \((\text{indennità di accompagnamento})\), that – as previously stated - is a payment available to severely disabled people, regardless of their age, based on an assessment of their needs. It is paid irrespective of the claimant’s financial conditions and financed by the central government through taxation. It is available to people who are totally (100 percent) disabled because of physical or mental ill health, who cannot walk without the help of a companion, or who need constant assistance due to their inability to carry out everyday tasks. It amounts to 487 Euros a month for all the users (whatever the needs). Claimants apply to their Local Health Authority which decides whether they meet the (vague) eligibility criteria set by national legislation. The payment enables the disabled person to buy commercial services or can be passed on to care-giving relatives; there is no control over its actual use and no care plan is made. The indennità is completely detached from the provision of in-kind services.

The indennità was first introduced in 1980 for disabled people aged below 65 and was extended to the over-65s in 1988, although some of them started receiving it before that. In 1984 2.7 percent of the older people received it and this percentage rose to 5.0 percent at the beginning of the nineties (1991) (figure 7.5). A decade with no significant increase – the percentage of users was 5.5 percent in 2001 – was followed by a period of enormous growth (2001-2008) in which the percentage of elderly users grew to 9.5 percent (figure 7.6). The percentage of older people receiving it rose from 6.0 percent (2002) to 7.7 percent (2005) and to 9.5 (2008), ie it rose by 58 percent in seven years between 2002 and 2008 (table 7.8). The increase in the size of the users’ group was not the outcome of any change in the policy design, as there was actually no change in the features of the companion payments at all.
FIGURE 7.6
Percentage of older people (65+) receiving the “companion payment” (indennità di accompagnamento)


TABLE 7.8
Older people receiving companion payment, percentage of population 65+ and percentage of the increase since 2002.

<table>
<thead>
<tr>
<th></th>
<th>2002</th>
<th>2005</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage of the 65+ receiving the companion payment</td>
<td>6.0</td>
<td>7.7</td>
<td>9.5</td>
</tr>
<tr>
<td></td>
<td>(+ 28%)</td>
<td>(+ 58%)</td>
<td></td>
</tr>
</tbody>
</table>


Some three out of four companion payments’ recipients are older people. The percentage of 65+ receiving it rose by 58 percent in six years, from 6.0 percent (2002) to 9.5 percent (2008), while the design of the benefit did not change at all. It was an unintended transformation that turned actually out to be the main change of the decade in the Italian public long-term care system. Several reasons explains why it happened. They concern how needs and demands have been changing, the features of the Italian Long-term care policies and the traits of the overall welfare state as well.

The increase of the elderly population. Within the older people, the speed of the enlargement was particularly high in the group of those aged 75 and over (+23 percent from 2002 to 2009)\(^{29}\) who – within the older people - are the main users of the companion payment.

\(^{29}\) In the same period, people aged 65-74 increased by 6 percent.
The spread of information and awareness. In the past the information on the national companion payment was quite restrained among older people and their families. Many, furthermore, did not believe that they could be entitled to a non means-tested cash-transfer because of disability; they believed that welfare entitlements concerned exclusively pensions, health care and poverty. The take-up ratio, therefore, was quite low. In the last decade information has widely spread and new generations of older people are more aware of their rights. Even if this phenomenon cannot be measured, there is a widespread consensus among the experts that it had a key role in raising the take-up ratio.

The increasing number of migrant workers. Over the last decade, the number of migrant workers has risen enormously and the indennità is the main benefit that can be used by families to remunerate them. The tax allowance to support privately paid care, in fact, amounts only to some 10-15 percent of the indennità and, in addition, the tax allowance can be used only with formal employment while the “companion payment” can be received even if the assistant is not regularly employed (as it is often the case). The need to pay for the migrant care workers has pushed an increasing number of families to look for public economic support to bear the costs of it and, in turn, to apply for the companion payment.

The scarcity of home care services. The spread of migrant care workers is linked to the lack of an adequate provision of services in kind. Their scarcity is a trait shared by the all the areas in the country, even if to different degrees. Furthermore, the supply of home care is mostly made of the Assistenza Domiciliare Integrata (ADI), ie health related inputs (nursing, physio), whereas the provision of social care services is particularly small. The only public support for social care ADL (Activities of Daily Living) needs, thus, is for the utterly majority of the older people the companion payment.

The weaknesses of the policies against poverty and unemployment. The comparative analyses prove that in Italy the policies against poverty and unemployment are weak and underfunded (Eg Eurostat, 2009). In the past other disability benefits have been used, to a certain degree, as hidden unemployment benefits/income support; especially in the poorest areas of the country (some Southern Regions). Apparently, in the last decade the companion payment has been increasingly used in this not appropriate way, ie provided to an older person and used to support the unemployed son or daughter.

Even if this trend looks quite consistent, it is to deal with caution. In fact, in the South of the country the disability rates are higher than the national average (a finding consistent with the fact
that there the degree of education and the income are lower). Nevertheless, the higher disability rate explains only partially the higher number of users.

- **The lack of a national assessment tool.** There is not a national assessment tool to figure out who can receive the companion payment and who cannot according to clear eligibility criteria. The law states that the *indennità* is provided to those “who cannot move without the help of a permanent assistant” and/or “needs a 24 hours assistance even if he or she can make some small daily actions”. It does not go further and leaves, thus, a huge degree of discretion in the hands of the professional assessing the claimants at local level. It is, thus, possible for them to discretionally widen the number of users while complying with the formal rules.

- **The institutional incentives.** The companion payment is financed by the State, with no budget ceiling while the Regions (through their Local Health Authorities) to decide whether or not the claimants can receive it. As the Regions don’t pay for it, they have an incentive to accept the applications. The mechanisms has been partially modified at the beginning of 2010, with effects still unclear (Gori, 2010).

**7.12. Conclusion**

In Italy, since the beginning of the 90s all the experts have underlined the negative consequences of a welfare system too focused on the cash provision. It was widely expected that a change in the balance between cash and care would take place. Instead, the change has not occurred and the provision of cash benefits has grown more than the services in kind actually did.

In order to develop home care services in kind, a national reform was needed. In fact, services in kind are responsibilities of Municipalities and Regions, that cannot bear anymore the pressure due to the increasing demand of services. The State, instead, has never been involved in funding services in kind and there is huge consensus among experts that it should promote their development (mostly at home). The national reform, nevertheless, has not occurred and this is most due to the lack – in the national politics – of a political constituency concerned with care in kind.

On the other hand, companion payment rose from 6,0 percent (2002) to 9,5 (2008) of older people aged 65+ receiving it, ie by 58 percent in seven years, without any political choice in that direction but due to a number of pressures discussed above.
7.13. References


8. Home Care in Norway

Mia Vabø

8.1. Introduction

Home care in Norway forms a significant part of a universal health and social care system. Various forms of home based care, involving nursing care, personal care and practical assistance are available on a universal basis, dependent on need and not on age or ability to pay. No applicants are excluded a priori on the basis that they should make their own provisions or that their families are expected to provide for them.

The Norwegian public home care system emerged in the early 1960s as a part of an elderly care policy aiming at avoiding segregation among older people. A core idea of the post war policy was to enable people to participate and take an active part in society in spite of infirmity and old age. Together with improvements in the pension systems and better housing standards, home care provision was believed to prevent social exclusion and passivity of older people. It was also argued that home care was good for the elderly because it would postpone institutionalization, and because it would ensure older people good contact with their own family and with the community as a whole.

Ever since home care became a part of public welfare provision in the early 1960s, volume of service provision, mix of service elements and organizational arrangements has been in a process of change. This paper addresses these changes and explore (1) how the role of home care in Norway has changed from a preventative role stressing practical and social care for elderly with moderate care needs towards a more medicalized role providing personal care and nursing care for the most frail, disabled and chronically ill (old and young). Further, the paper explore (2) how modes of governance, pushed by competing drivers of change, have gradually changed the home care organization (see also Vabø, 2009). The paper finally focuses on some contemporary strategies and schemes aiming at attracting and retaining staff and of providing a high quality and user oriented care service. But first a few words about the legal framework of the home care service.

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31 In this chapter, the concepts ‘home based care’ ‘home care’, ‘home nursing’ and ‘home help’ refers to a publicly funded and mainly publicly provided needs tested service, regulated by a piece of social legislation.
8.2. Legal framework

Home care in Norway forms a part of a comprehensive infrastructure of public health and social care services. The National Health Plan for Norway (2007-2010) states that services of high quality should reach out to everyone regardless of their financial situation, social status, age, gender, and ethnic background. Furthermore, the plan states that proximity and local knowledge provide the best opportunities to achieve individually adapted service provision and user influence. Hence, the government upholds a multi-level model of the health and social care system where hospitals (national level) have their role tightly confined to medical interventions that cannot be efficiently or safely performed in the community whereas municipalities (N=430) are assigned the responsibility for primary health care and for long term care, i.e., various kinds of institutional care (nursing homes and special housing) and home-based care. Long term care constitutes a comprehensive sector within Norwegian municipalities—2/3 of the municipal spending for long term care amounts to approximately 2/3 of costs in the hospital sector which is 2.14 percentage of GDP.

The Municipal Health Service Act (1982) requires municipalities to provide ‘essential medical services’ to all inhabitants and the Social Service Act (Act 1991) requires municipalities to provide ‘essential practical help’ for inhabitants who are not able to care for themselves.

Even though municipalities are (increasingly) influenced by central government through judicial acts, funding, instructions, guidelines, and accountability arrangements, Norwegian municipalities are free to organize their services in the way they find most adequate. The profile and mix of care services offered to the elderly people in Norway vary greatly between different municipalities (Huseby & Paulsen, 2009). To day most municipalities offer home care services available around the clock. Nursing care, personal care and domestic care constitute the core services of home-based care, but other services are also offered such as meals on wheels, alarm services, respite care, home counseling, occupational therapy, physiotherapy, heavy cleaning and janitorial services.

8.3. The changing role of home care in long-term care

Along with a range of welfare arrangements home care in Norway expanded greatly in the first decades after World War II. Voluntary associations of women played a ‘push role’ for this development, and their own care activities were gradually assimilated into public welfare programs and turned into paid work. The development of municipal home care services brought about a new
historical situation for frail elderly who now could choose to stay in their own home even with increasing care needs, instead of being forced to move either to their children or to an old age home. Surveys carried out between the late 1960s and mid 1980s indicate that older people increasingly preferred public rather than family help, even when children were living close by (Daatland, 1990).

In the first era from 1965-1985, state funding was generous and the reimbursement system acted as an incentive to expand home care provision. In 1980, the number of home care recipients was four times higher in than in 1965. (Vabø, 1998). Home help (domestic help) covered 16 percent and home nursing 12.4 percent of the population 65+.

In 1986 legislative changes delegated the responsibility for a wide range of services to the municipalities with the aim of encouraging an integrated approach to the supply of care. The idea was to offer people a health care arrangement where medical treatment, rehabilitation and care were weaved together in a cohesive continuum. Accordingly, home services, which were traditionally divided in two segments – home help (domiciliary care and social support) and home nursing (personal care and nursing care) became more or less integrated.

Ironically, the decentralization reform was proclaimed at the same time as concerns about the economy began to emerge (Seip, 1991, p.41). As the previous reimbursement system based on earmarked grants from central to local state was then replaced by block grants, municipalities experienced that resource allocation became stricter. In the following years, the volume of home help (domestic care) levelled off, in covering approximately 16 % of the population 67+ both in 1980 and 1990. (Daatland, 1997, p 40). Still the gross expenditure per person 65+ on home based care was almost doubled between 1980 and 1982 (Daatland, 1997, p 35), mainly because home nursing (which at that time became more or less integrated with home help) took over some of the task earlier performed in institutions. Home nursing measured by number of full time employed equivalent per person 65+ increased from 0.1 percent in 1970, 0.4 percent in 1980 and 0.8 percent in 1992 (Daatland, 1997, p 36)

In the years after the decentralization reform, the role of home care service gradually changed from a preventive role aiming at postponing institutional care for elderly people toward a role of providing, rehabilitation, medical assistance and nursing care for the frail and sick elderly and terminally ill. This changing role must be seen in relation to the declining volume of institutional care in the late 1980s. This trend can be illustrated by the fact that the proportion of residents 80+ in institutional care homes/nursing homes increased steadily from 52 percent in 1960,

32 Daatland (1997) note that statistics changed in 1994 and figuers on user rates before and after 1994 are not directly comparable.
through 56 percent in 1970, 64 percent in 1980 to 73 percent in 1997 and 77 percent in 2005 (SSB, 2010). The fact that beds in institutions are increasingly reserved for the oldest old may to some extent be explained by better health among the elderly. But it also reflects higher housing standards in general and higher level of special service housing and expansion of community service, such as home nursing.

In line with the aging in place policy, substantial investments in care for the elderly was made by the turn of the century, including the building of sheltered housing/service housing (omsorgsbolig) which are intermediary solutions between ordinary nursing homes and retirement flat. Among the 49 000 people who lived in these kind of facilities in 2006 only 5 percent were younger than 67+. However, only 1/3 of them lived in a staffed service house (Otnes, 2007) whereas the remaining received ordinary home care i.e. home nursing and home help.

Statistical data indicate that the shift of focus from institutional care to home care is prominent. As demonstrated in fig. 8.1, the percentage of man-labor years in institutional care decreased from 67,2 percent in 1987 to 46,2 percent in 2007, whereas in the same time span the percentage of man-labor years in home based care increased from 32, 8 percent to 53, 8 percent. It should however be emphasized that some of the service houses staffed by the home care service may be very similar to traditional nursing homes. Accordingly, the distinction between institutional care and home care has become blurred and therefore the development is probably less radical than the statistical data indicate.
FIGURE 8.1
Number of man-labor years in institutions and home care 1987-2007, percentage.

Source: Statistic Norway analyzed by Brevik, NIBR

*What is home care, and who are the users?*

As mentioned at the outset two different service elements have traditionally been included in home care – that is home help (domestic tasks such as shopping, cleaning, laundry and social support) and home nursing (around the clock) which involves also personal care including bathing, managing bodily functions and preparing meals. In recent year, we have seen a growing specialization within home nursing. Some home care agencies offer psychiatric nursing and/or intensive care nursing for people with severe and unstable health conditions.

In addition to the two core service elements of ‘home care’, most municipalities offer meals-on-wheels, counseling, handy man service, alarm service, physiotherapy, respite service etc. If these services were included in the concept ‘home care’, user rate among elderly will increase by 10 percent (Otnes, 2010).

The amount of home are provided for individuals vary greatly with needs. In recent years a register with individual encrypted information about all recipients of care in Norwegian municipalities (IPLOS) give us information about the average hours of home care per week. This new statistics tell us that the average number of hours for elderly people 67+ with extensive needs is
15 hours, for people with average/ much needs 5 hours and for people with small needs 2 hours for assistance. (http://www.ssb.no/pleie_en/tab-2010-07-08-07-en.html)

Home nursing (personal care and nursing services), regulated by the Health Service Act (1982) is free of charge, whereas municipalities are relatively free to charge people for home help (practical help such as laundry, cleaning and gardening). However, user fees should not exceed full costs (services should be non-profit) and low income earners (i.e., people with the lowest pension level) should never pay more than NOK 150 per month (approximately 20 EURO). Most municipalities have an income graded fee for home help (practical help). However, the way in which user fees are determined and the level of payment vary greatly between municipalities (ECON, 2006).

User rates in home care have increased by 17 percent from 1992 to 2009. However, the increase is mainly in home nursing and home nursing/home help in combination; the number of people who receive home help (domestic help) only, has decreased by 35% in the same period of time (http://www.ssb.no/pleie_en/tab-2010-07-08-05-en.html). It is also striking that user rates among people 67+ has declined, whereas user rates among younger people has increased (see fig. 8.2). In 1992 the user rate among elderly 67+ was 19.4 percent; in 2009 it was 17.3 percent (SSB 2010). Even though governments have promised to secure that “more hands” are provided for frail elderly, additional budget allocations have de facto favored the younger disabled (see fig. 8.2). After 2006, this trend has increased. Today 60 percent of the service volume in home care is provided for people aged 67 and younger. The scope of home care services has expanded – services are not anymore regarded to be a part of ‘elderly care’ only, but are increasingly regarded an option for people with disabilities, chronic diseases, drug addicts and psychiatric patients. In addition people who are terminally ill (i.e., cancer patients) are the responsibility of home care as many people prefer to receive terminal care at home rather than in a hospital.
FIGURE 8.2
Home based care, number of elderly users 67+ and users younger then 67, 1989-2006

Source: Statistic Norway, analyzed by Ivar Breivik at NIBR 2009

The difference in service volume between young and old care recipients is in particular evident among people with extensive care needs\(^{33}\). The average number of assigned hours pr week among people aged 18-47 years with extensive needs was 58 whereas among those aged 67-79 the average number was 17.3 and among those aged 80-89 only 12.7.

(http://www.ssb.no/pleie_en/tab-2010-07-08-07-en.html) These contrasting figures probably indicate that younger people to a larger degree are expected to live an independent, active and outgoing life.

Concerning younger disabled, it should be mentioned that most municipalities offer practical assistance through ‘user led personal assistance’ – BPA (Brukerstyrt personlig assistanse). However, BPA is rarely used in care for the elderly. In 2009, 2,535 persons received personal assistance; only 7.7 percent was aged 67+.

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\(^{33}\)Extensive needs’ is based on the definition used in Norwegian National statistics linked to individual needs for care, IPLOS. IPLOS is a register with individual encrypted information about all recipients of care in Norwegian municipalities. The functional disability level of each care recipient is determined based on their score on 17 indicators concerning their ability to cope in everyday life.
**Home care staff**

Compared to the other Nordic countries public care provision in Norway is regarded to have a more medicalized profile. In Norway, 18 percent of care staff is registered nurses. The number of registered nurses in Sweden is only 5 percent, in Denmark 10 percent and Finland (closer to Norway) 15 percent. (Szebehely, 2005) Whereas front line managers and care assessors in Sweden are social workers, they are typically registered nurses in Norway. In a typical 24 hour urban home care team (on week days) 1/3 of staff are registered nurses and almost half of the staff are auxiliary nurses (Econ 2009). Among the remaining lower skilled or unskilled care workers there are a substantial number of immigrants, in particular in urban areas. Homme & Høst (2008) found that 1/3 employees in the care sector of Oslo are immigrants.

**Family help and home care**

As mentioned earlier, frail elderly Norwegians generally prefer public rather than family help. Still, research into the home care sector reveal that the responsibility for elderly living at home de facto was based on a shared responsibility between public and private (family) care provides. A widespread substitution theory stating that families are inclined to withdraw their care responsibility when public care providers take their place has been rejected. According to Daatland & Herlofson (2003a, 2003 b), the widespread use of home based care (as an alternative to residential care) has mobilized family members to share the responsibility with public care providers. Evidence form surveys indicated that adult children of both sexes provided parents with more practical help than previous generations, although in a different manner. Caregivers were providing less intensive care as care burdens were to a larger extent being shared among siblings (Lingsom, 1992).

Filial obligations have remained strong and care provision is de facto often based on a complementary mix of private (family) and public care (Daatland & Herlofson, 2003). It is normally expected that formal care providers assume responsibility for “hands on care” such as cleaning, personal care and nursing care whereas family members expected to secure that elderly family members live a meaningful life (Daatland et al., 2009). However, tasks are increasingly being offloaded from the public home care services and families may feel pressed to compensate for lack of public help (Vabø & Szebehely forthcoming). Between 1997 and 2005, the number of people who received domestic home help was reduced by 14 percent. In the same time span people who reported that they had received help form relatives increased from 9 percent to 14 percent (Svalund, 2005). The number of people 67+ receiving unpaid care from family and friends has
increased since 1985 and more than half of those who regularly receive help from relatives, friends and neighbours reported that they also receive formal home care (Otnes, 2010:138).

Norwegian municipalities are obliged to offer care salary for family members as a substitute for home care services. However, nobody is entitled of such benefit by law and hence eligibility criteria vary greatly between different municipalities. Statistics indicate that care salary is most commonly offered to and used by parents of disabled children and only rarely by spouses of elderly. In 2009, 9,121 people received care salary; only 19 percent was aged 67+.

Local variations

In Norway financing care for the elderly and disabled is the responsibility of municipalities, although with a considerable co-financing from central government (approximately 50/50 local and national tax funded).

As mentioned earlier Norwegian municipalities are required by law to provide care for all citizens who are in need of medical assistance and/or who are completely unable to manage daily tasks. However, municipalities are free to organize services in the way they find adequate. Comparison between municipalities reveal that municipalities are characterized by different service profiles, ie by different balance between nursing homes, home care and service housing and also by different level of funding. The lowest level of municipal funding is NOK 34,500 per person 67+ whereas the highest level is 182,000 per person 67+ (Huseby & Paulsen, 2009) It should however be noted that most municipalities are clustered in the middle between these extremes; and should also be noted that variations in funding between different municipalities may be explained by the fact that municipalities are different in several ways. They may for instance have different population composition (high or low number of elderly people), different population density then also long travel distances for home care staff. Moreover, the figures do not take into consideration that some municipalities may add more resources to the care sector through user fees. To put it short: Funding level is to a large degree explained by different structural conditions and levels of needs. According to Daatland (2009) one should not regard elderly care in Norway as a kind of lottery; most people will have their needs met. This view is supported by surveys indicating that four out of five of recipients of home care regard the service to be good or excellent (Huseby & Paulsen, 2009).
8.4. Home care organization through shifting logics of governance

As already mentioned a comprehensive decentralization reform was implemented in Norway in 1986. As the previous reimbursement system based on earmarked grants was replaced by block grants, municipalities became urged to pay more attention to cost control. The need for stricter priority-setting and targeting of services called for smarter ways to organize services. Like many other European countries, Norway became influenced by the global wave of NPM reforms and (like in many other countries) public sector changes are often talked about as being the only driving force behind change. In line with Wise (2002) I find it important to highlight that also other competing drivers of change have made an impact on public sector institutions, such as the demand for democratization and empowerment, and demand for greater equity. In this section I will outline how the Norwegian homecare service first became influenced by a call for democracy and empowerment and later by the NPM reform integrally intertwined with reforms aiming at social justice and enforceable rights (see also Vabø, 2011b).

The mid-1980s – horizontal decentralization and collaboration

The first era after the decentralization reform in 1986, buzzwords in politics stressed awareness of local problems, flexibility, proximity and user participation (Wærness, 1984). As mentioned earlier, these new ambitious welfare goals were proclaimed at the same time as the number of beds in nursing homes was reduced and responsibilities for frail elderly pushed ‘down’ to the home care sector. The mix of care staff changed as more nursing staff was required.

The typical organizational arrangements for home care in the late 1980s /early 1990s was a decentralized group structure, each group providing care services for the population of a specific geographical area. In order to improve the utilization of caregiver staff, formerly segmented services – home nursing and home help – were more or less integrated. Decision making power within care teams was delegated to front line staff – not only to professionals like nurses and auxiliary nurses, but also to lower-skilled and unskilled home helpers who spent more time with clients and thereby got first hand knowledge of the everyday life of clients. This decentralized structure reflected a belief that care needs were complex and shifting and that the needs assessments and allocation of services should be conducted by those closest to the service recipient.

As municipalities had become increasingly focused on cost containment, several attempts were made to consider whether ‘hidden’ care resources could be mobilized from families and civil society (Daatland, 1997). Steps were taken to enhance civic engagement, volunteerism and self-help
and a number of suggestions for stimulating family care through payment for care, information, support and respite services were suggested (Sosialdepartementet, 1992). People were supposed to be active collaborative partners in the provision of care. Within the self regulated care teams, this policy aim was translated into a working principle labeled ‘help- to-self-help’, a principle presuming that elderly will benefit from being as self-sufficient as possible. Care workers were encouraged to utilize potential coping resources of clients and even to push them to be more self-reliant. Even though these slightly paternalist professional ideals was avoided in some extent, they were sometimes used to justify the need for lower demand for services and to justify that services was kept on a minimum level. Interviews with different stakeholders (users, family members and staff) revealed that disagreements occurred in terms of how well individual care recipients were coping (Vabø, 1998).

_Late 1990s a push towards vertical integration_

Rather contrary to the strategy aiming to transform citizens into active collaborative partners was the view that people in need of care are right holders with clear entitlements. During the winter of 1990, the protests of activist (middle class) citizens turned into a nationwide people’s movement, later known as ‘the elderly revolt’ (eldreopprøret). An increasingly sharp tone for public debate indicated that the social right to services as perceived by the population was strong (Vabø, 2011a). Attention was increasingly focused on entitlements, output and quality of services (rather than on political debates concerning who should get what).

In the years to follow two different (but still intertwined) trends of governance emerged, both of which represented a push toward centralization and vertical integration: One trend was driven by classic bureaucratic values such as predictability, equality before the law, and due process. The Social Service Act of 1991 stipulated that people had certain procedural rights in relation to local care providers; they had the right to an individual needs assessment, the right to make their views known, to receive a written and well-founded decision, and the right to appeal to a higher court. Even though substantive rights to care were still limited (as allocation of care services always will be based on some kind of needs-test), municipalities were now pushed to put on paper what they regarded to be an adequate level of support. Municipalities were also required to be more accountable ‘upwards’ to central government, partly through a new section of the ‘Act relating to the public supervision of health services’ (1984). The new act of 1992 required health and care
services to implement *internal control* (internal audit). Moreover, a sharper focus on internal control in LTC was also promoted by the Quality regulation of 1997 (Sosial og helsedepartementet, 1997). Accordingly the previous self-regulated care agencies were pushed to formalize work routines and performance.

A second trend was driven by the New Public Management movement and the quest for cost efficiency, competition and accountability through contractual and quasi-contractual relations (Hood 1991). Whereas these trends did not have much impact in rural areas, many of the biggest municipalities reorganized their home care service in line with a *purchaser-provider mode*. The model suggested that responsibility for assessing and approving the granting of a contract for services became separated from the responsibility of providing care. At first, the purchaser-provider split was implemented as a necessary step towards competitive tendering. The idea was that the public care authority should tender and purchase services on behalf of the public, and the provider could be either a private agency or a public sector agency operating at arm’s length from the public care authority. Later, many municipalities implemented the model also when they did not plan to tender out services. It was argued that the purchaser-provider split would make them better positioned to demand quality and to control and manage quality. Above all, it was argued that this structural arrangement would improve the ability of municipalities to deal with the new bureaucratic requirements imposed by the central government. It was believed that specialized care assessors would be able to take a more detached view of care needs than the care staff (Blomberg, 2004; Vabø, 2007).

Public debates became increasingly influenced by a market discourse, in particular in electoral campaigns where right wing parties advocated private provision and free choice. However, compared to Sweden and Denmark, Norwegian municipalities turned out to be reluctant to rely on private for-profit providers for care services. Only a few right-wing municipalities such as the city of Oslo and Bergen have implemented free-choice system\(^3\), whereas all the largest municipalities and cities implement some form of purchaser–provider model – even though the municipality did not have plans to tender services out to private sector providers. In these bigger municipalities, responsibilities were being removed from the front-line level and transferred to a specialized purchaser unit within the local authority.


\(^3\) In Oslo the free choice model meant that nursing care and home help (domestic care) were once again separate services. Today 18 percent of home help recipients have chosen private provider. In 2012 the city is planning to implement a system of free choice also in home nursing.
The contemporary hybrid home care organization

The new governance arrangements of the late 1990s suggested a shift of decision making power from front line staff to “overseers” and specialized purchasers. Care provision became talked about as ‘deliverance of goods’ not as communicative and relational work or as moral responsibilities (Vabø, 2007; Haukelien et al., 2009). However, caregiver staff in close contact with care recipients did not meet many citizens acting as consumers or customers. They continuously experience the requirement to deviate from contracts, and to vary staff-time allotments in order to meet unforeseen needs of the frailest elderly (Vabø, 2006). And since the new structural arrangement was put into practice at the turn of the century, it has gradually become recognized that collaboration between purchaser and provider is necessary. A survey among purchaser officials indicates that collaboration between purchasers and providers occur on regular basis (Gammelsæter, 2006). Needs assessors are dependent on the day-to-day observations of care staff to reach a proper decision about needs. Therefore, care staff is expected to report to purchasers when they perceive that time and formal needs decisions are inadequate. They are also expected to respond adequately to unstable and shifting needs. Hence, in practice, the division of responsibilities between purchaser and provider is rather blurred (at least in the case of public providers) Narratives from care staff reveal that care provision is based on a complex mix of predefined service elements and contextual adaptations made by care staff. (Vabø, 2011b)

Even though care staff reports that they are co-responsible for needs assessments, they also report that preconditions for making (re)assessments has been undermined as time resources had been increasingly scarce and pre-structured. Interviews with care staff and care recipients indicate that work schedules leave no extra time slack for contextual investigations. Hence, care staff perceived themselves as responsible doers more than as responsible enablers. They are responsible for providing safe and sound care, but do not (like in earlier days) have the responsibility for making contextual inquiries into the coping capacity of individual care recipients. In addition staff discontinuity makes communication between staff and care recipients complex and communication failures do occur (Vabø, 2011b).

8.5. Contemporary strategies of reform

Despite the optimistic conclusion from user surveys (i.e. Huseby & Paulsen, 2009) the public debate on Norwegian elderly care in general tend to be pervaded by a crisis discourse. Since the
‘Elderly Revolt’ in the early 1990, the right of frail elderly citizens to receive high quality public care has remained high on the agenda. Media-protests and efforts to mobilize a new elderly revolt occur regularly and new associations and ad-hoc organizations have been added to the plethora of associations working for the elderly. Accordingly there is a constant quest for better service quality and thereby also a constant quest for attracting and retaining skilled care staff.

**The constant quest for better quality in care**

The great majority of Norwegian citizen consider that older people’s needs should be a public responsibility. In public debates on elderly care, middle class campaigners are taking on an offensive and confrontational role in fighting for improved quality in care. A telling example is ‘Seniorsaken’ (Senior Matters), an association launched in 2001 by a popular Norwegian comedian, supported by a range of celebrities and people from privileged positions in the media. ‘Seniorsaken’ shares some views with the populist Norwegian extreme right wing party, Framskrittspartiet (the Party of Progress) which, despite its neo-liberal profile, also campaigns for enforceable rights, generous public spending and high quality services. It is argued that since Norway is one of the richest oil-nations in the world, it should be able to provide the best elderly care in the world (!) Both ‘Seniorsaken’ and other associations concerned with the welfare of older people are all committed to an entitlement discourse. Last year, a coalition of six associations for the elderly joined forces to launch a campaign – the Elderly Care Campaign 2009 – working intensively towards the September 2009 general election. The main issue they raised was that of improving the enforceability of citizen’s rights, for instance by suggesting how prevailing quality regulations should be extended and made more concrete.

The call for better quality in care for the elderly is a recurrent issue in public debates in Norway and one of the most decisive issues for Norwegian voters (Vabø, 2011). In response to this public concern, the label ‘quality’ has become ever-present in policy making and is frequently used as a prefix for various measures such as national accountability arrangement, business management and competitive tendering (TQM, out-put control, benchmarking ) as well as alternative anti-market measures based on collaboration between local service providers and trade unions.

All public care services in Norway are regulated by a quality regulation (“Kvalitetsforskriften”) which provides some general descriptions of vital quality aspects – for instance that people should have accommodated help to get dressed/undressed, to decide for themselves when they want to get up in the morning etc. The regulation obliges municipalities to
have plans and written procedures telling how they intend to implement these regulations. The overall responsibility for supervision and monitoring of health services in Norway is the Norwegian Board of Health together with 19 County Medical Officers (CMOs). The Norwegian Board of Health co-ordinates supervision activities carried out by CMOs in each county. The CMOs are making naming and shaming reports based on their inspections. For instance in Asker - a suburban municipality outside Oslo – the CMO recently made a devastating report concerning the local home care service. The municipality got a remark telling that they did not satisfy the quality regulation. The inspection revealed that the municipality did not fulfil the quality regulation in that elderly people with symptoms of dementia did not get a primary contact person. Some of the elderly, who had several visits a day, had more than twenty home helpers during one month. (http://www.helsetilsynet.com/no/Tilsyn/Tilsynsrapporter/Akershus/2010/Asker-kommune-hjemmeboende-)

An important aspect of ‘quality improvement’ and ‘quality management’ concerns various forms of quality assessments. Numerous different indicators are used to measure quality. On a national level quality is measured through KOSTRA (Municipality-State-Reporting), based on rather broad indicators (level of educated staff, sickness absence among staff etc.) (http://www.helsedirektoratet.no/kvalitetsforbedring/kvalitetsindikatorer/nasjonale_kvalitetsindikatorer_6274.) On the local level, municipalities use various forms of quality measures. In Oslo for instance, user satisfaction surveys are conducted every second year. Findings from these surveys are used in benchmarking and associated service development as well as in public debates. However, among scholars they are frequently criticized because they lack sophistication and because they tend to be based on a rather low response (Romøren 2005) rate.

Norwegian municipalities were also encouraged by the national health authorities to follow the recommendations of the National Strategy for Quality Improvement in Health and Social Services (http://www.helsedirektoratet.no/selectedtopics/quality_improvement). By the turn of the century, all local care providers were encouraged to have their quality assured. Quality initiatives were, however, not based on a specific methodology or method but rather on an abstract and general management conception, like the idea of total quality management (TQM), a multi-facetted concept originally formulated in the car industry.

Although the enthusiasm for improving quality has been great, the concept is slippery and the meaning elusive (Vabø, 2007). A research project focusing on the implementation of quality management in home care revealed that interpretations of the concept are colored by different
interests and values that various players possessed by virtue of their previous experience and positions. Different players think and speak about quality from different ideological position: whereas administrative managers and consultants talk about quality management in light of the contractual logic of the NPM precepts, care staff tend to interpret the same quality measures from the taken-for-granted presumption that care giver staff possess considerable discretionary freedom. In the view of care staff, quality is not about conformance to certain requirements; quality is about creating a professional ethos of care. The research project concluded that different interpretations of quality were swirling around in the care sector, also within a single municipality and accordingly some quality initiatives ended up pulling the home care organization in different directions (Vabø, 2002).

Initiatives aiming at ‘quality care’ are continuously being based on disparate conceptions of ‘quality’. Internal audit services for instance tend to base their activity on a managerial conception of quality, putting emphasize on performance targets and performance monitoring (Mikkelsen et al., 2005). A rather different notion of quality has been dominating in a comprehensive program: ‘The Quality Municipality Program’ instigated by a coalition of three different ministries and four different trade unions. The program puts an emphasis on the staff-client relations and seeks to find ways to enhance user satisfaction and ways to lower work strain and sickness absenteeism (Båtsvik et al., 2007; Hovik, et al., 2010). In this context ‘quality’ is closely linked to the question of attracting and retaining staff.

**Attracting and retaining care staff**

In Norway, as elsewhere the problem of attracting and retaining health care staff is high on the agenda. The Norwegian Directorate of Health and The Norwegian Association of Local and Regional Authorities have funded several joint programs aiming at improving skills and qualifications of both managers and care staff. ‘Kompetanseløftet 2015’ (the competency boost 2015) is a vigorous pull to increase the competency of care staff in order to meet the needs of a growing population of frail elderly.

Carrying labels like “Clever with People”, “Proud and Unique”, “Increased ethical competency” these programs aim to motivate individuals to value the responsible and ethical spirit of care staff. It is argued within these programs that improved skills and competency will empower staff to improve service provision. Evaluation reports (Haukelien et al 2009, Moland et al., 2010) indicate that care staff feels more secure and able to face difficult situations as they get more
education. They also feel that skills and knowledge contribute to make care work more meaningful. However, the same evaluation report exposes that the care staff consider that the competences of front line leaders and staff is not sufficiently utilized in the overall planning and organization of service provision. The overall planning and organization of care is not informed by the skills of practitioners – but by officials and consultants who (more or less) are committed to abstract managerial principle picked from the NPM agenda.

New strategies aiming at hiring and retaining staff are running alongside continuous efforts to rationalize service provision. Retrenchments of the last decades have narrowed the timeframe for performing care tasks and thus the latitude of care staff to act flexibly and to show humane considerations. Scholars have paid considerable attention to increase in work pressure, sickness absenteeism and burn out among care workers (Elstad & Vabø, 2008)

In 2002, The Norwegian Labour Inspection Authority made comprehensive national investigations into the working conditions in home care. Reports concluded that psycho- social work conditions had worsened due to an increasingly high time pressure. Based on these investigations a campaign was launched aiming at improving work condition for home care staff. Inspections and following up inspections indicate that more efforts have been made to improve work conditions and staff reporting that time pressure have been reduced from 80 to 67 per cent from 2002-2004. Above all this campaign paid attention to the responsibility of employers in providing decent working conditions for home care staff. Home care employers were urged to be more accountable to the Labour Inspection Authority. A research project commissioned by city of Oslo (Steinhaug et al., 2008) reveals that the purchaser provider organization in home care (see above) had created confusion concerning this responsibility. The purchaser provider split was organized to strengthen the procedural rights of care recipients but no consequential analysis was made concerning the consequences on work conditions of care staff. The responsibility for working condition had become dispersed and accordingly more difficult to comply with.

This skepticism toward the purchaser provider organization ( particularly in combination with competitive tendering) is shared by the trade union of care workers (Fagforbundet) of care workers (Fagforbundet Nordstrand, 2004) It is believed that the purchaser provider arrangement will contribute to undermine the autonomy of care workers and hence also their enthusiasm for work. Together with a range of control efforts (evaluation, new documentation routines and inspections) it has increased the burden of paper work and contributed to distract attention away from the core activity in care work. As mentioned above the trade union for care staff
(Fagforbundet) fight against the NPM wave of reforms, but support an alternative quality strategy based on agreements and collaboration between national/local authorities and trade unions.

Efforts made to improve the qualifications of care staff obviously have made some progress. The Norwegian Office of the Auditor found that the number of man-labour-years by qualified staff (in front line service provision) had increased by 22 percent from 2003 to 2007 and the number of man-labour-years by unskilled staff had decreased by 6 % in the same period of time (Riksrevisjonen, 2009). Even so, a research project focusing more profoundly on the history of Norwegian education and recruitment strategy (Høst, 2008) conclude that efforts to modernize the education for care workers has failed (see below).

A story of failed modernization
Home care work has always been women’s work. The great expansion of public care provision in the 1960s went hand in hand with women seeking gainful employment. Middle aged women who wanted to make a small income of their own found that home care work was meaningful work, easy to combine with homemaking in their own household. Later, as home care services became more narrowly directed towards more frail elderly in need of nursing care, the composition of care staff changed toward more educated staff. The auxiliary nurse education attracted many women, in particular unskilled nursing assistants who had learned care work by experience, but also adult women and young girls who entered the work force. This education became very popular and auxiliary nursing became one of the largest occupational groups within the welfare state. Criteria such as age and work experience from care and nursing contributed to a pattern where the typical auxiliary nurse was to be an adult woman with long practical experience from elderly care.

However, according to the social scientist Håkon Høst, the auxiliary nurse education turned out to be a story of “failed modernization” (Høst, 2008). Whereas the education from the start was a part of a vocational education system administered by the sector authorities, it gradually became integrated into the overall educational system at the upper secondary level. People aged 16-19 were given a statutory right to undertake a secondary education, including auxiliary nursing. The age flexibility in the education program was removed. Adults were no longer to be admitted to the ordinary auxiliary education, but were supposed to shorter courses outside the upper secondary school system. Many adults were rejected on the ground that they did not have this statutory right. Hence, the modernization of the education system contributed to disconnecting auxiliary nurse education from the established recruitment base. Efforts to construct career profiles where auxiliary
nurse education is completed at age 20 was however not successful. There has been a drastic reduction in the number of students and auxiliary nurse education has decreased in status. Younger people did not regard these educational courses as a part of their life plans. Rather, the educational courses (health and social care) was constructed as low status and became a kind of secondary education available for those who were not able to compete for more popular courses. Young people did not want to work in care for the elderly, but used the educational course as a stepping stone to re-enter general education. The majority of applicants for auxiliary nurse education are still adults – middle aged women who have long practical experience with paid and unpaid care work. Although recent reforms have to some extent revitalized the “old” recruitment pattern, the education system is fragmented – some students have the right to free public education while others have to pay for it and still other have their education paid for by their employer. All in all, Høst (2008) regards the reforms in auxiliary nurse education to be unfavourable for the care sector as it has contributed to lower the status of auxiliary nursing.

8.6. Conclusion
Norwegian home care has been in a constant process of change ever since it became a part of the public health care system in the 1960s. In this chapter I have demonstrated how the service have changed from a supportive social service aiming to encourage elderly people to live an independent life at home as long as possible, toward a health and social care service for both younger and older citizens in need of health and social care. The organization of home care has been pushed by competing drivers of change. Home care evolved from the third sector and was from the very beginning characterized by the helping spirit of women. The core idea of home based care – to encourage people to continue a life in their own home – has never been abandoned. However, the notion of home care as an enabling process stressing values such as flexibility and care, has been challenged by more static notions of home care as ‘entitlements’ and ‘commodities’ allocated according to formal eligibility criteria. These notions became prominent in the 1990, partly because the procedural rights of citizens were strengthened, partly because the NPM wave of reforms encouraged public service providers to reimagining care provision as commodities in a market. These new conceptions of home care pushed the home care institution toward more formalized and hierarchic work organization. A stronger emphasize on vertical integration meant that the time and attention of care staff was more governed by work schedules and formal report systems. However,
new routines did not fully displaced the helping spirit of home care staff. Research into the process of reforms (Vabø, 2007; Vabø, 2009) indicate that, as home care institution has been pervaded by conflicting policy aims and administrative reforms, it has become a field of tension where the need for reform occur continuously. For the purpose of this project it should be emphasized that Norwegian reform policy have not followed the mainstream marketisation strategy to the same extent as other Nordic countries, but has maintained a ‘Nordic’ approach of reform’ characterized by decentralization, democracy and consensus. Even though, choice and competition is high on the policy agenda; and even though efforts of managerialization still are made, reforms under way are to a large extent based on collaborations between governments and trade unions of care staff.
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9. Home Care in Sweden

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9.1. Introduction

Eldercare services in Sweden have been characterised as being provided on a universal basis, that is comprehensive, publicly financed and high quality services available to all citizens according to need rather than ability to pay. Also characteristic of the universal welfare state is that the same services are directed towards, and also used by, all social groups (Sipilä 1997). Nordic scholars have discussed whether this image of a universalistic Nordic care regime is or ever has been accurate (see e.g. Anttonen, 2002; Rauch, 2007). From a historical perspective, however, the development of municipal home-care services, which in Sweden started in the 1950s, was an important step in the building of the Swedish welfare state. Home care was the first form of eldercare to be offered not only to the poor, but to all social groups in the society. The services were regarded as an individualised alternative to the more standardised forms of care available in old-age homes, and the services soon became very popular and widely used (Szebehely, 1998). This was possible because the services were not only formally accessible (i.e. that all social groups were eligible and that there were services available for most, though not all, who needed them). The services were also affordable even for those with fewer resources and attractive enough to be preferred also by the middle class (Vabø & Szebehely, 2011). In this sense, it can be argued that home care was used on a universal basis.

Around 1980, public home care was used by 16 percent of older people (65 years+) in Sweden. At that time, the coverage was similar in the neighbouring Nordic countries, and clearly higher than in the rest of the world. In 2008, 9 per cent of older people were receiving home care in Sweden (Szebehely, 2005a; Nososco, 2009). The Nordic countries are no longer homogenous with respect to home-care coverage, and several European countries have higher coverage of home-care services than Sweden (Huber et al., 2009).

The decline of the number of home-care recipients in Sweden was particularly dramatic among younger elderly, but the use of home care has been reduced also among the oldest old (80 years+): from 34 per cent in 1980 to 22 per cent in 2008 (Szebehely, 2005a; Nososco, 2009). While

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the decline in the younger age group to some extent can be explained by health improvements, this is not the case among the oldest (Thorslund et al., 2004). Even when controlling for changes in reported needs and in mobility limitations, the probability of receiving home care was clearly lower in the early years of 2000s compared to the end of the 1980s (Larsson, 2006).

In the same period, there has been an increase in care by family members of frail older persons, both to older people outside the formal care system and as a complement to formal services (ibid; Szebehely & Trydegård, 2007). Despite the fact that in Sweden, as in all the Nordic countries, children are not formally responsible for caring for their older parents, families to provide an increasing amount of care. It has been estimated that between 1994 and 2000, the families’ share of all community care increased from 60 to 70 per cent (Sundström et al., 2002). Daughters in particular have increased their informal assistance: in 1994, 22 per cent of single-living older persons (75 years+) received help from a daughter; by 2000 this figure had risen to 33 per cent (Johansson et al., 2003).

What are the driving forces and mechanisms behind this trend towards re-familialisation of Swedish eldercare? Is it intended by policy makers? Has home care become less popular among Swedish older persons and if so, what could be the reasons – reduced quality or raised user fees, i.e. have the services become less attractive and/or less affordable? Have the services become less accessible? And if so, is this the result of legislative changes affecting eligibility criteria, or have the services become more strictly targeted without any decisions made by central policy makers? Are there at all any deliberate decisions at central or local government level behind the decline of home-care services?

Another important trend in the last decades is the shift towards private for-profit provision of the tax-funded home-care services. In 1993, only 2 per cent of the users of tax-funded home-care services received help from a private provider, mainly not-for-profit (NBHW, 1999). Today (2010), 19 per cent of the home-care hours are provided by for-profit private companies and to a very small extent by non-profit organisations (NBHW, 2011). How can we understand this trend towards marketisation of Swedish home-care services? Is it intended by policy makers? Is it caused by older home-care users’ dissatisfaction with the publicly provided services? Are there legislative or other national policy changes behind the increase of private provision? If so, is the increased use of private providers justified by efficiency and/or quality arguments? Do we know whether the introduction of private provision actually saved public monies and improved quality?
In order to answer these questions, we will describe the particular character and recent changes of Swedish home-care services. Of specific interest for the Swedish national report is the process by which an older person with care needs gets access to the home-care services. The fact that a service is offered according to need, means that citizens do not have an absolute right to services. The individual’s entrance to home-care services (as well as to other needs assessed services) is via the discretion of a gate keeper. Therefore we will focus on the encounter between the older person and the care manager – the public officials who assess care needs and decide on the services that will be provided.

9.2. Home-care services in Sweden: legal framework and coverage

Care of older and disabled persons is governed at three levels. The central government's instruments of control are legislation, policy declarations and state subsidies. The state also executes supervision through the National Board of Health and Welfare (Socialstyrelsen). At regional level, the county councils (landsting) or regions (21 in all) are responsible for the major part of health and medical care. At local level, the 290 municipalities (kommun) of different size and character are legally obliged to provide home-based care services as well as residential care for care-needing persons of all ages.

Home care in Sweden is regulated by the Social Services Act (introduced in 1982) as are most care services for older and disabled people, including nursing homes which were moved from the health care sector at the regional level in 1992 (the so-called Ädel-reform). The Social Services Act is a goal-oriented framework law ensuring a general right to assistance if the need ‘cannot be met in any other way’, but without detailed regulations or specific rights. Everybody has a right to claim public service and support at all stages of life, and local authorities have a mandatory responsibility to see to that these needs are met. The assistance should be of good quality and given in ways that ensures a ‘reasonable level of living’. A process of needs assessment is carried out by a care manager – a ‘needs assessment officer’ acting on delegation by locally elected politicians (this process is described in more detail later in the paper).

In 2008, out of 1.7 million older persons (65 years+), around 300,000 individuals (18 per cent) received one or more services according to the Social Services Act: 145,000 (close to 9 per cent) received home-care services (often in combination with other services such as safety alarm) and 96,000 (close to 6 per cent) were staying permanently in residential care. The rest (around
60,000 individuals or 3.5 per cent) received other forms of support such as day care, short term residential care or solely safety alarm or meals on wheels (NBHW, 2010a).

Home-care services include help with **household tasks** like cleaning, shopping, laundry and cooking (or the delivery of ready made food), as well as **personal care** such as bathing, getting dressed and moving around. **Emotional and social support** is also regarded important aspects of the service. The amount of home care can vary from help once a month to 6-8 or even more visits per day on a 24 hour basis. In 2008, 35 per cent of the home-care users received less than 9 hours of help per month (2 hours per week), another 35 per cent received between 10 and 49 hours per month, 17 per cent received 50-119 hours per month and 3 per cent received 120 hours per month or more.\(^{37}\) On average, a home-care user received around 7 hours of help per week (NBHW, 2009a).

The **Health and Medical Services Act** regulates the authorities’ obligations to assure the entire population good health and care on equal terms, and to conduct health and medical services so as to meet the requirements for good care. The act regulates the health care services, including hospital treatment, primary health care and home nursing.

The boundary line between home care and home nursing is not entirely clear and may differ between different municipalities. In principal, the home-care services provide help with all aspects of personal care that an able bodied person would do for herself, including getting dressed or taking medicine. Often also wound treatment and diabetes injections are regarded the responsibility of the home-care services. The home-nursing services are responsible for more advanced medical tasks.

Formally, a registered nurse is responsible for health care related tasks, even when these tasks are delegated to a home-care worker (NBHW, 2008a)

County councils (the regional, politically elected assembly) are responsible for health care services, also for home medical services in regular housing (home nursing), but can transfer this responsibility to the local authorities, which is the case in two thirds of the 290 Swedish municipalities. Due to this divided responsibility, there are no national statistics on home nursing services, but the number of older people living in their ordinary homes receiving such services has increased in recent years and today more than half of the home-care users also have some kind of home nursing (NBHW, 2009b). The division of responsibility and the collaboration between home nursing (within the health care system) and home care (within the social service system) is very much of current interest. Recently the government has appointed a committee to investigate how to

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\(^{37}\) For 7 per cent of the users there was no information on hours, and 3 per cent of the registered users did not receive any help at all.
shift the responsibility for home nursing to the municipality in the 1/3 of the municipalities where the county council is still responsible for home nursing (Swedish Government, 2010).

Even though the Social Services Act is the central piece of legislation regulating eldercare in Sweden, other laws are also of relevance. In 1994, new Disability legislation was introduced, including LSS (*The Act concerning Support and Service for Persons with Certain Functional Impairments*) and LASS (*The Assistance Benefit Act*). LASS is since January 2011 part of the Social Insurance Code (*Socialförsäkringsbalken*). In contrast to the Social Services Act, this is a more absolute special rights legislation, explicitly singling out persons with certain extensive functional impairments (not caused by normal ageing), and the available measures which the local authorities have an obligation to fulfil to ensure these persons “good living conditions”. Compared to the goal of the Social Services Act – ‘reasonable level of living’ – this goal is more ambitious.

In relation to home care the personal assistance scheme, regulated by the Social Insurance Code, is of particular interest. The scheme covers personal assistance for persons with extensive needs for assistance. A person above the age of 65 may not become a user of personal assistance, but since 2001, he or she can keep the right to personal assistance even if the number of hours may not be increased. Today, out of 15,000 people who are eligible for personal assistance 13 per cent are 65 years or older, receiving on average close to 100 hours of assistance per week (Swedish Social Insurance Agency, 2009). In an interview study of older persons receiving personal assistance, one of the interviewees said: ‘I was lucky to get my stroke before 65’ (Forssell, 2004, p.86). The drastic wording reflects the more generous public contributions for younger disabled persons compared to older people in similar circumstances.

Yet another form of services has become available through a reform in 2007, *Tax-subsidised household services*. Taxpayers are entitled to deduct 50 percent of the expenditure up to SEK 100,000 on household services, including care services. The deduction, then, is up to SEK 50,000 (close to € 5,500) per person and year if the service company has a business tax certificate. The services may be carried out in their own home or in a parent’s home. These services are not needs assessed, and they are not regulated by the state or local authority, but as we will discuss, they may serve as a functional equivalent to the tax-funded home-care services in some cases. In 2009, 3.5 per cent of persons 65 years and older used the tax deduction; the majority bought services for less than € 600 during the year (Sköld & Heggemann, 2011). The deduction is used significantly more often by high income older persons than by those with lower incomes. Thus in the Swedish context,
still privately purchased services play a marginal role compared to both family care and publicly funded services.

9.3. Financing home care

Sweden is probably the world’s most generous country when it comes to public spending on eldercare (Huber et al., 2009). The vast majority of eldercare expenditure comes from municipal tax (around 85 percent), another 10 percent comes from national taxes (NBHW, 2007a).

However, for several decades, the public spending on eldercare has not kept pace with the ageing population. Between 1990 and 2000, public resources for eldercare in relation to the number of 80 years+ in the population were reduced by 15 per cent and between 2000 and 2005 by 10 per cent (Szebehely & Trydegård, 2007).

The user pays only a fraction of the cost (4-5 per cent). No services are means tested, but user fees are related to income and the amount of help provided. Before 2002, there were large municipal variations in the user fees, and the fees were rapidly increasing in many municipalities. High user fees were regarded an issue of concern since they negatively affected the access to services, in particular for low-income older people, but it was also regarded unfair that older persons with high pensions in some cases had to pay extremely high fees. Therefore in 2002, a national max-fee reform was introduced which capped the fees in home care as well as in residential care to (at present) SEK 1,696 per month (around € 185).38 Persons with low incomes are exempted from paying fees and one out of five home-care recipients pay no fees at all due to low incomes (SALAR, 2007, p.72). Municipalities still have discretion in setting the fees up to the ceiling but they may not exceed their actual costs. Many municipalities use the fees as a device for reducing demands (for less intensive care) by setting the fee at a relatively high level for smaller amounts of help.

9.4. Governance and organisation of home care

The very high degree of autonomy vis-à-vis the central government (including the right to locally levy taxes) is considered typical for Scandinavian municipalities. Within the limits prescribed by the legislation, locally elected politicians decide on tax rates, establish local goals and guidelines,

38 Besides the user fee for care, elderly persons in residential care pay separately for meals and accommodation.
and set budgets. Not surprisingly there are large municipal differences in eldercare, although in terms of coverage the municipal variation has declined (Trydegård & Thorslund, 2010).

Besides its legislative power, the role of the central state in governing eldercare policies is mainly restricted to policy declarations, supervision and state subsidies. A significant change took place in 1993 when the vast majority of earmarked subsidies were abolished and transformed to ‘municipal block-grants’ leaving the municipalities to make their own priorities between different welfare services (Palme et al., 2003). From the end of the 1990s, however, policy declarations (action plans) combined with financial incentives have become increasingly important steering devices (NBHW, 2010a). Also supervision through the National Board of Health and Welfare (NBHW) has been intensified and stressed in recent years, for instance via annual open comparisons of municipalities’ elder-care operations for benchmarking purposes (Trydegård & Thorslund, 2010). After decades of decentralisation, there is now a trend towards increased state control. The max-fee reform for eldercare services introduced in 2002 is one example.

An important legislative change that instead increased the local autonomy took place in 1991 when a new Local Government Act was introduced. This act gave the municipalities a larger scope to shape their internal organisation, including the right to introduce a split between purchaser and provider, and to contract out the provision of care services to for-profit providers. By 1993, 10 per cent of Swedish municipalities had introduced a purchaser-provider model; only ten years later, the share had grown to 82 per cent and today virtually all municipalities have introduced such a model (Gustafsson & Szebehely, 2009).

As mentioned in the introduction of this paper, private providers within the tax-funded home-care services increased from 2 to 19 per cent between 1993 and 2010. Until recently, the outsourcing to private providers took place after a process of competitive tendering. After a competition, the local authority could choose to contract out a geographical home-care district or a nursing home to a company or (in practice much more rarely) non-profit organisation, or to keep the provision in public hands. More recently, and encouraged by the introduction of a new act: Free to Choose - Act on Freedom of Choice (LOV), implemented in 2009, this kind of competition has become less common. The act regulates local authorities that want to introduce consumer choice for their tax-funded care services. The individual user then chooses from among the authorized providers the one perceived as having the best quality care. All providers receive the same reimbursement (according to the amount of help decided by the needs assessor), and are thus competing by service quality, not by prize.
One aspect of the high degree of municipal autonomy is that the municipalities may decide whether or not to open up eldercare to private providers. In 1999, privately provided eldercare services were more common in larger municipalities and in municipalities dominated by the conservative party (Trydegård, 2003). Today, in two thirds of the Swedish municipalities (65 per cent) still all home care services are publicly provided. In contrast, in 4 per cent of the municipalities more than half of the tax-funded home care services are provided by private companies (NBHW, 2011). The two biggest cities in Sweden have chosen different ways forward in this respect: 59 per cent of the home care hours in Stockholm are privately provided compared to zero in Gothenburg (ibid).

It seems probable that in the near future more municipalities will introduce consumer choice and open up to private providers. In 2009, more than 60 percent of the Swedish municipalities had applied for a state subsidy aimed at encouraging the introduction of choice models. By spring 2010, in addition to the 16 percent of Swedish municipalities that already had introduced a consumer choice model, another 25 per cent had decided to do so (NBHW, 2010b).

The Government expresses strong hopes that the introduction of consumer choice models will increase the older users’ influence over the services and that the competition in itself will enhance quality (Ministry of Health and Social Affairs, 2007). Within the choice model, private, but not public, providers are allowed to offer additional service, by which the older persons can ‘top up’ the needs-assessed, publicly funded offering. The tax deduction for household services introduced in 2007 makes these ‘topping-up’ services more attractive as the user pays only half the cost.

9.5. Changes in other policy fields

One important change in the health care field that clearly has affected the home-care services is the radical cut of hospital beds since the early 1990s. Between 1992 and 2005, the number of beds was reduced by almost 50 per cent. This has led to a reduction in the length of stay in all forms of hospital care. For example, the average length of stay in geriatric care was reduced from 21.5 days in 1993 to 12 days for those 80 years and older in 2005 (NBHW, 2007a). The reduced length of stay in hospital was an intended effect of the previously mentioned ÄDEL-reform from 1992, which comprised a strong economic incentive for the municipalities to find care outside the hospital for patients who, according to judgment by a physician, are ready for discharge but no longer can manage on their own. The municipalities are obliged to pay the hospital stay for these patients
(Trydegård, 2003). As a result older people more often leave hospital with remaining care needs which in turn has increased the demands for municipal eldercare services, in residential as well as in home based care. Both forms of eldercare services have therefore become increasingly strictly targeted to those with greatest need.

As mentioned earlier, in principal, the local politicians can decide on how to prioritise between different welfare areas. However, all priorities have to be made within existing financial resources and the economic recession in the early 1990s placed severe strain on municipal finances. The tax revenue declined due to increasing unemployment, and during the same period, municipalities’ decision latitude in raising tax rates were actively restricted by several central government financial incentives (Palme et al., 2003). Furthermore, increased government ambitions in other welfare areas without full compensation to the municipalities for the increased costs, have also reduced the scope of action for the municipal politicians. Important legislative changes include the Disability Act 1994 (which enacted more generous and detailed legislation with extensive rights for persons with certain disabilities) and the School Act 1995 (which made it mandatory for municipalities to offer childcare to all children 1-12). Municipal resources allocated to these two fields have increased significantly since the early 1990s, particularly for disability services. While the municipal resources for eldercare were unchanged between 2004 and 2008 (despite an ageing population), the resources for childcare increased by 4 per cent and for disability services by 13 per cent (Swedish Government, 2009/10). In the most recent report on social services, the National Board of Health and Welfare concludes: ‘Older people’s need for care have been sacrificed for other groups’ need for support’ (NBHW, 2010a, p. 23).

The combination of reduced resources and increased needs has had a major impact on eldercare services. Probably as a result of increasingly tight municipal budgets, many municipalities are shifting their focus from residential to home-based care. ‘Ageing in place’ has been a policy goal in Sweden since the 1950s, but the reduction of places in residential care has been particularly radical since the year 2000: between 2000 and 2008, 23,000 places (20 per cent) have disappeared. In the same period the number of home-care recipients has increased by some 20,000 individuals. The municipal resources spent on residential care have decreased by 8 per cent while the resources for home care increased by 18 per cent (NBHW, 2010a). The rapid decline of residential care is an issue of concern for the Government, and since 2009 the municipalities can apply for an earmarked investment grant for the building of housing for older persons (ibid). This might change the balance
between residential and home-based care in the future, but for the time being, it is obvious that the home-care system is having to deal with increasingly frail older persons.

9.6. The entry to the care system

The individual older person’s entry to the home care system goes via a municipal social worker, a care manager, who is delegated to assess the needs and to decide if a person is entitled to assistance and if so, the type and amount of help received. It is a single entry system, i.e. the manager can decide on both home care services of various kind and residential care. The care manager’s actions and decisions are considered as ‘exercise of public authority’, and therefore surrounded by strict legal rules, to ensure the citizens a correct and impartial treatment. Yet another security measure is the citizen’s right to appeal against negative decisions and have one’s case assessed in an administrative court (Rönnbäck, 2011).

This Swedish model is built on trust in the care managers’ professional discretion. Services considered universal must be distributed equitably, and the gate-keepers of the system must carry out the investigation thoroughly, with regard to the individual’s unique situation, the legal rules, and also the local conditions and resources (Lehto et al., 2001). The National Board of Health and Welfare has underlined the importance of a highly professional handling of the needs assessment process and elaborated national guidelines for the required qualifications of care managers in eldercare as well as disability care (NBHW, 2007b; NBHW, 2008b). The majority of care managers are social workers with a university degree at bachelor level.

As a consequence of the tighter resources for eldercare, many municipalities have elaborated restricting local guidelines for their care services. These have turned out to have a strong impact on the care managers’ assessment and decisions, and increasingly, care managers are urged to consider the municipal budget and make the necessary priorities. Further, studies have shown that the needs assessment often takes its starting point in the “municipal tool-box”, i.e. people’s needs are transformed into what services the municipality can offer, and a suitable client is thus constructed (Lindelöf & Rönnbäck, 2004).

With the introduction of a purchaser-provider split in the majority of Swedish municipalities since the early 1990s, the care managers have a specialized role as purchasers of services and care. After having assessed the older person’s need for assistance, the care manager purchases the services from a public or a private provider. In the increasing number of municipalities where a
consumer choice system has been introduced, the care managers are supposed to give the older person consumer guidance about all the available – public and private – providers of care (in some areas, e.g. in Stockholm, up to 80-90 companies); then the ‘customer’ decides which one to choose. It is also the care manager’s responsibility to follow-up the cases and to see to that the older person receives the services and care he/she is entitled to according to the care decision, and also to scrutinize the care quality.

It has been argued that the introduction of the purchaser-provider split implied a significant change in the daily organisation of home-care services. It brought about an increased distance between the ‘office’ and the ‘work-shop’; between the decisions and the actual provision of help. This implied new demands on exactness and clarity in the ‘order’, and increasingly often the work task is connected to a standardised time frame (5 minutes to make a bed, 10 minutes to change diapers or 15 minutes to make breakfast). New instruments have been developed for measuring the quality of care and for controlling that the tasks performed are in accordance with the needs assessment. A basic assumption underpinning these organisational models is that an older person’s care needs are stable enough to be pre-regulated – an opinion held by economists and reform agents but highly contested by home-care staff (Vabø 2006).

In the latest proposal on eldercare (Government Bill, 2009/10:116), the Government emphasizes the importance of needs assessment of good quality, being equal in all Swedish municipalities. The National Board of Health and Welfare has been commissioned to develop a standardised instrument and a manual for the needs assessment, the interventions and the documentation of the process.

To summarise: The care managers’ discretion to negotiate with each elderly home-care user and to adapt the services to needs and preferences is a precondition for individualised home-care services and thus for the quality of care. This latitude for discretion has diminished in later years as restrictive local guidelines have come to dominate over professional judgments. Moreover, the demands to create pre-regulated packages for the purchasing of services have standardised the care managers’ work. The newly suggested national instruments for needs assessments will further undermine the professional judgement.

39 Examples taken from guiding principles for assessing care needs and allocating home-care services in a particular Swedish municipality, but similar guidelines are widely spread.
9.7. Cash versus services

In regard to international comparisons, cash for care allowances play a marginal role compared to services in Sweden (Huber et al., 2009). There are, however, a few programs offering cash for care. Already in the 1940s, an attendance allowance (in Swedish: Anhörigbidrag) was introduced in many municipalities. The allowance can be regarded as a ‘symbolic payment’ since it is far too low to pay proper wages. Today, the payment is often between € 100 and 400 a month and goes to the person needing care (Szebehely, 2005b). In principal, the allowance could be used to pay a (migrant) care worker in the informal economy, but that is probably very rare. Another form of cash for care was introduced in the 1950s: the possibility for a family member to be employed by the municipality as family carer, generally paid by the hour.

These two programs show a similar pattern of expansion and reduction as the home-care services. The peak was in the late 1970s and since then, the number of persons who get the payments has declined drastically. In 2006, about 5,000 persons got an attendance allowance, while less than 2,000 persons were employed as family carers. Many municipalities do not offer these possibilities at all (another example of the high independence at the municipal level in Sweden) (ibid.; NBHW, 2007c).

The only form of payment for family carers that is not dependent on the municipal discretion is the allowance for care of close relatives introduced in 1989 (in Swedish: Närståendepenning). This is a legal right to income-related payment and leave of absence, covering 80 per cent of the individual’s ordinary income. It applies for persons who have a relative or close friend in a terminal care situation at home, in residential care or in hospital. The leave is not related to actual provision of care; also people who just want to stay close to the terminally ill person are eligible. A medical opinion is required. In 2010, the maximum length of this allowance was extended from 12 to 20 weeks. However, the 10,000 persons who used the allowance in 2009 used only two weeks on average (Swedish Social Insurance Agency, 2009).

Within the consumer choice model of home-care services, the user cannot choose a family member as care provider. In contrast, the personal assistance scheme introduced in 1994 as part of the special disability legislation (LSS/LASS) gives the users a wider choice. Via the state financed assistance allowance, the user can choose to act as the employer or to let the municipality, a non-profit organisation or a for-profit company employ the assistants. Family members within or outside the household may be employed as personal assistants, and it has been estimated that around one
quarter of the individuals working as personal assistants (mainly on a part time basis) are family members of the disabled person (Government Report, 2008:77).

9.8. **The home-care workers**

Care work for older or disabled persons is mainly a female occupation; over 90 percent of the employees in the care sector are women (SALAR, 2009, p. 75). The work force is relatively mature; one third of the care workers are older than 55 (ibid, p. 79). The vast majority of the employees are care workers (assistant nurses, nurse’s aides or personal assistants); less than 15 per cent are registered nurses or supervisors, managers or needs assessors (ibid).

The staffing statistics do not differentiate between care of older and of disabled persons, nor between home care and residential care. Another weakness of the statistics is that the privately employed (but tax-funded) care work force is not reported on a regular basis. In 2007, 20 per cent of the public employees in care of older or disabled persons were employed by the hour. Of those who were employed on a monthly basis, only 39 per cent worked full time. The average activity level among part time workers was 73 per cent of full-time; among hourly employees about 37 per cent (SALAR, 2009). A significant proportion of part-timers would prefer to work longer hours (Nyberg, 2003).

An increasing proportion of the care workers in care of older or disabled people are foreign-born; in 2008, 18 per cent were born outside Sweden (3 per cent were born in other Nordic countries, 6 per cent in Europe or North America and 9 per cent in Africa, Asia or Latin America). In the metropolitan areas like Stockholm, more than 40 per cent of the care workers are foreign born (Statistics Sweden, 2010). There is no active recruitment of care workers from other countries; the vast majority of workers born in other countries have migrated for other reasons, many as refugees. Currently the local authorities manage the recruitment of the staff they need for care work. Sick leave among care workers is higher than in many other occupations, but has been decreasing since 2002 (SALAR, 2009). Also the turnover rate is slightly declining and was 14 per cent in 2009 (NBHW, 2010a).

For home-care workers in Sweden, publicly or privately employed, there are no mandatory qualifications, other than what is stated in the Social Services Act: that staff have ‘suitable training and experience’. Of all eldercare workers (those employed by the hour excluded), 73 per cent had some kind of vocational training in 2007; slightly more in residential care and less in home care
The relatively low training level is an issue for policy makers. In recent years, several state subsidies have been offered to the municipalities in order to encourage them to provide training for already employed care workers and thus raise their vocational skills. However, for the moment there are no plans to introduce minimum standards for formal training.

The two largest occupational groups in home care are assistant nurses (undersköterskor) and nurse’s aides (vårdbiträden). They are supervised by home care supervisors (often social workers with university training) and registered nurses, supplemented by occupational therapists and physiotherapists on a more consultative basis. Assistant nurses typically have 2 or 3 years of upper-secondary nursing training which they may have acquired before starting to work as care workers or they may have received the training as part of their job, paid by the employer (the municipality). Nurse’s aides have a shorter education, often provided by the municipality.

The two groups of care workers have similar workdays; both are providing household tasks such as cleaning, laundry, cooking meals, etc., as well as ‘body work’, including help with dressing, bathing, toileting and handing out medicine. They also regularly contact health care providers, and both occupational groups are engaged in relational aspects of work and other social and recreational activities. Half of the assistant nurses and one quarter of the nurse’s aides also give insulin injections on delegation from a registered nurse. In comparison to the other Nordic countries, the Swedish home-care workers have much less contact with a supervisor – only one third of the Swedish workers have a meeting with their supervisor at least weekly, compared to two thirds in the other Nordic countries taken together.40

9.9. The home care users

The regular statistics on home-care services provide information on age and gender, but not on social background or care needs. Of all home-care users above the age of 65 years, 68 per cent are women and 72 per cent are 80 years or older. A larger proportion of women than men receive home care in all age groups, except for the oldest old (95 years+) (NBHW, 2009a). The female dominance is mainly due to the longer life expectancy among women and the larger numbers of single-living women in older ages. It is important to note that very few older persons in Sweden live with their off-spring. Older couples rarely receive home-care services; according to one calculation only 4 per

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cent of married or cohabiting older persons (65 years+) receive home care compared to 10 per cent of single-living women and 14 per cent of single-living men (NBHW, 2010a).

A large scale living conditions survey is carried out yearly by Statistics Sweden. This survey can be used to shed some light on home care users over time, see table 9.1.41

TABLE 9.1
Care needs and other characteristics among home-care users in Sweden 1988-89 and 2004-05. Per cent of home-care users and significant differences between the years

<table>
<thead>
<tr>
<th></th>
<th>1988-1989 (n=374)</th>
<th>2004-2005 (n=292)</th>
<th>Difference between the years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need help with cleaning</td>
<td>96.2</td>
<td>95.2</td>
<td>n.s.</td>
</tr>
<tr>
<td>Need help with shopping</td>
<td>66.0</td>
<td>75.9</td>
<td>**</td>
</tr>
<tr>
<td>Need help with laundry</td>
<td>67.0</td>
<td>71.1</td>
<td>n.s.</td>
</tr>
<tr>
<td>Need help with cooking</td>
<td>37.2</td>
<td>50.3</td>
<td>**</td>
</tr>
<tr>
<td>Need help with all four tasks</td>
<td>28.9</td>
<td>45.8</td>
<td>***</td>
</tr>
</tbody>
</table>

  of which need help also with:

<table>
<thead>
<tr>
<th></th>
<th>1988-1989 (n=374)</th>
<th>2004-2005 (n=292)</th>
<th>Difference between the years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bathing</td>
<td>69.0</td>
<td>83.9</td>
<td>**</td>
</tr>
<tr>
<td>Getting dressed</td>
<td>25.1</td>
<td>45.8</td>
<td>**</td>
</tr>
<tr>
<td>Getting up from bed</td>
<td>23.1</td>
<td>40.4</td>
<td>***</td>
</tr>
<tr>
<td>Have difficulties carrying 5 kg</td>
<td>63.1</td>
<td>77.3</td>
<td>***</td>
</tr>
<tr>
<td>Have difficulties walking 5 minutes or entering a bus</td>
<td>71.0</td>
<td>80.5</td>
<td>**</td>
</tr>
<tr>
<td>Receive help from children, other non-residing relatives or friends</td>
<td>36.5</td>
<td>55.1</td>
<td>***</td>
</tr>
</tbody>
</table>

Source: Authors' own calculations of Statistics Sweden’s Living Condition Survey

*** p<0.001; ** p<0.01

As shown in Table 9.1, the care needs among the home-care users have increased since the end of 1980s. The fact that significantly more home-care users report receiving care by family members as a complement to the tax-funded home care in 2005 (see table 9.1) suggests that the increase in home care is also attributable to the aging population.

41 According to the survey, in 1988-89 12.3 per cent of the elderly (65 years+) received home-care services compared to 9.3 per cent in 2004-05. This is relatively well in line with the regular statistics: in 1988, 11.3 per cent of the population 65+ received home care compared to 9 per cent in 2005 (Ministry of Health and Social Affairs, 1997; NBHW, 2006)
care hours did not keep pace with the increasing needs. Also the amount of help provided has increased: in 1988, 28 per cent of the home care users received more than 25 hours per month, in 2005 this was the case for 38 per cent of the users (not shown in the table) (Ministry of Health and Social Affairs, 1997; NBHW, 2006).

Previous analyses by the authors of the same data show that the decline of home-care services have affected in particular older persons with smaller care needs while family members have increased their help not only to those older persons who no longer receive help from the tax-funded home-care services, but also (as table 9.1 suggests) to those older persons who still receive help but seemingly not enough (Szebehely & Trydegård, 2007). There does not seem to be any class related difference in the use of home-care services: in 2005, older persons with lower and higher levels of education used the tax-funded home-care services to the same extent when controlled for age and class related differences in health and care needs. Both groups have been affected in the same way by the service decline. However, there is a clear class-related pattern in the consequences of the reduced coverage of home care: care by family members has increased mainly among older persons with lower levels of education while older persons with higher levels of education increasingly are purchasing services provided by the market and paid for out of their own pockets (ibid). Thus the trend of re-familialisation has not affected all social groups similarly.

In this context it is important to note that a majority of older people in Sweden prefer to receive help from the home-care services or from a spouse. Only around 10 per cent prefer to get help from a daughter or another relative or friend, and there are no class differences in this respect (ibid).

9.10. Assessment of quality

In the last 20 years, there has been an emphasis on quality assurance and quality measurements in Swedish eldercare services. The Social Services Act includes a general declaration that services and care under the act should be of good quality and that the care quality should be systematically and continuously developed and secured. Local authorities are obliged to establish systems for the quality work, and professionals and authorities on national and local levels are working intensely to develop reliable and valid measurements or indicators of care quality.

In recent years, the National Board of Health and Welfare together with the Swedish Association of Local Authorities and Regions have published annual ‘Open comparisons’ between
municipalities and local units, and a ‘Guide for Older Persons’, with the main goal being to develop the quality of care and improve the transparency of the care system, giving the care recipients and their families information of the quality of care at local level, and thereby increased possibilities to make informed choices in the consumer choice model (NBHW, 2010c). Many municipalities have also developed local quality assessment tools, often used for surveys to the users and their families.

The users of home-care services are generally fairly satisfied with the services they receive. In 2008, the Swedish government commissioned the Swedish National Board of Health and Welfare to conduct biannual national user satisfaction surveys. In 2010, the survey was sent to more than two thirds of alleldercare recipients of tax funded eldercare services in Sweden. The response rate was 70 per cent for those receiving home care. On a scale of 1–100 the average level of satisfaction with home care was 75. The study found no class difference in evaluations of service quality. Older people with a university education were just as satisfied with the services as were older people with compulsory education only (NBHW, 2010d).

The Government expresses very strong hopes that the introduction of private provision and in particular the consumer choice model will improve the quality of care (Ministry of Health and Social Affairs, 2007). So far, however, no systematic differences between private and public providers have been found (Vabø, 2005). Consumer choice models in home care are still relatively new and very little is known about older people’s experiences of these models. There are a few studies from Stockholm, where consumer choice in home care was introduced in 2002. These studies show that home-care users in general appreciate the opportunity to choose a provider, however, more important was the ability to affect the actual care provided (Hjalmarsson, 2003). In another early evaluation report from Stockholm, representatives for the local authority and the private companies argued that the introduction of the consumer choice had increased the quality of home care services. Charpentier (2004) also found that the public expenditure had increased due to higher costs for administration and also, that the time spent by staff moving between users had increased.

A large survey conducted in 2008 (covering more than 11,000 home care users in Stockholm) found no difference in perceived quality between privately and publicly provided services. However, five waves of the same survey since 1995 show a gradual decrease from 45 to 36 per cent of the care users reporting being ‘very satisfied’ with the ‘general quality of the received home care’. If those who reported to be ‘fairly satisfied’ are included, the level of satisfaction is
more stable – a decrease from 83 to 81 per cent (USK, 2009, p. 18). In any case, competition through consumer choice models seemingly did not improve the quality of care.

9.11. Conclusion

At the outset of this paper we identified two trends of home-based care for older people in Sweden: a decline in the take-up of tax-funded services followed by an increase of care provided by family members – a trend that we labelled re-familialisatio n; and an increase of private provision within the tax-funded services – a trend we labelled marketisation. We asked how to interpret these trends: what are the driving forces and mechanisms behind the changes?

We can conclude that the changes of home-care services in Sweden are driven by a combination of ideologically based market reforms and severe strain on municipal finances. The changes are caused by both legislative changes at the state level and policy decisions at the municipal level. The interplay between central and local decision making is complex, and it is clear that the eldercare sector is affected also by changes in policy fields outside the sector itself.

The decline of tax-funded home care is not a result of legislative changes at the national level. The social legislation still ensures the individual a right to assistance if the needs cannot be met in any other way. Children and other relatives still have no formal responsibility to care for frail older people, and there are no proponents for increased family care in Sweden. But at the local level, many municipalities are adapting to tighter budgets by introducing stricter guidelines for the needs assessment resulting in raised thresholds for eligibility for services. The reduced coverage of home care is thus the result of decisions at the local level which in turn are affected by economic pressure since the recession in the early 1990s. But the municipal actions are also circumscribed by decisions at the central level (e.g. increased national ambitions for disability services as well as for childcare, and restrictions in the municipalities’ right to raise the tax-rates) and at the regional level (a drastically reduced number of hospital beds). However, the decline is probably to some extent also a result of an exit from services by older people themselves. Despite a positive view of tax-funded care services in principal, older people seem to have turned away from the services in practice. Raised user fees (which despite the max-fee reform in 2002 are relatively high for those with smaller care needs and high income) and organisational changes of the home-care services

42 The national survey reports a slight increase in user satisfaction between 2008 and 2010, but the National Board of Health and Welfare argues that it is too early to discuss any trends (NBHW, 2010d p.19).
(such as an increasingly pre-regulated and task-specific way of organising the services) may have made services less attractive.

The Swedish eldercare system is certainly changing very rapidly. The reduced coverage of home care seems to have hit all social groups in a similar way. Working class and middle class older people use the services to the same extent (controlled for class related differences in health) – at least this was the case in 2005. But the reduction of the tax-funded services has not had the same consequences for all social groups. Older people with less education are receiving more family care, while older people with more education instead to a higher extent than earlier buy private services, financed out of pocket. Thus, re-familialisation seems to be an unintended consequence of the contraction of the tax-funded services for less well-off groups of older people.

The trend towards marketisation of Swedish home-care services is more clearly intended by policy makers at the national level. Important legislative changes include the new Local Government Act of 1991 which made it possible for Swedish municipalities to out-source their tax-financed home-care services to private providers. Another market oriented piece of legislation is the Act on Freedom of choice (2008), aimed at facilitating the introduction of consumer choice models in the publicly financed care services. Also the tax deduction for household services, introduced in 2007, is an important legislative change supporting market solutions.

In practice, the combination of income related user fees, consumer choice models and the tax deduction creates an incentive for well-to-do older persons to choose private providers for their tax-funded and needs assessed home-care services which they can complement by buying extra services from the same staff, paying half the actual cost thanks to the tax deduction. For the same social group of older persons but with smaller care needs, the tax deduction serves as an incentive to entirely refrain from the tax-funded home care and instead buy private services.

The accumulation of such small gradual changes may lead to major institutional changes in the long run and to a creeping selectivisation. The Swedish home-care services still seem to be used and appreciated by rich and poor alike. But home care as a universal and individually adapted welfare service is under threat. Extrapolating the present trends, more resourceful groups may become less willing to use the tax-financed services, and the public home-care system may thus become increasingly dominated by groups with fewer resources which in turn, in the longer run, may lead to reduced quality.
9.12. References


USK (2009), Hemtjänsten i Stockholm – en enkät till brukarna hösten 2008, Stockholms stads utrednings- och statistikkontor AB.


VABØ M. (2006), « Caring for people or caring for proxy consumers? », European Societies, no. 8:3, pp. 403-422.

This study identifies how 9 European countries have reformed their home help systems for elderly and disabled, by identifying the drivers of changes and responses in the organisation, provision, regulation and quality of home care/help. Cross-national variation in reforms in home care policies influence the involvement of different care sectors and the use of services vs. cash benefits, shape the degree of formalisation/informalisation and the degree of professionalization, and also contribute to the quality of care.

The study provides a timely overview of recent reforms in the organisation and governance of home care systems in 9 European countries, and elucidates what are the intended and unintended results of the reforms, in particular how reforms have affected outcome for users.