

Costanzo Ranci
Emmanuele Pavolini *Editors*

Reforms in Long- Term Care Policies in Europe

Investigating Institutional Change and
Social Impacts

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Acknowledgments

We became interested in long term care reform for many reasons, the most intriguing of which was that Long Term Care has been one of the few welfare policy areas in which radical, expansive changes and new reforms have taken place in the last years, in contrast with the inertia and tendency towards retrenchment affecting mainstream welfare areas such as pension systems. Yet, in spite of the dramatic changes in the field, and the increasing relevance of long-term care in our aging societies, we realized that no book till date had set out to explain these trends.

We did not want to just give a description of the changes that have taken place in Long Term Care, but also to provide a general interpretation of the broad trends now shaping the field. We wanted to understand how these changes developed; which social and political actors played a significant role in bringing them about; and what institutional mechanisms contributed to the de-freezing of this increasingly relevant policy field. Lastly, we wanted to take into account not only the social and economic drivers for reform, the institutional process and the policy design, but also the social impact of these reforms. By analyzing and explaining how these changes developed throughout Europe, we also wished to contribute to the ongoing discussion about the limits and potential for innovation of current welfare states.

In order to avoid a mere collection of national case studies, we decided to bring together some of the best academic expertise in this policy field, and so asked our colleagues to work with us to build a common analytical framework for the study and subsequently to engage in the analysis of our collective preliminary results. The research group for the study had the opportunity to work together at a series of seminars-funded by SPI-CGIL (the most important Italian trade union including workers and pensioners)-which were held in Milan (2009) and Rome (2010).

We thus first wish to sincerely thank SPI-CGIL, particularly Riccardo Terzi (Director of the SPI-CGIL Research Unit), for sharing our aims and supporting this research project by providing all the funding necessary to organize the seminars and to sustain the national research groups involved in the research. IRES (*Istituto di Ricerche Economiche e Sociali*), and especially Maria Luisa Mirabile, Director of Research in the Social Policy department and editor of *La Rivista delle Politiche Sociali (Italian Journal of Social Policy)*, also played a relevant role in the organization and the scientific coordination of the research and seminars.

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Costanzo Ranci
Emmanuele Pavolini

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Part I
Concepts and Measures

Chapter 1

Reforms in Long-Term Care Policies in Europe: An Introduction

Emmanuele Pavolini and Costanzo Ranci

1.1 Introduction

Long-term care (LTC¹) is one of the most rapidly developing policy areas in Europe, where significant institutional change and innovation have taken place over the last two decades throughout the continent. In contrast to mainstream policy fields (e.g., pensions, labor market policies, and health care), where attempts to reduce public intervention has been the most common trend (Castles 2004, 2005; Korpi and Palme 2003; Pierson 2001), LTC has seen a broader scope of transformations, ranging from retrenchment and cost containment to a growth in public financing and an expansion of coverage. In many European countries, LTC policies over the last two decades have been characterized by a recognition of social rights on the one hand and yet increasing social responsibilities on the other (Morel 2006). This book is aimed at describing these general trends, identifying the factors, which explain these broad developments, highlighting both the main differences between European countries and outlining the main consequences of the various policy developments that have taken place.

¹ We use here a broad definition of LTC, namely, as “a range of services required by persons with a reduced degree of functional capacity, physical or cognitive, and who are consequently dependent for an extended period of time on help with basic activities of daily living (ADL), such as bathing, dressing, eating, getting in and out of bed or chair, moving around and using the bathroom. This personal care component is frequently provided in combination with help with basic medical services such as help with wound dressing, pain management, medication, health monitoring, prevention, rehabilitation or services of palliative care. LTC services can also be combined with lower-level care related to help with instrumental activities of daily living (IADL), such as help with housework, meals, shopping and transportation” (OECD 2011). This definition, however, fails to consider income scarcity, material deprivation, poverty, and housing distress, factors, which are often related to dependency.

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As outlined in greater detail below, our approach to LTC policies is characterized by an institutional perspective. In this book, LTC is seen as one of the main grounds to test the innovative capacities of European welfare systems. Contemporary welfare systems have historically failed to fully recognize the need for care as a social risk, and care as a social activity that has to be supported and promoted. For many decades, care has been mainly considered either as a private obligation or as an individual (or community-based) activity, which has to be replaced by public intervention only in very limited circumstances (lack of family ties, loneliness, poverty, very high degree of disability; Daly and Lewis 1998; Finch 1989; Leira and Saraceno 2004). Institutional changes in LTC policies in the last two decades have brought about a clearer and broader recognition of care as a basic need of citizens and as a social right in many countries. This is a paradoxical result if we consider the timing and the specific conditions under which this process has taken place. The 1990s and the last decade will be largely remembered as an historical phase characterized by welfare cuts (or attempts to do so) and a narrow reorganization of the service provision. However, the trends, which occurred in the LTC field, stand in stark contrast to this general trend within a large number of countries. Yet, how was this possible in a time of cost containment and welfare retrenchment? Furthermore, what were the main driving forces and the most prominent obstacles in this process? What social and institutional forces were activated in order to obtain, or prevent, this result? How has innovation been shaped and what were the institutional mechanisms? What has been the impact of these changes on entitlements to care, on the organization of care provision, and on the care labor market?

We also envisage that our study of the transformations that have occurred in LTC policy in various European countries can help to identify the conditions and social and political processes through which contemporary welfare systems have a chance to change in the attempt to respond to emerging new social needs in a time of strong budgetary restrictions (Bonoli 2006; Taylor-Gooby 2004). Institutional change in LTC policies is not a unidirectional process, but it has taken manifold configurations and has triggered diverse impacts in different countries. While some countries have completely redesigned the setting of their LTC policy, other countries have changed few aspects, or they have just reduced or increased the generosity of previous programs. Even the classic categorization of European countries into distinct care regimes (see below) has partially come under question as a consequence of these changes (Rauch 2007). The purpose of this research is to identify both the commonalities and the specificities of the process of change, and to provide a general interpretation of the direction taken by these changes in Europe.

The countries, which we included in our study, belong to different “welfare regimes” in Europe. Spain and Italy constitute the *Southern European* regime, France, Germany, and Austria the *Continental* regime, the United Kingdom is part of the *Anglo-Saxon* regime, and Sweden and Denmark are part of the *Scandinavian* regime. The Netherlands is a special case, characterized by a combination of Nordic and Continental patterns. The Czech Republic is also included as it belongs to the Central-Eastern European countries, which we also wished to analyze. In order to avoid a mere collection of national case studies, the analysis has consisted of

Table 1.1 An explanatory framework for analyzing policy change

Characteristics of the LTC policy field (institutional setting and level of integration)	
Why	Old solutions vs. new needs and problems problem pressure/public policy crisis
Who	Diagnosis Mobilization of social and political actors and coalition building
How	Mechanisms of institutional change (policy reforms/incremental innovation/adaptation)
What	Outcomes/impacts on funding and coverage levels Regulation of the (formal and informal) care system Work conditions/providers

comparative research carried out by an international group of scholars who are experts in LTC policies in their respective countries. This group of scholars used a common framework for analyzing the transformations in the LTC policies in each country. This framework was based around responding to four key questions:

1. *The “why” question:* What are the causes or factors associated with the development of a specific LTC policy change?
2. *The “who” question:* Who are the coalitions of actors who push for change or stability, what are their values, interests, and resources and their internal composition?
3. *The “how” question:* What are the concrete mechanisms that allow institutional change or stability (inertia)?
4. *The “what” question:* What have been the main impacts of these changes on those with LTC needs, the (formal and informal) organization of care and the working condition of care workers?

This framework was developed by adapting existing frameworks from the academic literature. Indeed, in the literature, there are different approaches to explaining the different institutional settings for social change: from economic to cultural explanations, from political power to a neoinstitutionalist approach (Hacker 2004). Some scholars have tried to adopt multicausal explanatory models of welfare institutional settings configuration. For instance, in their studies on welfare policies in western countries, Esping-Andersen (1990) and Ferrera (2005) developed frameworks in which different explanations are considered and mixed. In order to answer our key research questions, we have adopted the explanatory scheme outlined in Table 1.1, partially based on Ferrera’s (2005) framework.

As the main focus of the book is the changes that have occurred in LTC policies, the first point is the reconstruction of LTC as a policy field. This issue is discussed in the next section of this chapter, with special focus on the institutional characteristics of this policy field. The following section (Sect. 1.3), discusses our institutionalist perspective in respect of the current literature on care regimes. Our goal is not to provide a further typology of care regimes, but to grasp from this discussion the most

important elements characterizing a care regime as an institutional setting wherein change and reforms take place. In Sect. 1.4, we develop our analytical framework for our study of institutional change in the LTC sector in Europe, starting with the “why” question. We argue that the innovation process in the LTC sector begins with a “problem pressure” or a “public policy crisis” that takes place when “old” institutional solutions no longer fit new needs and problems. As a consequence, new solutions must be adopted. Often, old and new actors with specific stakes in LTC policy start to mobilize and reciprocally interact. Through their actions, specific diagnoses and solutions are proposed and discussed. Institutional change can therefore be described as the result of a complex mechanism whereby institutional preconditions lead to the mobilization and intermediation of actors, leading in turn to coalition building. Indeed, the “agency” factor is one of the most relevant aspects that will be investigated in our research in order to answer the “who” question.

Next, we will address the “who” and “how” questions in Sects. 1.5 and 1.6, respectively. Indeed, the overall logic of institutional change can assume different shapes (Streeck and Thelen 2005), ranging from abrupt change to incremental innovation or simple adaptation in continuity with the previous situation. In order to evaluate the continuity/discontinuity of this change, we consider the outcomes, or impact of these policies in Sect. 1.7, looking at the impact of reforms and innovation on the care system, with special attention to funding and coverage level, public regulation, and the working conditions under which care is provided.

1.2 LTC Policies: A Traditionally Low Institutionalized Policy Field

While it is relatively easy to define LTC activities, it is more difficult to define what exactly an LTC policy is. However, the issue is important both for theoretical and empirical reasons. As already noted by Hecló and Wildavsky (1974), more than 35 years ago, a policy is a “variable,” not a constant: the boundaries of a policy field shift over time; they are controversial and in themselves are contested among different actors. Taking a neoinstitutionalist approach (March and Olsen 1989), we expect that, once the LTC policy field has been framed in a specific country in a certain way by a series of actors and acts, unless something relevant happens (e.g., a broad change in people’s needs), the specific definition will have an impact on the way LTC policies develop: the prevailing conditions of various dimensions of LTC (such as health care, work-life balance policies) affect the way in which issues are determined, actors play in the field, rules are applied, and, mainly, solutions are proposed and adopted to avoid the onset of inertia.

LTC has historically been a less “institutionalized” policy field than other welfare policies such as health care, education, and social security. The need for care is a relatively “new social risk” compared to relatively “old social risks” such as poverty or unemployment (Ranci 2010; Taylor-Gooby 2004). LTC emerged in the public discussion only in the 1990s, when population ageing became a more widespread

and growing problem (see Chap. 2 for further details). For a long time, people whose care needs made them dependent on others were not acknowledged the basic rights of citizens (Leira and Saraceno 2004). Instead, they were considered as “dependent family members” or as social assistance recipients. As Saraceno (2008a) articulates, “entitlement to receive care was framed implicitly as an entitlement to be cared for by a female family member. It certainly did not result in a social right.” On the other hand, caring for frail older people was not only considered a moral obligation to be shared by families and society, but it was also constructed as the responsibility of women rather than men. Furthermore, responsibilities to care for older relatives do not allow for the same social entitlements such as paid leave, income support, or pension contributions that are associated with maternity leave. Finally, it is only recently that care policies in some countries have recognized not only the care problems of the dependent but also the material and psychological vulnerability of informal caregivers (Costa and Ranci 2010).

For a long time, therefore, care has been considered as an informal activity that is part of family-based reciprocal obligations, and it has not developed as a professional field characterized by standardization (Ungerson 1997). The relational nature of care as an interpersonal activity implying only a basic professional competence has meant that LTC services are not heavily formalized and has also prevented the rationalization of professional skills and services as it has occurred in the health care domain, where technical and professional skills are more widely recognized. This fact explains why, in contrast from what happened for health care rights, social care rights have been very poorly defined both in terms of service provision and quality requirements. In many countries, care services still have a vague and broad definition, ranging from social assistance to personal help. Professional care workers and care recipients have few uniform criteria that can be used to assess the real contents of care services as well as their quality. The high labor intensity of care services also explains why care is a field highly affected by cost increases and low productivity, preventing the development of a professional market-based provision of services (Baumol 1996).

The most relevant consequence of the lack of formalization of LTC services is that normative definitions and official statements about eligibility criteria do not automatically get put into practice (Leira 1992). Often, there is a great deal of uncertainty about care entitlements. First, the multiple dimensions attached to providing “care” (personal help, social interaction, support for mobility or basic everyday life activity, and so on) have made it relatively difficult to develop specific technical protocols. The needs’ assessment of the dependent is complex in itself as it encompasses multiple aspects, some of which are subject to subjective interpretation. Second, care has been perceived as a relational activity implying a specific adaptation to the needs of the recipient. Notwithstanding this, much effort has been made to provide professional care workers with standardized protocols, of which flexibility, listening capacity, sensitivity, and personal confidence are considered as valuable requirements (Malley and Fernández 2010). As care is still considered a “labor of love” (Finch and Groves 1983; Ungerson and Yeandle 2007), standardization and technical specifications have been very difficult to implement.

Further problems emerge in the organization of care services. Low productivity and high exposure to cost increases (every improvement in the efficiency would imply a significant deterioration in quality) have historically paved the way for a very low growth of private care services (Pauly 1990). Care services have been hugely based on public financing and more recently on the presence of nonprofit providers (Ascoli and Ranci 2002). Only lately new private actors (such as private insurances) have entered the field, attracted by the huge increase in demand for care and the availability of public funds (OECD 2011). In the public sector, the low qualification of care workers and the shortage of qualified providers that operate in the care sector have curbed the growth of care services. The more recent turn to the principles of “ageing in place,” stressing the convenience of care policies focused on domiciliary help rather than the supply of residential facilities, has had further implications for this aspect. On the one hand, as home care services cannot be delivered on a 24 hour basis, they need to be supplemented with additional forms of private or informal domiciliary help. On the other hand, the increasing combination of care and cash measures has been developed on the implicit assumption that an informal, semiformal, or formal caregiver is available to meet the beneficiaries’ need for care (Evers et al. 1994; Pfau-Effinger et al. 2009). Whatever is the level of standardization of professional care, therefore, a relevant part of the responsibility for care is still shared by recipients or their informal care network (if they have one; Österle 2001).

As a consequence of both the weak legal status of social rights to care and the difficulties of implementing a complete care service organization, care can be defined as a supply-conditioned right even in the most generous welfare states, “expressing the intention of government, but not necessarily establishing an entitlement to be claimed here and now. To a considerable extent, the needs of the care dependent are met outside public budgets, by nonpublic bodies or by private individuals, who by necessity or choice accept the responsibility for care provision” (Leira and Saraceno 2004, p. 26).

The gap between official statements regarding the social right to be cared for and the actual organization of the care service system constitutes a peculiar characteristic of care policy, and of the LTC policy field more specifically. Care provision must follow requirements that have been officially stated in the entitlements structure, but it also requires specific organizational conditions that are very often difficult to guarantee for the reasons outlined above. This fact can be understood in terms of Dahrendorf’s (1988) classic distinction between entitlements and provision. Entitlements are defined by Dahrendorf (1988), and also by Sen (1981), as “socially defined means of access” or “entry-tickets” (Sen 1981, p. 11). Provisions are those “things one is entitled to,” “the whole range of material or immaterial choices that may be open up by entitlements” (Sen 1981, p. 12). It is exactly in the space between what is stated about an individual’s basic entitlements to be cared for and the provision of care services on the ground that a relevant part of the problem pressures affecting LTC systems has emerged. The “care deficit” problem emerged in Europe as a critical problem in the early 1990s and it revealed not only the weak status of social rights related to care, but also the poor development of the care service infrastructure. Waiting lists; a high level of rationing, combined with the poor quality of existing

care services; a high reliance of charity or philanthropic institutions providing care; increasing costs shifted on patients and their relatives; and the lack of domiciliary help: all these aspects resulted not only in a limited expansion of the care delivery systems, but also in the weak capacity of European welfare states to better organize service provision. On the other hand, in Scandinavian (and partially Anglo-Saxon) countries where a service-led approach to LTC was already developed (Pavolini and Ranci 2008), care services showed a strong trend toward increasing costs due to low productivity and cost disease, asking for a significant reduction in their provision. In both cases, therefore, a tension between the declared level of entitlements and the actual level of provisions emerged. Also, it is mainly in that space that institutional change has occurred over the last two decades as we will see below.

1.3 Varieties of LTC Regimes

We limit our study of changes in LTC in Europe to the last two decades, when most of the major transformations in LTC policies have taken place. The early 1990s therefore constitute our starting point. At that time, the LTC policy field was structured differently throughout Europe. Two aspects are relevant in this perspective: the institutional setting and the level of integration of the policy domain. By the former, we refer to the *policy legacy* shaping the institutional field of LTC in each country. Policy legacy deals with the type of welfare state tradition (residual, universalistic, etc.) that was specifically dominant in the LTC policy field before reforms started. Policy legacy usually plays a big role in policy reforms due to the fact that it is one of the most influential “structuring” forces in the debate, particularly in determining which direction the reforms should take: actors used to a specific type of welfare state setting will try to apply or to adapt this traditional setting to “new” or less institutionalized policy fields (such as LTC). More specifically, the organization of care in the private or public spheres (e.g., by churches, nonprofit care institutions, care professionals hired by public authorities or by private providers) might create the basis for different perceptions and options of solutions. For instance, the spread presence in Italy of a care gray market run mostly by migrant women, independent from public policy supply, has been and is still nowadays a very relevant sociostructural phenomenon taken into consideration in the LTC policy arena. The opposite situation takes place in Scandinavian countries where there is a strong and consolidated presence of public professional care supply, which is organized and tends to be considered when discussing issues such as “freedom of choice for the dependent person.”

By the latter, we refer to the level of integration of the LTC policy field in each country. An “integrated” policy field is characterized by the existence of a recognized policy field and by joint packages and agencies of intervention. In contrast, we have a policy field structured through “loosely” connected domains. While there is some overlap in organization by different government departments, there is little integration overall, and so intervention runs through separate and parallel institutions and organizations, often with juxtaposed logics of functioning and levels of coordination.

Whether the level of integration of the policy field facilitates or does not facilitate policy change is hardly debatable. The more integrated a policy field is, the more common definitions of problems and solutions are shared by the different policy actors, and the more likely is the formation of strong policy coalitions forwarding or opposing new reforms in the public arena. On the other hand, the more fragmented the LTC policy field, the more contrasting interests shape the policy arena, and the more difficult the introduction of radical changes becomes. A certain level of integration in the LTC policy community therefore seems crucial to allow an appropriate change to this policy field.

The concept of *care regimes* can be fruitfully used to synthesize the two dimensions just considered. This concept has been proposed as a reaction to the well-known concept of “welfare regimes” of Esping-Andersen (1990), and it reflects the critics advanced by many scholars, mainly feminists (O’Connor 1993), to an analytical perspective only focused on the state and market and the relationship between these two institutions, not paying attention to the role played by the family and gender relationships in the practical provision of welfare services (Alber 1995). Therefore, new typologies of “regimes” have been developed in the attempt to incorporate the state–family nexus in the cross-national comparative analysis. In our perspective, care regimes are to be considered as institutional forms codifying peculiar social entitlements (i.e., social right to be cared in the case of need) and related forms of service provision or support (Anttonen and Sipilä 1996; Bettio and Plantenga 2004; Rostgaard 2002). In the present study, the point in question is not related to the classification of specific countries, or the identification of the “right” number of clusters, in order to distinct such regimes. Rather, our use of the concept of “care regimes” is aimed at identifying the main factors explaining cross-national variations in the distribution of caring responsibility among the different actors of the care system (State, family, voluntary sector, market) in order to identify the institutional setting and the level of integration of this policy field in the different countries considered.

Care regimes have been firstly defined in relation to the extension of State responsibility to provide care in contrast with family obligations. This is the approach suggested in a seminal paper by Daly and Lewis (1998), where the authors distinguished between Scandinavian countries (where care is made available to people by the State on a universal basis) and continental countries (characterized by the privatization of care, via family or voluntary provision). Anttonen and Sipilä in their well-known paper on European social care services (1996) honed this framework, adding two aspects:

1. the difference between State and family care responsibility is associated with a higher or lower activity rate of women in the labor force;
2. between the State-based model and the family-based model lies an intermediate model (a central European subsidiarity model), where responsibility for care lies with the family but the volume of social care provision is at an intermediate level.

More recently, empirical studies of national care systems and the development of comparative analysis have contributed to an attenuation of the strong contrast

between state-led regimes and family-led regimes. Still in the feminist perspective, care regimes have been identified by considering to what extent they contribute to the degendering of welfare states (Knijn and Ungerson 1997), so identifying care regimes in respect of the strength of the so-called male breadwinner/female caregiver model. In the same perspective, Bureau et al. (2007) introduced the concept of “predominate support strategy” distinguishing between public (universalistic), targeted, and family models. Analyzing home care, they found that public support can be either formal care service provision or economic support for informal caregiving. The former is predominant in countries adopting a public strategy (Sweden, the Netherlands) and the latter is predominant in family care-based countries (Germany, Italy).

In a different perspective, focused not on familialism but on the tradeoff between work and care, care regimes have been identified according to the extent to which women have the right to choose between working and caring. According to Rostgaard (2002), the main policy factor is not the distinction between in-kind service provision and cash benefits distribution, but the extension of public intervention. She identifies three models: a female care giver model (women stop working in order to provide care, public provision is mainly through cash benefits); a dual breadwinner model (extensive public provision of care, women mostly at work), and a family–work model (abundant supply of public services, an elevated compensation rates of cash benefits, and flexibility in the labor market, allow families to choose their own preferable care arrangement).

A different perspective has been developed by scholars who took into account not gender relations, or the care/work tradeoff, but the institutional setting within which public care is provided, i.e., the institutional logic according to which care services are organized and provided to the population (Bettio and Plantenga 2004; Jensen 2008). In this respect, care regimes should be considered as further developments of traditional welfare regimes, from which the new programs take the basic regulatory and institutional setting. From this perspective, three main systems have been identified: a Beveridgean approach (where LTC has been integrated within the existing public regulatory system for health and social services, based on universal principles); a social risk approach (LTC has been recently recognized as a new “incomplete” social right); and a social assistance approach (services are provided on the basis of assistance principles, and public care is considered as a means-tested, complementary solution). A similar analysis is proposed by Simonazzi (2009), who identifies care regimes on the basis of their entitlement structure. Simonazzi distinguishes a Beveridge-oriented system (care services are universally defined but are means-tested or income-related), a Bismark-oriented system (a universal scheme is aimed at avoiding social assistance), and a Mediterranean model (based on the principle of social assistance). France is considered as a mixed case between the Beveridgean and Bismarkian systems.

In a similar neoinstitutionalist perspective, Alber proposed to look at the institutional organization of social service provision. Indeed, the public intervention in this field is often characterized by a high level of vertical and horizontal subsidiarity: local public administrations, voluntary and church-related organizations each take a relevant part of the responsibility to provide care (Alber 1995). Therefore,

cross-national variations should be explained by paying attention to the institutional and organizational features of the national social services systems, with special attention paid to intergovernmental relations.

This institutionalist approach seems relevant as it is focused on both the recognition of social care as a social right and the organization of care provision. As already explained, LTC regimes are organized on two levels—entitlements and provisions—among which there are relevant gaps and tradeoffs. Care regimes identify not only different forms of care provision, but also specific forms of recognition of care as a social right. Entitlements have been established in order to select the right to access to services and provision, to limit opportunistic behaviors, to control costs and quality of services. It is highly probable that the institutional setting has been inspired by previous knowledge and experience in similar policy fields, such as care for older people, health care, and income support benefits. Thus, the new entitlements to LTC can be variously related to other rights that had previously been recognized. The entitlement structure requires that some form of public responsibility (both to cover cost and provide services or support) should be developed and institutionalized. This is exactly the focus of our research. In our perspective, therefore, care regimes are to be considered as institutional forms codifying particular social entitlements (i.e., the social right to receive care in the case of need) and related forms of service provision or support (including coverage of costs of care).

1.4 The “Why” Question: Opportunities and Constraints of Long-Term Care Policy Change

A series of factors have contributed to the path for institutional change in LTC policy. In comparative social welfare theory, this aspect is commonly considered in terms of *problem pressure*. Problems may rise from the outside as well as from the inside of the welfare state: on the one hand, social and economic transformation can create new social needs that are not adequately addressed by the existing measures, while on the other hand, inner financial or political constraints can call for a change in the previous institutional setting. Therefore, problem pressure can be considered as a window of opportunity for enlarging public intervention, but also as a new constraint requiring significant reduction in the existing public programs.

A problem pressure can be understood, according to Ferrera (2005), as an increasing gap between (emerging) social needs and the preexistent repertoire of policy measures aimed at addressing these needs. Conventional social programs can be understood as policy solutions that were found to solve previous problems: but social and/or institutional new situations can make the traditional repertoire of solutions obsolete, or inadequate. A new response is therefore needed, even though this is not always recognized. Only when this gap is recognized in the public arena, then a “public policy crisis” may be opened, and innovation has some chance of taking place. In this process, therefore, problem pressure is a necessary, though on its own insufficient, condition for institutional change and policy innovation.

Assistance for frail (older) people has historically been one of the first and most widespread forms (since the Middle Ages) of social aid through the use of shelters for the (older) poor. After World War II and until the 1980s, there were policies that we can define as “elder care” with a definition that is, however, partially different from the one adopted today for LTC. Those policies were less directed to persons with a reduced degree of functional capacity and more to older people with limited means. The typical policy instrument of traditional care policies until the 1980s was residential institutions for the poor, or lone older people, sometimes (but not necessarily) dependent, whereas nursing homes (designed for people with a mix of health and social care needs) were less diffuse.

From the 1970s, under the pressure of specific interest groups, new public programs were introduced in many European countries to address the need for care and social reintegration of adults with disabilities. Scandinavian countries also developed a generous supply of care services for older people as part of their generous approach to welfare (Anttonen and Sipilä 1996). With the relevant exception of adults with disabilities, chronic diseases, and heavy dependence were not wholly recognized as particular social risks in other European countries. Services such as nursing, long-term rehabilitation, and social care were considered as residual, mainly provided by families, voluntary organizations, public or religious institutions specialized in humanitarian help and social assistance. Until the beginning of the 1990s, only few European countries had introduced a nation-wide program recognizing LTC as a clear social right. Public programs were mainly aimed, at that time, at supporting the income, and only indirectly the care needs of dependent people: poverty, not care needs, was considered the real social risk, which people had the right to be protected against.

The 1990s were the turning point for LTC policies in many European countries. Many relevant social changes had put renewed pressure on the existing systems of LTC. The demographic structure of the population begun to change all over Europe as a consequence of the ageing process: an effect of the improvement of the material living conditions of the middle classes but also of the better quality of health care (see Chap. 2). Contrary to many pessimistic predictions, the higher number of old people has come with a reduced relative degree of morbidity and dependency, therefore increasing only moderately the number of people in need of care (Lafortune and Balestat 2007). However, if not the quantity, it was the quality of care that increasingly became significant: the higher percentage of dependent older people increased the need for *multidimensional* care, with the social and health aspects of care becoming strongly interrelated. If demographic trends only partially contributed to increasing the pressure for change, it was the transformations occurring in the social organization of care that hugely changed the situation. For many decades, the provision of care had been mainly granted by family networks in most of European countries. In 2001, Österle estimated that informal care still covered around three quarters of the total care for people with disabilities in western European countries, attributing a very secondary role to public protection. Starting from the 1990s, this (either implicit or explicit) intergenerational reciprocity system has been increasingly weakening for a number of reasons (Österle 2001; Saraceno 2008b), as outlined below.

First, the transformations in the forms of households helped to increase the demand for care, which could not be satisfied by members of the same household: the numbers of older people living alone has in fact been increasing in all European countries, while the number of those living with their children has been decreasing (see Chap. 2 for details). This was set against a progressive decrease in the potential for support from kinship networks. A first factor was the worsening of the old-age dependency ratio as a consequence of the reduction in the effect of the generation turnover. The rise of the older population, joined with the progressive reduction in the fertility rate, has reduced, and is still progressively reducing, the availability of family caregivers. A second factor, which has weakened the caregiving capacity of informal networks, is the increase in female participation in the labor market. The effects of higher female employment on informal care for older people are not clear. According to some research (Costa and Ranci 2010; Lamura et al. 2003), the increase in female employment rates does not significantly reduce caregiving activity when it is only for a few hours per week, while it has an appreciable effect on caregiving for those who require continuous assistance, making home care services or institutionalization in residential facilities necessary. Generally, while there is uncertainty over the decline in the number of informal caregivers, it is likely that the total time spent on caregiving has been constantly decreasing over the last few decades.

Therefore, the persistent increase in female participation in the labor market (especially of women aged between 40 and 60 years), and the corresponding increase in the number of dependent aged people, have conjured together to bring the dominant traditional, family-based care system close to a collapse. The organization of families and the integrity of relations between generations were put under pressure. Moreover, the presence of a dependent person in low-income families increased the risk of poverty, and the augmented use of private care services by the most dependent exposed the poorest groups in the population to further risk of poverty. In other words, a social reorganization based on dependency has been taking place in the last two decades. Dependency therefore challenged the integrity of relations between generations within families. Alternative solutions were not readily available. The traditional response to the lack of family care was the institutionalization of dependent older people in residential facilities: a solution increasingly too expensive as the quality standards of these structures improved. Such facilities were also less accepted as a viable solution, as the type of care provided can often compromise resident's independence.

The reduction in family care obligations and the subsequent increase in care requirements have together created a strong pressure on public health care systems, on the cash programs aimed at supporting the income of the dependent, and on the local assistance programs providing the dependent with residential institutions, home care, and daily services. The demand for these services increased at a time when cost containment, rather than service expansion, was the issue most at stake (Pierson 2001). The highest pressure came from the rising costs of hospitals and high-intensity caring needs, but also local assistance programs were increasingly under pressure because of the growing number of people requiring home care and daily care services. Therefore, many countries had to reduce their health care system's

operating costs and local social assistance by redirecting the rising demand for care to less expensive care options, or by reshaping the preexisting care programs.

As a consequence, a tradeoff emerged between the need to provide more and more people with care not supplied by families on the one hand, and the need to control the huge increase in public costs, mainly weighting on public health systems on the other. This problem went unresolved for many years as no suitable solution could be found. However, this was, in our view, a good condition to foster institutional change in many countries. The Nordic and Anglo-Saxon countries, which had already developed an extensive public structure of social services, had to adapt their care provision systems to the new situation. The Mediterranean and Central-Eastern countries, in contrast, could enjoy a stronger support provided by family solidarity even though the tendency of women to participate in the labor market had become very high, especially in latter countries. Continental countries were much more deeply affected by the ageing process and the weakening of family ties than other countries on the one hand; and at the same time they could not rely on an already established structure of public care services, on the other. Therefore, they had to create innovative solutions in order to find a way to get through the Scilla of enlarging entitlements and care provision and the Cariddi of cutting public expenditures.

As already stated, an increasing gap between problems and solutions does not necessarily lead to policy innovation (Ferrera 2005). However, the gap can lead to a public crisis, encouraging new actors to bring new ideas and solutions to the policy arena. Counterforces will often resist change and therefore a collective decision-making process will be required. In the field of LTC policy, the absence of the definition of “long-term care” in many countries created additional problems. In contrast, in the countries where a working definition of care for the dependent was already in use, a redefinition of the term had to take place in order to facilitate the operation of new policies. In countries where LTC was nonexistent, a new policy field had to be invented and new political and technical definition of “long-term care” had to be agreed about among the relevant policy actors.

1.5 The “Who Question”: The Role of Actors in LTC Policies

An analysis of LTC policies and institutional change cannot avoid the issue of *agency*: as Lundquist (1980) wrote many years ago, the policy actors are those who make policies, not contextual factors. Capano and Howlett (2009) underline the importance of agency and, in particular, of policy leadership in the event of significant changes: “radical changes develop through a complex process in which focal events, critical junctures and policy windows offer opportunities for change. Therein lies the case for the strategic role of agency; the ongoing momentum has to be taken advantage of (. . .). Policy entrepreneurs are those capable of discovering new needs and solutions, of dealing with a high degree of uncertainty, and of resolving the problem of collective coordination” (Capano and Howlett 2009, pp. 225–226). The same scholars also argue that policy leadership is not necessarily an individual mission, but a collective

Table 1.2 The actors potentially involved in the LTC policy arena

Public actors	Private social actors
<i>National level</i>	
National governments (role of ministries of finance vs. other “welfare” ministers)	<i>Actors with direct interests in provision</i> Trade unions representing care workers
LTC ministry or the main ministry formally in charge of LTC policies (if present)	Private welfare-related enterprises (e.g., health insurance companies, etc.)
Other welfare sectors institutional actors/stakeholders (health care ministry, etc.)	The Church or other (nonprofit) delivery agencies
Top civil servants working in the LTC policy area	
<i>Subnational or supranational level</i>	
Local governments	<i>Actors with a more general interest in LTC</i> Trade unions in general
The European Union	Representatives of private economic enterprises Intellectuals/experts (economists, etc.) Carers/users’ associations Mass media

undertaking, involving different people at different institutional levels and policy stages: “to produce effective policy change, simply changing the agenda (matching new solutions to old problems or reframing the meaning of policy) is not enough: the ‘new’ solutions must pervade all policy domains, and leadership must be provided at different institutional levels and areas of policy” (Capano and Howlett 2009, p. 227).

Given the policy field analyzed, the main actors playing a role in the LTC arena can be divided into two broad categories: public and private actors (see Table 1.2). Of the public actors, there is a first set working mainly at the national level: governments (with possible internal conflicts among ministries in charge of the budget—Ministry of Finance—and welfare ministries always seeking more resources), the specific Ministry formally in charge of LTC issues (if there is one), other welfare policies actors with their own agenda and interests in LTC policies (e.g., to shift burden and costs from their own policy field to LTC), and the top bureaucracy dealing with the LTC policy area. A second set of public policy actors are those coming from local governments (given the importance of these actors in many countries for LTC policies) and from the European Union (through directives, benchmarking, etc.).

The private actors can also be divided into two broad subsets on the basis of their type of interest. We can differentiate between actors primarily interested in influencing LTC policy, because they have a direct stake in LTC provision (trade unions on behalf of workers in the sector; private enterprises providing care services; the Church; health insurers willing to open up new markets; and other, often nonprofit, delivery agencies as direct providers of services) and actors with a more general interest in the development of LTC policies (from users’ associations to experts, mass media and representatives of private economic enterprises, and again, trade unions), where the concept of development can point to possible different ideas about reform (either improving public financial support as in the case of users’ associations, or cutting down welfare costs as in the case of the representatives of private economic enterprises).

What is important about these actors is not only who they are and how they individually try to influence LTC policies, but also how they interact with each other, participating in (more or less) stable leading “coalitions” (Sabatier 1988), which will be examined in this study in terms of beliefs, interests, and resources.

1.6 The “How” Question: Institutional Change and LTC Policies

Institutional change, in reference to LTC policies, can be understood as change in the main institutions regulating the financing and provision of interventions in favor of persons with LTC needs. By institution, we adopt Hall and Thelen’s (2009) definition: “sets of regularized practices with rule-like quality in the sense that the actors expect the practices to be observed; and which, in some but not all cases are supported by formal sanctions. They can range from regulations backed by the force of law. . . to more informal practices that have a conventional character” (p. 9). How institutional change occurs is at the heart of a decades-long debate. Among all the possible explanations, we have focused on two: the Hall (1993) model of three orders policy change and Streeck and Thelen’s (2005) typology of institutional change.

In his seminal paper of 1993, Peter Hall described three types of policy changes, depending on the “order”/level in which these changes take place: “third-order” policy changes take place when there is a shift in the overarching goals that guide policy in a particular field; “second-order” ones are related to changes in the techniques or policy instruments used to attain those goals and the easier changes are the “first-order” ones related to the precise settings of these instruments. Somewhat differently, Streeck and Thelen (2005) adopt a typology, which underlines how along with more traditional explanations of institutional stability (which they defined “Reproduction by adaptation”) or abrupt/disruptive institutional change (“Breakdown and replacement”), often due to external shocks,² there is a chance of incremental but disruptive institutional change through “gradual transformation.” This second explanation argues that institutional change can be incremental and not necessarily abrupt. Far-reaching change can be accomplished through the accumulation of small, often seemingly insignificant adjustments: gradual transformation means institutional discontinuity caused by incremental, “creeping” change, often endogenous and in some cases produced by the very behavior an institution itself generates. Therefore, significant change can often emanate from inherent ambiguities and “gaps” that exist by design or emerge over time between formal institutions and their actual implementation or enforcement: “these gaps may become key sites of political contestation over the form, functions, and salience of specific institutions whose outcome may

² This is one of the most widespread explanations of change in the social sciences, based on the idea that institutions tend to be path dependent (once a certain institution is set, due to a series of events, it tends to maintain inertia over time and finishes with reinforcing itself with a lock-in effect); only in the case of relevant external shocks (e.g., relevant economic and political crisis) will institutional change take place (Pierson 2001).

be an important engine of institutional change. . . Political institutions are not only periodically contested; they are the object of ongoing skirmishing as actors try to achieve advantage by interpreting or redirecting institutions in pursuit of their goals, or by subverting or circumventing rules that clash with their interests” (Streeck and Thelen 2005, p. 19). Streeck and Thelen propose five types of gradual transformative change: *displacement*, *layering*, *drift*, *conversion*, and *exhaustion*.

With a perspective integrating the previous one, Palier (2010) has explained the defreezing process that has recently characterized the Bismarckian welfare systems on the basis of the accumulation of small, incremental changes: “because of the ‘stickiness’ of welfare state institutions (Pierson 2001), and because of their huge popularity, governments were not able to change the whole system even when they claimed that these systems were failing to deal with economic and social issues. Rather, changes were initially incremental, passing through an intermediary phase based on a relatively ‘silent’ evolutionary institutional transformation (changes in financing, changes in power relations), that . . . facilitated structural reforms based on a new social policy paradigm. . . Even these new social policies have not entirely replaced the former ones, but merely contributed to a conversion of the old system to the new goals” (Pierson 2001, p. 365). The idea here is that the structural addition of institutional transformations over many years has constituted a sort of “critical mass” causing, without an explicit political decision, a radical discontinuity with the old welfare system. Only a long-time perspective on change is able to catch the real impact of a sequence of institutional relatively minor events, not individually significant if not considered within a more general sequence.

This is why we consider the institutional changes in LTC policy that have occurred in a time span of two decades, ranging from the early 1990s to the end of the first decade of the 2000s. This extended time span is essential to allow a consideration of the whole range of changes taking place all over Europe, generally moving a part of the welfare state that was considered, at the beginning of this period, as residual or marginal in most of the European countries, to occupying a more central position, being the object of relevant nation-wide reforms. This process has occurred through an exponential number of major and minor institutional changes, which need to be considered in their time and logical sequence in order to understand what has been their social and institutional impact. We thus rely on theories of institutional change stressing the temporal succession of events in order to contextualize our findings. Finally, we argue that most of the recent literature on institutional change mechanisms has two shortcomings, which become relevant when applied to studying LTC policies:

1. The literature does not usually take into consideration institutional multilevel relations in each country.
2. The focus of research in the last two decades has been mainly on “welfare retrenchment” more than welfare restructuring and expansion.

First, the fact that the international literature is more focused on national mechanisms of policy change, though it might make sense in other fields of policy, becomes a more inadequate choice when applied to welfare policies such as LTC, where a relevant

role is played by local actors. Therefore, following Alber (1995), we argue that, no matter which institutional change theory is adopted, there is a need to introduce as a focus of analysis not only the national level but also the local one and the interplay between these two levels as a key area where institutional change takes place (also due to the fact that LTC is a relatively decentralized policy area): some sort of multilevel institutional change has to be considered.

Second, most of the recent literature on institutional/policy change tends to investigate how governments are able to “impose losses” without losing political power (Clasen and Siegel 2007): the main issue deals with “welfare retrenchment,” whereas, in the case of LTC policies, what seems to be happening in most countries is a situation that can be better described in terms of either “welfare restructuring” or “expansion.” This means that institutional change mechanisms have to be interpreted as a way of not necessarily reducing welfare protection but of rearranging or expanding it.

1.7 The Impact of LTC Reforms/Change

Coming to analyze the implementation of LTC reforms, we can focus on four different impacts: the level of expenditures and coverage levels; the level of familization or defamilization of care; the organization of the care delivery system; and the working conditions of workers providing care, either on an individual or collective basis. The first impact is related to the impact of innovations on the entitlements to and the provision of LTC. While universalism has been considered as the basic principle of innovation in some countries, selectivity on the basis of need and means testing has been the main goal elsewhere. As care is still mainly grounded on the families’ care capacity throughout Europe, institutional changes also have to be evaluated in respect of their impact on family care arrangements, in order to understand the extent to which they have favored (or reversed) a further defamilization of care. As far as the impact on the regulation of the care system goes, innovation has assumed different configurations, varying from State centralization to local decentralization of public responsibilities, and from assuring more equality in the care provision to diversifying services in order to meet the demand of emergent specific targets. Further impacts have been related to the efficiency and the quality of care provision: a number of new measures have been introduced in order to increase the productivity of care services, to guarantee freedom of choice to users or to empower them, or else to better integrate social and health care (Da Roit and Le Bihan 2010).

Institutional change in LTC policies has not only affected the care delivery system, but it has often been closely linked to specific employment strategies. In many countries, cash for care programs (and public measures supporting, or tolerating, the growth of a transnational care market grounded on the low-cost supply of care work by immigrants), have led to the development of low-skilled, low-paid, care jobs. Home care services have been strongly advocated almost all over Europe as a strategy to keep “ageing in place,” but this care activity remains low-skilled and low-paid in many countries, so contributing to the occupational growth in a marginal,

lowly professionalized sector. At the same time, a new generation of social measures has been introduced in many countries to support the caring responsibilities of informal caregivers (including both family members cohabiting with the dependent persons and other family members and friends). Further programs have been aimed at supporting the work–care conciliation strategies of informal caregivers (also by protecting their work rights and supporting their contributory pension records). Generally speaking, therefore, care policies have not only impacted on the care needs of the dependent, but they have also contributed to the creation of new, low-skilled jobs in the field, and have affected the caregiving activity of working women.

References

- Alber, J. (1995). A framework for the comparative study of social services. *Journal of European Social Policy*, 5(2), 131–149.
- Anttonen, A., & Sipilä, J. (1996). European social care services: Is it possible to identify models? *Journal of European Social Policy*, 6(2), 87–100.
- Ascoli, U., & Ranci, C. (Eds.). (2002). *Dilemmas of the welfare mix. The new structure of welfare in an era of privatization*. New York: Springer.
- Baumol, W. J. (1996). Children of performing arts, the economic dilemma: The climbing costs of health care and education. *Journal of Cultural Economics*, 20, 183–206.
- Bettio, F., & Plantenga, J. (2004). Comparing care regimes in Europe. *Feminist Economics*, 10(1), 85–113.
- Bonoli, G. (2006). New social risks and the politics of post-industrial social policies. In K. Armingeon & G. Bonoli (Eds.), *The politics of post-industrial welfare states. Adapting post-war social policies to new social risks* (pp. 3–26). London: Routledge.
- Burau, V., Theobald, H., & Blank, R. H. (2007). *Governing home care: A cross national comparison*. Cheltenham: Elgar.
- Capano, G., & Howlett, M. (Eds.). (2009). *European and North American policy change. Drivers and dynamics*. Oxon: Routledge.
- Castles, F. G. (2004). *The future of the welfare state: Crisis myths and crisis realities*. Oxford: Oxford University Press.
- Castles, F. G. (2005). Social expenditure in the 1990s: Data and determinants. *Policy and Politics*, 33(3), 411–430.
- Clasen, J., & Siegel, N. (Eds.). (2007). *Investigating welfare state change*. Cheltenham: Edgar.
- Costa, G., & Ranci, C. (2010). Disability and caregiving: A step toward social vulnerability. In C. Ranci (Ed.), *Social vulnerability in Europe. The new configuration of social risks* (pp. 159–185). Basingstoke: Macmillan.
- Da Roit, B., & Le Bihan, B. (2010). Similar and yet so different: Cash-for-care in six European countries' long-term care policies. *The Milbank Quarterly*, 88(3), 286–309.
- Dahrendorf, R. (1988). *The modern social conflict. An essay on the politics of liberty*. Berkeley: University of California Press.
- Daly M., & Lewis, J. (1998). Introduction: Conceptualizing social care in the context of welfare state restructuring. In J. Lewis (Ed.), *Gender, social care and welfare state restructuring in Europe* (pp. 1–24). Aldershot: Ashgate.
- Esping-Andersen, G. (1990). *The three worlds of welfare capitalism*. Princeton: Princeton University Press.
- Evers, A., Pijl, M., & Ungerson, C. (Eds.). (1994). *Payments for care. A comparative overview*. Brookfield: Ashgate.

- Ferrera, M. (2005). *The boundaries of welfare. European integration and the new spatial politics of social protection*. Oxford: Oxford University Press.
- Finch, J. (1989). *Family obligations and social change*. London: Routledge.
- Finch, J., & Groves, D. (Eds.). (1983). *A labour of love: Women, work and caring*. London: Routledge.
- Hacker, J. (2004). Privatizing risk without privatizing the welfare state. *American Political Science Review*, 98(2), 243–260.
- Hall, P. (1993). Policy paradigms, social learning, and the state: The case of economic policy-making in Britain. *Comparative Politics*, 25(3), 275–296.
- Hall, P., & Thelen, K. (2009). Institutional change in varieties of capitalism. *Socio-Economic Review*, 7(1), 7–34.
- Hecló, H., & Wildavsky, A. (1974). *The private government of public money. Community and policy inside British politics*. London: Macmillan.
- Jensen, C. (2008). Worlds of welfare services and transfers. *Journal of European Social Policy*, 18(2), 151–162.
- Korpi, W., & Palme, J. (2003). New politics and class politics in the context of austerity and globalization: Welfare state regress in 18 countries, 1975–1995. *American Political Science Review*, 97(3), 425–446.
- Knijin, T., & Ungerson, C. (1997). Introduction: Care work and gender in welfare regimes. *Social Politics*, 4(3), 323–327.
- Lafortune, G., & Balestat, G. (2007). *Trends in severe disability among elderly people: Assessing the evidence in 12 OECD countries and the future implications* (OECD Health Working Paper No. 26). Paris: OECD.
- Lamura, G., Melchiorre, G., Quattrini, S., Balducci, C., Spazzafumo, L., & Barbagallo, M. (2003). Eurofamcare. *Giornale di Gerontologia*, 52, 5.
- Leira, A. (1992). *Welfare States and Working Mothers: The Scandinavian Experience*. Cambridge: Cambridge University Press.
- Leira, A., & Saraceno, C. (2004). Care: Actors, relationships and contexts. The multidimensional concept of care. In B. Hobson, J. Lewis, & B. Siim (Eds.), *Contested concepts in gender and social politics* (pp. 55–83). London: Elgar.
- Lundquist, L. J. (1980). *The hare and the tortoise: Clean air policies in the United States and Sweden*. Ann Arbor: University of Michigan Press.
- Malley, J., & Fernández, J.-L. (2010). *Measuring quality in social care services: Theory and practice*. *Annals of Public and Cooperative Economics*, 81(4), 559–582.
- March, J. G., & Olsen, J. P. (1989). *Rediscovering institutions*. New York: Free Press.
- Morel, N. (2006). Providing coverage against new social risks in Bismarckian welfare states: The case of long-term care. In K. Armingeon & G. Bonoli (Eds.), *The politics of post-industrial welfare states*. London: Routledge.
- O'Connor, J. S. (1993). Gender, class and citizenship in the comparative analysis of welfare state regimes: Theoretical and methodological issues. *The British Journal of Sociology*, 43(4), 501–518.
- OECD (2011). *Help wanted? Providing and paying for long-term care*. Paris: OECD.
- Österle, A. (2001). *Equity choices and long-term-care policies in Europe*. London: Ashgate.
- Palier, B. (Ed.). (2010). *A long good-bye to Bismarck. The politics of welfare reform in continental Europe*. Amsterdam: Amsterdam University Press.
- Pauly, M. (1990). The rational nonpurchase of long-term-care insurance. *Journal of Political Economy*, 98(1), 153–168.
- Pavolini, E., & Ranci, C. (2008). Restructuring the welfare state: Reforms in long-term care in western European countries. *Journal of European Social Policy*, 3, 246–259.
- Pfau-Effinger, B., Flaquer, L., & Jensen, P. H. (2009). *Formal and informal work. The hidden work regime in Europe*. London: Ashgate.
- Pierson, P. (2001). *The new politics of the welfare state*. Oxford: Oxford University Press.

- Ranci, C. (Ed.). (2010). *Social vulnerability in Europe. The new configuration of social risks*. Basingstoke: Palgrave.
- Rauch, D. (2007). Is there really a Scandinavian social service model? *Acta Sociologica*, 50, 249–269.
- Rostgaard, T. (2002). Caring for children and older people in Europe—A comparison of European policies and practices'. *Policy Studies*, 23(1), 51–68.
- Sabatier, P. (1988). An advocacy coalition framework of policy change and the role of policy-oriented choice. *Policy Sciences*, 21(1), 56–71.
- Saraceno, C. (2008a). *Gender and care: Old solutions, new developments?* Annual Hirschman Lecture delivered at the European University in Florence, Italy.
- Saraceno, C. (Ed.). (2008b). *Families, ageing and social policy. Intergenerational solidarity in European welfare states*. Cheltenham: Elgar.
- Sen, A. (1981). *Poverty and famines*. Oxford: Clarendon Press.
- Simonazzi, A. (2009). Care regimes and national employment models. *The Cambridge Journal of Economics*, 33(2), 211–232.
- Streeck, W., & Thelen, K. (Eds.). (2005). *Beyond continuity: Institutional change in advanced political economies*. Oxford: Oxford University Press.
- Taylor-Gooby, P. (2004). *New risks, new welfare*. Oxford: Oxford University Press.
- Ungerson, C. (1997). Social politics and the commodification of care. *Social Politics*, 4(3), 362–382.
- Ungerson, C., & Yeandle, S. (Eds.). (2007). *Cash for care in developed welfare states*. Basingstoke: Macmillan.

Chapter 2

Long-Term Care Systems in Comparative Perspective: Care Needs, Informal and Formal Coverage, and Social Impacts in European Countries

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and Alessia Sabbatini

2.1 Introduction

The aim of this chapter is to provide an overview of long-term care (LTC) policies in Europe and other OECD countries in order to contextualize the findings presented in the other chapters of this book. While the individual country case studies outlined in subsequent chapters offer detailed accounts of LTC policies in various countries throughout Europe, this chapter develops a broad framework based on comparative statistical data, which in turn sets out the general background to transformations that have taken place in recent years with respect to both the demand for and the institutional responses to LTC. This chapter is organized around four themes central to the organization of LTC in Europe: the characteristics and the changing demands of LTC recipients; the organization of informal care; the organization of public (statutory) support; and the impacts of the various “care regimes” on users and their informal carers.

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The picture that emerges identifies, on the one hand, a “universalistic” model, consisting of countries with elevated public spending on LTC, and consequently, highly developed services, and, on the other hand, countries with basic public expenditure, basic coverage, and LTC services, which remain underdeveloped. For the latter, the risk of increases in social and gender inequality is very high (according to relevant data, two-thirds of caregivers are women), particularly in terms of guaranteeing access to care for care recipients and in reconciling caring responsibilities and participation in the labor market for informal caregivers.

2.2 Demand for LTC

2.2.1 *The Ageing Population Over Time: Past, Present and Future*

Eurostat data clearly show that there has been a progressive increase in the older population in all European countries (Eurostat 2011). Indeed, over the last few decades, the proportion of the population aged 65+ has consistently grown, not only in Europe but throughout the OECD. This transformation is likely to have a significant impact on the majority of European countries over the coming decades with serious implications for pensions, health, and social care systems (Christensen et al. 2009; Comas-Herrera et al. 2006; European Commission 2011).

Eurostat (2011) figures estimate that, in 2060, the percentage of people aged 65+ in EU-27 countries will be 29.3 % of the total population. Compared with the 2010 average percentage (16 %), the increase will be in the region of 13 %. Similar trends can be found for the population aged 80+, which in 2010 represented on average 4 % of the population and is expected to exceed 10 % by 2060; in some Mediterranean countries such as Spain and Italy, it may be up to 14 %. The old-age dependency ratio, which measures the relationship between the population aged 65+ and the working-age population (15–64 years), was 23.6 % in Europe in 2010, is expected to almost double in value by 2060, reaching 52.4 %.

The data presented in Table 2.1 help to illustrate the dynamics of population ageing. In particular, it shows that the percentage of the older population (65+ years) increased by more than 70 % between 1970 and 2010 in southern Europe, as well as in Bulgaria, Romania, and Finland. More significant increases occurred in the proportion of the population aged 80+: Finland, Spain, Italy, Portugal, and Poland experienced increases of more than 200 % between 1970 and 2010, while almost all of the other countries registered increases of more than 100 %.

2.2.2 *Disability and Dependency in Europe: Some Estimates*

It is possible to distinguish between three different theoretical approaches to the study of the relationship between demographics, increased life expectancy, and disability; all of which are based on the assumption that disability rates are growing. The first

Table 2.1 Percentage of the population aged 65+ and 80+ in 1970, 1990, and 2010 (ranked by percentage of the population aged 65+ in 2010). (Source: Adapted by the authors from Eurostat 2011)

	Percentage of population aged 65+			Percentage of population aged 80+		
	1970	1990	2010	1970	1990	2010
Germany	13.5	14.9	20.7	1.9	3.7	5.1
Italy	10.8	14.7	20.2	1.6	3.1	5.8
Sweden	13.6	17.8	18.1	2.3	4.2	5.3
Austria	14.4	14.9	17.6	2.1	3.5	4.8
Spain	9.5	13.4	16.8	1.5	2.8	4.9
France	12.8	13.9	16.6	2.3	3.7	5.2
UK	12.9	15.7	16.4	2.2	3.6	4.6
Denmark	12.2	15.6	16.3	2	3.7	4.1
The Netherlands	10.1	12.8	15.3	1.7	2.9	3.9
Czech Republic	11.9	12.5	15.2	1.5	2.4	3.6
Greece	n.a.	13.7	18.9	n.a.	3	4.6
Portugal	9.2	13.2	17.9	1.3	2.5	4.5
Bulgaria	9.4	13	17.5	1.4	2.1	3.8
Latvia	11.9	11.8	17.4	2.1	2.8	3.9
Belgium	13.3	14.8	17.2	2.1	3.5	4.9
Estonia	11.7	11.6	17.1	1.9	2.5	4.1
Finland	9	13.3	17	1.1	2.8	4.6
Hungary	11.5	13.2	16.6	1.5	2.5	3.9
Slovenia	n.a.	10.6	16.5	n.a.	2.2	3.9
Lithuania	10	10.8	16.1	1.6	2.7	3.6
Romania	8.5	10.3	14.9	1.1	1.7	3.1
Malta	n.a.	10.4	14.8	n.a.	1.9	3.3
Luxemburg	12.5	13.4	14	1.7	3.1	3.6
Poland	8.2	10	13.5	1.1	2	3.3
Cyprus	n.a.	10.8	13.1	n.a.	2.3	2.9
Slovakia	9.1	10.3	12.3	1.2	2	2.7
Ireland	11.1	11.4	11.3	1.9	2.1	2.8
<i>Average</i>	11	12.9	16	1.7	2.8	4.1

n.a. not available

approach (the theory of the expansion of disability; Gruenberg 1977) assumes that the increase in longevity has resulted in a prolonged period of disability in the final phase of life due to an increase in the survival rates of those with illnesses and also a growth in the prevalence of age-related diseases. A second approach is that of the “compression” of disability (Fries 1980), for which the increase in longevity is related to a shorter period of disability at the end of life, due to an improvement in the treatment and prevention of disease. The third approach (“dynamic equilibrium”; Manton 1982) is based on the assumption that there has been a slight increase in the rate of mild disability and a corresponding increase in the rate of severe disability, due to an improvement in healthcare.

However, while various surveys conducted in Europe report differing rates of disability among older people (Lagergren and Batljan 2000; Bajekal and Prescott 2003; Cambois et al. 2006; De Hollander et al. 2006; Ekholm et al. 2006), the

general trends do not support the argument that disability rates are rapidly increasing. For example, one study on trends in disability in the older population in 12 OECD countries,¹ conducted by Lafortune and Balestat (2007), suggests that there is clear evidence of a decline in the rate of disability among older people in 5 of the 12 countries examined (Denmark, Finland, Italy, Holland, and the United States). In three countries (Belgium, Japan, and Sweden), there has been an increase in the rate of disability among those aged 65+, while in two countries the rate has remained stable. In France and the United Kingdom, different sources reveal such different trends in the disability rate in the older population that it is impossible to reach any conclusion on the overall direction.

Lafortune and Balestat (2007) show that, although the increase in the older population has not been translated into a corresponding and timely increase in the number of individuals with disabilities (in fact, over the last few years, the disability rate has decreased to a certain extent within some countries), the problem of the increased demand for LTC by older people with disabilities remains significant. However, the ageing of the population and greater longevity of older people will most likely result in an increase in absolute terms in severe disability in the oldest old. Lafortune and Balestat therefore reject the assumption that there will be a general expansion in the disability rate and instead support Gruenberg's (1977) argument that this expansion will be concentrated among those with the most severe disabilities. Regardless of future trends, it can be seen that almost 20 % of Europe's older population is currently in need of assistance with the activities of daily living (ADLs) due to illness or disease, often chronic (see Fig. 2.1; EU-SILC 2008).

2.3 The Organization of Informal Care

2.3.1 *The Role and the Characteristics of Informal Caregivers*

According to OECD (2011) data, more than 10 % of adults in European countries provide unpaid informal care to family members and friends who have strong limitations in their daily living (see Table 2.2). The presence of informal caregivers varies from country to country (Eurofamcare 2006). Some countries in southern Europe have a relatively high percentage of informal carers (16.2 % in Italy and 15.3 % in Spain) while, on the contrary, some Scandinavian countries have a relatively low proportion (9.3 % in Denmark and 8.0 % in Sweden; OECD 2011).

The OECD (2011) analysis also showed that approximately two-thirds of caregivers aged 50+ are women. The "feminization" of caregiving is also reported by Costa and Ranci (2010), who noted the dominance of middle-aged women among caregivers, many of whom could potentially remain active in the labor market. Based

¹ Countries examined in the study: Denmark, Finland, Italy, Holland, United States, Belgium, Japan, Sweden, Australia, Canada, France, and the United Kingdom.

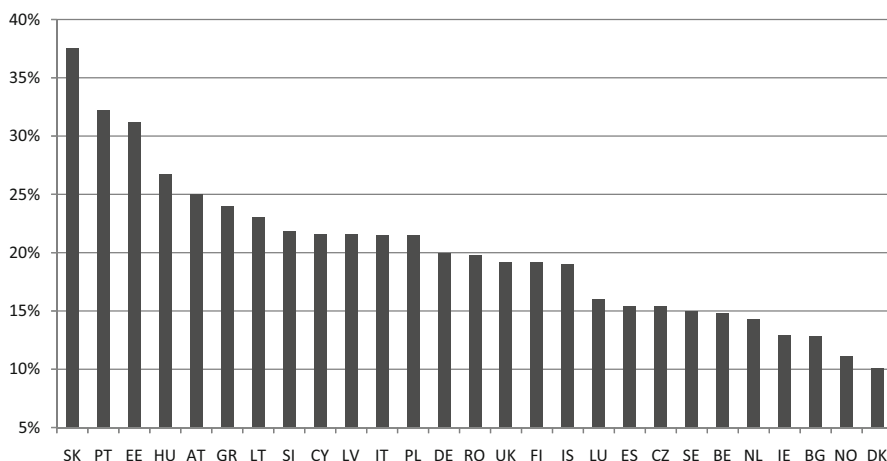


Fig. 2.1 The proportion of the population more than 65 years old with strong limitation in activities due to health problems for at least the last 6 months (2008). (Source: Authors' calculations based on EU-SILC (2008) data)

Table 2.2 Informal caregivers: percentage of the population reporting to be informal carers to people with strong limitations in daily living, different years 2004–2006. (Source: OECD 2011; OECD estimates based on the British Household Panel Survey [BHPS] for the United Kingdom and on the Survey of Health, Ageing, and Retirement in Europe [SHARE] for other European countries)

EU countries	Percentage of informal caregivers
Sweden	8.0
Greece	8.7
Denmark	9.3
Austria	9.8
Poland	10.3
France	10.7
Germany	11.0
The Netherlands	11.4
Czech Republic	12.0
Belgium	12.1
Ireland	14.6
United Kingdom	15.2
Spain	15.3
Italy	16.2

on this study, it can be seen that caregiving is to a greater extent becoming organized in the context of complex family dynamics, in which can be found adults from different generations.

2.3.2 Attitudes Toward Care

In terms of demand, there is some divergence among European countries not only in terms of their social–demographic characteristics, but also from a social–cultural perspective. A Eurobarometer survey from 2007 (Eurobarometer 2007) investigated

both respondents' preferred model of care in the case of the onset of dependency and also the balance between caring responsibilities and paid work among family carers of older people with disabilities. Figure 2.2 illustrates how in Europe there is a significant difference in the attitudes about the role of adult children in caring for dependent parents. At one extreme are the Scandinavian countries, together with France and Belgium, where the idea prevails that care should be provided first and foremost through formal services, either public or private. At the other extreme are central-eastern European countries, together with Greece, where more than 70 % of respondents believe that care provided by children is the best option. In other countries, family care is preferred, but to a lesser extent, particularly in southern European countries (Portugal, Spain, Malta, and Cyprus) and also in Germany and in Austria. In a more complex, intermediate position lie Italy, the United Kingdom, and Ireland, where preferences for informal and formal care are equal.

Opinions regarding the reconciliation of caring responsibilities and work in the labor market, important because it is mostly women who are affected, partially change these results. Country trends outlined in Fig. 2.3 remain unchanged; the majority of central-eastern European countries indicate that work by women should theoretically be sacrificed in order to provide care for older parents if required, while in contrast, those holding such a position in France, Benelux, and Scandinavia are in the minority. In the center, two groups of countries can be found, one in which 40–50 % of the population is in agreement with the idea that the career of the caregiver should be sacrificed (largely various countries of central, eastern, and southern Europe) and those in which the percentage is lower (30–40 %), in the Germanic and Anglo-Saxon countries in Europe.

However, if we consider responses to questions about caring for older relatives and for children at the same time, it is possible to see a strong congruence: there is a strong positive correlation between the two variables, equal to 0.829. Namely, respondents who feel that one should give up work to care for children are also likely to agree that children should give up work to care for their old parents. Nevertheless, almost all countries have on average lower rates of adherence to the idea that sacrificing one's career to provide care is the best option when compared with the idea that childcare is the optimal solution. For example, in Germany, the majority of the population is in agreement with the statement that parents provide the best childcare support (58 %), though only one-third of respondents overall are of the opinion that one's career should be sacrificed to offer care to dependent parents. There are only a few exceptions to this general rule, of which the most interesting cases are Greece and Italy (see Fig. 2.4): In the Greek region (Greece and Cyprus), the preference to leave work to provide care to their children is significantly higher than to provide care to dependent parents, while in Italy, the opinions about the two phenomena are closely intertwined and report virtually the same percentages.

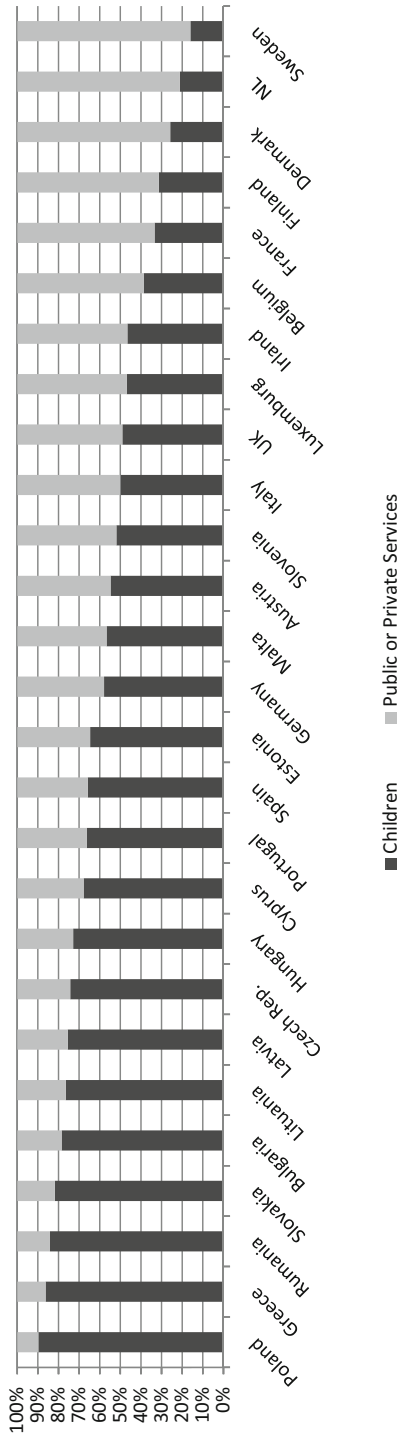


Fig. 2.2 Preferences for type of care desired in the case of parents becoming dependent in old-age—EU-27, 2007. (The data refer only to those who have experience of dependency). Legend: Adult children responding to the Eurobarometer survey were asked to respond to the question “In the case of one of your parents becoming dependent, which would be the best solution? The option “Children” was formed by grouping together the responses “to live with an adult child” or “to be cared for by an adult child living nearby”. The option “formal care services, either public or private” was formed by grouping together the responses “Through the provision of public/private services in his/her own home” and “In a long-stay care setting”. (Author’s calculations based on Eurobarometer (2007) microdata)

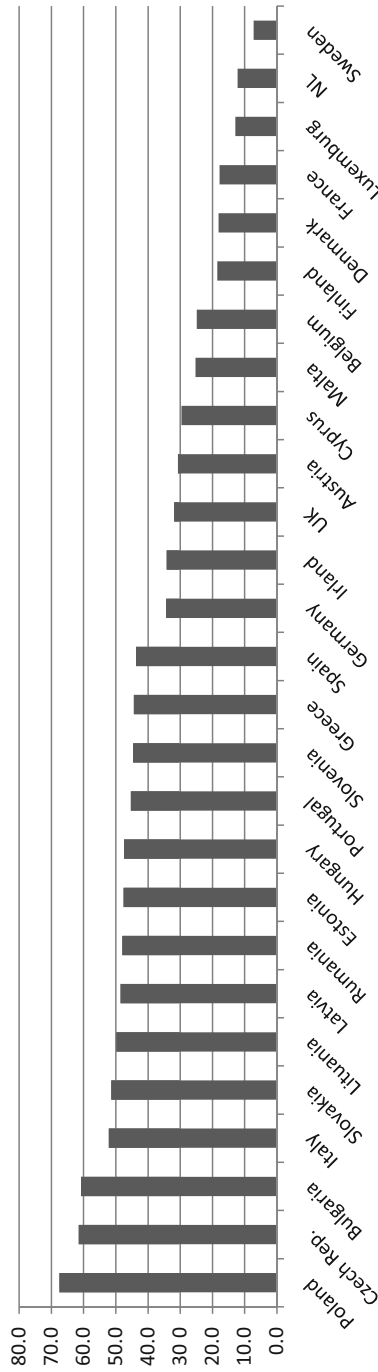


Fig. 2.3 Percentage of individuals who believe that adult children must care for their disabled parents even if this means sacrificing their career—2007. (The data refer only to those who have experience of dependency). (Source: Authors' calculations based on Eurobarometer (2007) microdata)

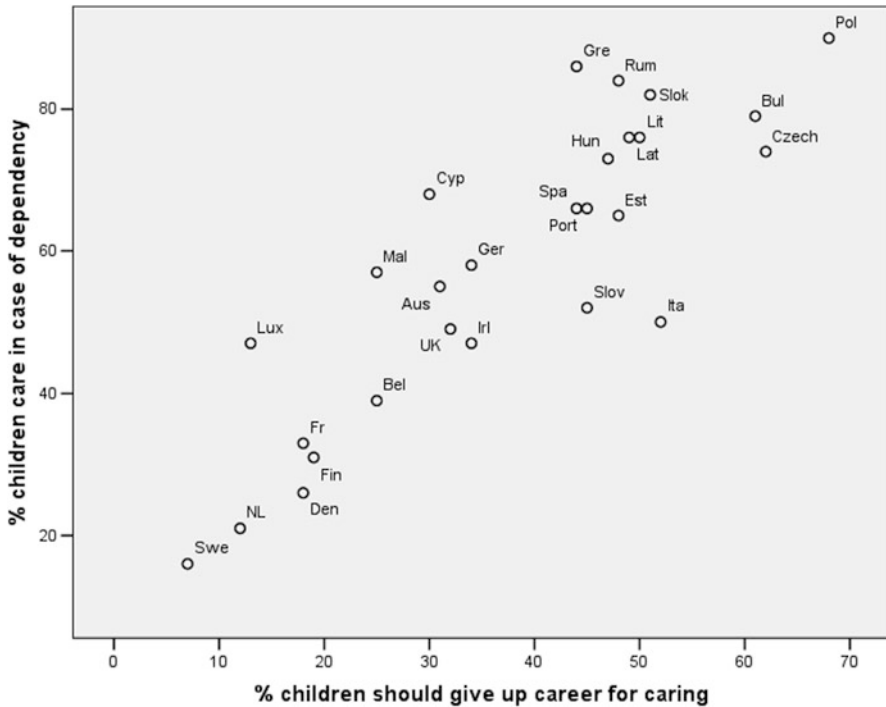


Fig. 2.4 Percentage of individuals who believe that children should provide care to dependent parents even if it means renouncing their career—2007. (The data refer only to those who have experience of dependency; these percentages do not vary significantly when considering the entire sample). (Source: Adapted from Eurobarometer (2007) data)

2.4 The Characteristics of Public Care Services

2.4.1 Coverage and Funding Levels

As LTC is defined in different ways in each European country, national systems of LTC in Europe often have very different characteristics (Kraus et al. 2010). In fact, in each of the various countries, programs of LTC were created at different points in time, with the objective of either complementing or substituting the preceding system of support for disability and dependency. In turn, this has resulted in the development of very different systems of LTC in each country. Furthermore, the delivery of care is often divided between different government departments and state agencies in each of the different countries, making comparison of the overall LTC system somewhat challenging. Finally, in almost all advanced countries, different methods are used for the financing of LTC (OECD 2005, 2011).

These diverse aspects help to explain why the current available statistics about public LTC programs are somewhat patchy (Oliveira Martins 2006; Fernandez 2009).

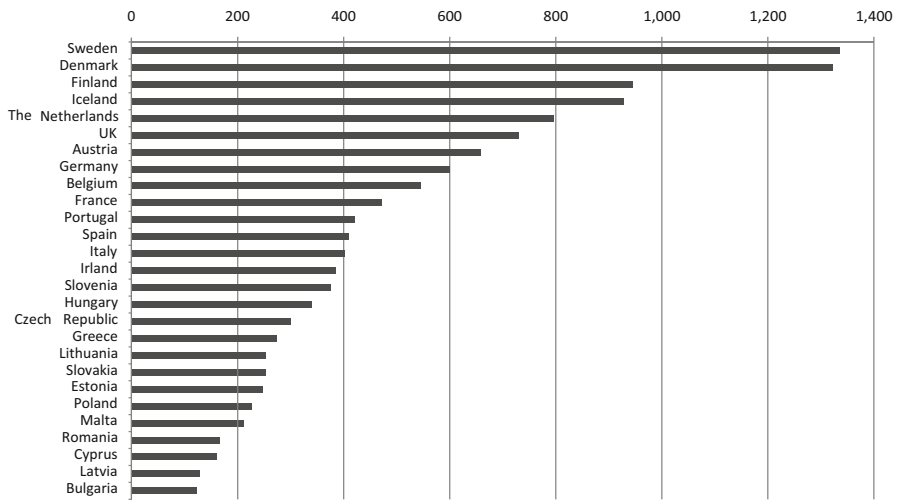


Fig. 2.5 Amount of public spending on LTC in PPS (purchasing power standard) euros per capita 2008. (Source: ESSPROS data, Eurostat 2010)

In spite of the quality and richness of the current data available from numerous institutions, which have recently published reports on LTC systems, there is often a notable imprecision within the information provided as well as a number of clear contradictions. For this reason, we limit our analyses to the data, which offer greater reliability and consistency over time.

As a general rule, it should be observed that state intervention in the area of LTC is still relatively underdeveloped, even in advanced countries. Total public spending on LTC in OECD countries is on average 1.2 % of the national GDP (the same average is also true for European countries). If social security for disability is included, spending as a proportion of GDP still only reaches 2 % on average. Eurostat (2010) estimates also indicate that social protection expenditure on the population of people with disabilities is around 8 % of total social expenditures and has remained relatively stable over the last decade. Nevertheless, LTC can be regarded as one of the policy areas, which have undergone the most significant reform over the last 20 years, even if there has been little evidence of a significant increase in public spending within the sector.

Before we look at expenditure dynamics, we first consider the differences on spending between European countries, looking also at OECD countries, when equivalent data are available (see Fig. 2.5). Based on Eurostat² data up until 2008, we can examine public spending on LTC in euros per capita, adjusted for the purchasing power of the different countries. Out of this analysis emerges a block of countries in which yearly spending on LTC per capita exceeds € 900, which includes the Scandinavian countries, Luxembourg, Switzerland, and Iceland. In these countries, LTC

² European system of integrated social protection statistics (ESSPROS), Eurostat.

Table 2.3 Trends in spending on disability, PPS euros per capita, 1990–2008. (Source: ESSPROS data, Eurostat 2010)

	1990	2000	2008
Denmark	687	1,092	1,604
Sweden		1,175	1,388
The Netherlands	976	763	718
United Kingdom	364	654	619
Austria	518	691	614
Germany		551	559
France		385	456
Italy	405	302	335
Spain	232	247	292

programs constitute one of the pillars of the welfare system, absorbing between 12 and 17 % of total social spending. Spending on LTC represents a share of more than 50 % of all health spending; a clear sign that these policies are now assuming a central role compared with other more traditional sectors of the welfare state.

In a second block of countries, yearly LTC spending represents between 700 and € 900 per capita: a significant amount, which indicates that there is a clear understanding of the need to invest in this area. In this block, the United Kingdom, the Netherlands, Austria, Germany, Belgium, and France can be found. Many of these countries have introduced new LTC programs in the last few years, thus augmenting previous levels of spending in this area, as illustrated in various chapters in this book.

A third block of countries is also evident, in which per capita spending exceeds € 300 but remains below € 700. The Mediterranean countries, together with Ireland and two central-eastern European countries, Slovenia and Hungary, fall into this block. All of the other countries, including most of the eastern European countries and Greece, are characterized by spending on LTC of less than € 300 per capita.

As a general rule, these data illustrate how the volume of spending absorbed by LTC policies depends primarily on the timing of institutional reform. The countries, which spend the most on LTC, are also those which have introduced specific LTC programs much earlier. In addition to the historical perspective has been the more recent institutional reform noted above, which has gradually improved the performance of many of these countries, including Germany and Austria, where the introduction of new reform programs was accompanied by an increase in public spending. In general, Mediterranean countries and central-eastern European countries spend less on LTC programs. The gap for the citizens in these countries, compared with the northern and central-western European countries, is very large; on average, a Swedish or Danish citizen has at least three times more funding available than an Italian or Spanish citizen.

Over the last two decades, a different dynamic developed between the different countries in relation to spending on LTC. ESSPROS data allow us to reconstruct these spending dynamics from the beginning of the early 1990s to 2008 (see Table 2.3). These data show the changing trends in various countries. Positive trends, however, can hide important variations in the spending programs aimed at the older population, as the ESSPROS data also include figures for (younger) adults with disabilities. In general, in spite of a growing demand for LTC services, public spending overall has

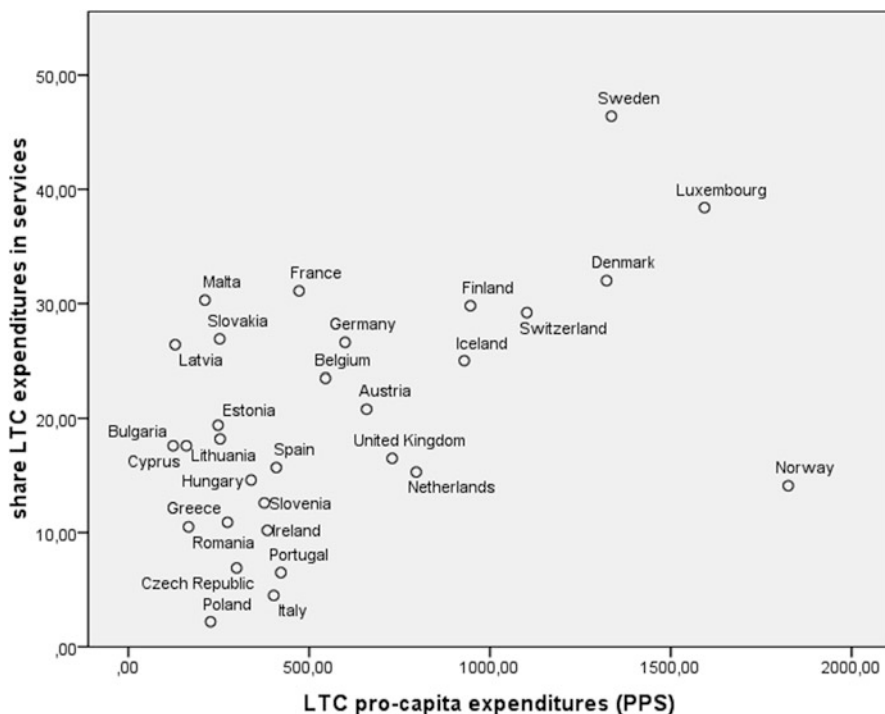


Fig. 2.6 Amount of public spending on LTC allocated to services; as a proportion of total LTC spending (GDP per capita), 2008. (Source: ESSPROS data, Eurostat 2010)

experienced a general difficulty to rise with the same pace. Institutional reform in this policy sector therefore developed with the aim of balancing the need to satisfy growing demand for services while simultaneously containing public spending.

The configuration of LTC systems changes considerably depending on whether in-kind services or cash transfers are offered. In-kind services are those in which care services are offered directly to recipients in form of residential or home care, while cash transfers have the effect of passing responsibility to individuals and families for organizing their own care services. The distinction between “care” and “cash” is, however, less clear than may appear to be the case. Over the last 10 years, various cash-for-care programs have been introduced in which monetary transfers are provided to acquire specific care services (Da Roit et al. 2007). However, available statistics do not always include these measures, and confuse them with other cash transfers for which there are few constraints (such as the case, for example, of the “indennità di accompagnamento” in Italy, or of the “attendance allowance” in the United Kingdom).

Taking into account these caveats, Fig. 2.6 confronts the share of spending allocated to LTC services with the generosity of their overall performance. The most generous countries are also those which invest to a greater extent in care service

provision (with the significant exception of Norway). This is not an unexpected result, since the cost of maintaining residential and home care services is greater than that related to a cash benefit. It is mostly the northern European countries who fall into this category, together with Luxembourg and Switzerland. Among the countries that have developed a significant complement of services also France and Germany are included (together with Belgium, Slovakia, and other smaller countries), that is the two biggest continental countries, which have also introduced new specific LTC measures in recent years. In the other countries, which have also introduced changes, including Austria, the United Kingdom, and the Netherlands (in which case, however, the Personal Budget is counted as a cash benefit even though it constitutes cash transfers solely for the purchase of professional services), the cash transfers make up almost 80 % of spending overall. Furthermore, these results are not particularly unusual if we consider the structure of LTC systems in these countries. Finally, less generous LTC programs are offered in the Mediterranean and eastern countries, where there is a strong propensity to develop almost exclusively only cash benefits.

If we consider the service coverage guaranteed within each LTC system, a more complete picture of coverage emerges highlighting the differences between the various countries. In this case, we consider only the level of coverage among the cohort of dependent older people, where the greatest need for care is concentrated. Figure 2.7 presents an estimate of how total coverage rates changed between the mid-1990s and the mid-2000s, when most of the institutional reforms took place. Looking at the overall rates of coverage, the Nordic countries, together with the Netherlands (and Israel), offer coverage of more than 20 % of the population aged 65+. High coverage (more than 15 %) can also be seen in Switzerland, Austria, the United Kingdom, and Sweden. The rate in Slovenia, the Czech Republic, and Germany is between 10 and 15 %. All of the other countries offer an overall rate of less than 10 %, with Italy and several central-eastern countries offering a less than 5 %.

Figure 2.7 shows the development of reforms in operation between 1995 and 2005. If the level of coverage measures the ability of LTC programs to satisfy the emerging demand for care, then the dynamics in place are clear. Three different trends can be identified. Some countries, including most of the Nordic countries such as Denmark, Norway, and Finland, and also some continental countries such as Austria and Slovenia, have extended LTC policies, resulting in a high level of coverage. A marked, positive dynamic has also allowed some other continental countries such as France and Spain, to reach a rate of coverage close to that of what Germany had already reached by the mid-1990s (around 10 %).

A second trend has affected the countries that had already reached a relatively high level of coverage in the period preceding that analyzed here. Namely, in the cases of Germany, Canada, and other central-eastern European countries (the Czech Republic and Ireland), there has been a stabilization of the level of coverage over the last decade. Other countries, however, such as Italy and most of the central-eastern European countries have reported an increase in coverage levels too small to have bridged the gap with the more advanced countries, thus further increasing the distance from European standards. Finally, some countries have experienced a retrenchment

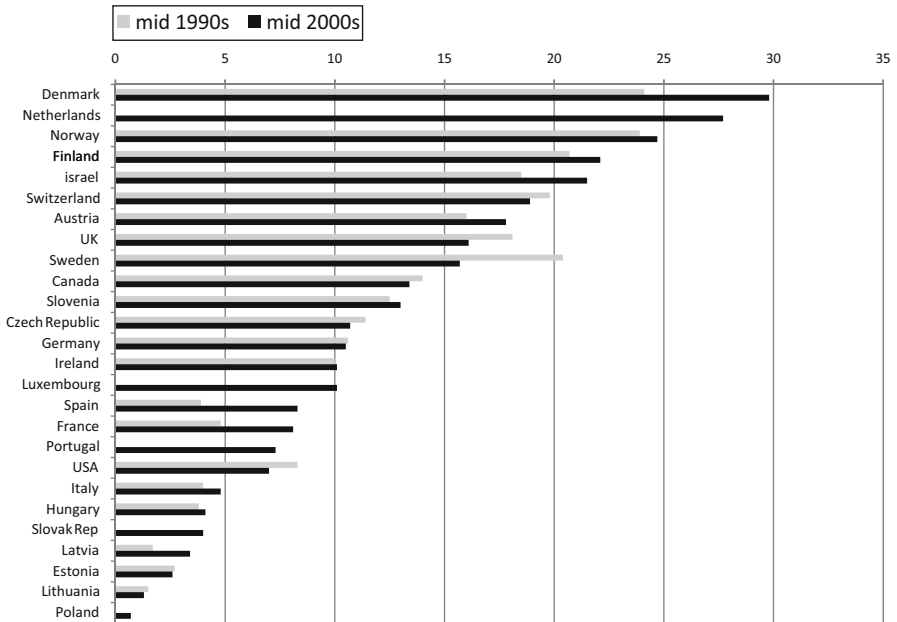


Fig. 2.7 Rates of coverage for LTC services for the population aged 65± mid 1990s—mid 2000s. (Source: ESPROSS data, Eurostat 2010)

of LTC programs, which arose due to the challenges of the significant costs for meeting the increased demand for care. This is an inverse of the trend reported above that affected countries, which had previously extended LTC programs, such as Switzerland, the United Kingdom, and Sweden.

The dynamics of the coverage naturally reflect the structure of LTC services that exists in each country. Available data only allow for an analysis of the difference between the coverage of home and residential care services. Over the course of the last 20 years, the emphasis has continually been placed on the development of home care services, largely not only because of the affordability of this option (especially if the coverage is not particularly intensive and also if service users contribute a fee), but also because it fitted the objective of trying to maintain dependent older people in their own homes (the catchphrase in Europe was in fact “ageing in place”). It is therefore unsurprising that there is a clear, linear correlation (as can be seen in Fig. 2.8) between the overall rate of coverage and the share of home care services (calculated by taking the total rate of coverage for the demand for home care services).³ While the proportion of individuals who use home care assistance reaches 80–90 % in countries with high rates of LTC coverage, the proportion of home care recipients

³ Available data, unfortunately, do not consider the coverage of cash benefits. However, the rate of coverage of home care services also contains the proportion of individuals who receive either “cash-for-care” services or sums of money only available for acquiring home care assistance.

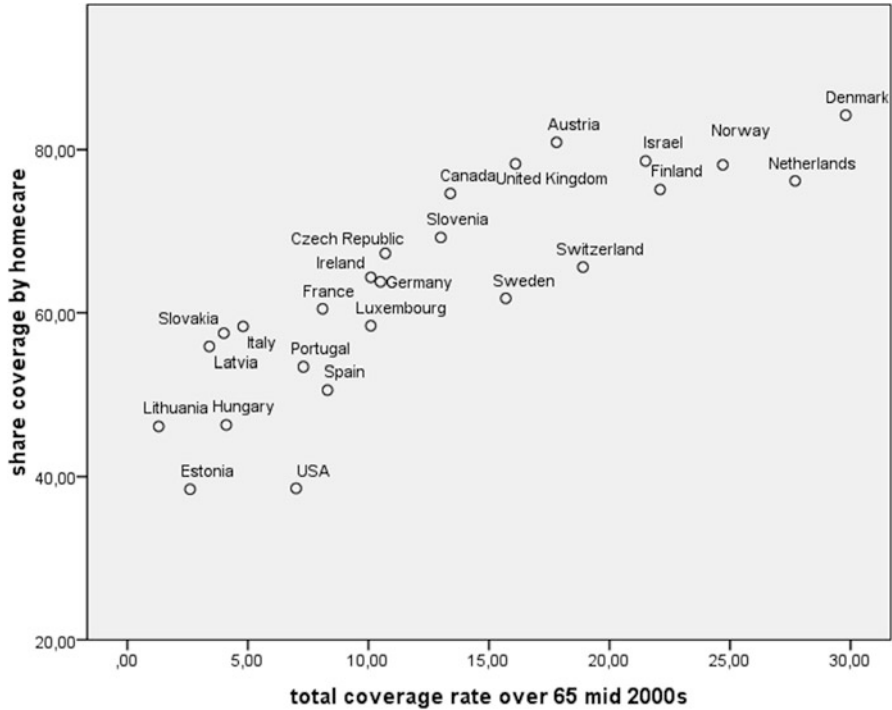


Fig. 2.8 Overall rates of coverage of LTC services for the older population (65+ years) and the rate of coverage provided through home care services—mid-2000s. (Source: ESSPROS data, Eurostat 2010)

is between 40 and 60 % of all users of LTC services in countries with more modest rates of coverage overall. These data indicate that the diffusion of LTC services has been mostly due to an increase in the provision of home care services.

The diverse mix of home and residential care also highlights a number of differences among European countries (see Fig. 2.9). The updated data from the mid-2000s shows the emergence of at least three groups of countries. The first group includes countries with a high rate of coverage for both home and residential care services—this is made up of the Nordic countries. Within this group, Sweden and Switzerland are something of an exception, having experienced a reduction in coverage rates for home care services, following “targeting” policies over the last few years (see also Fig. 2.10 for a comparison with the situation in the mid-1990s). A second group of countries is at the opposite extreme and is characterized by low levels of coverage of both home and residential care: included in this group are all of the central-eastern European countries and Italy. The third group includes France and Spain, which over the last 10 years have witnessed a significant improvement in their rate of coverage (see Figs. 2.9 and 2.10).

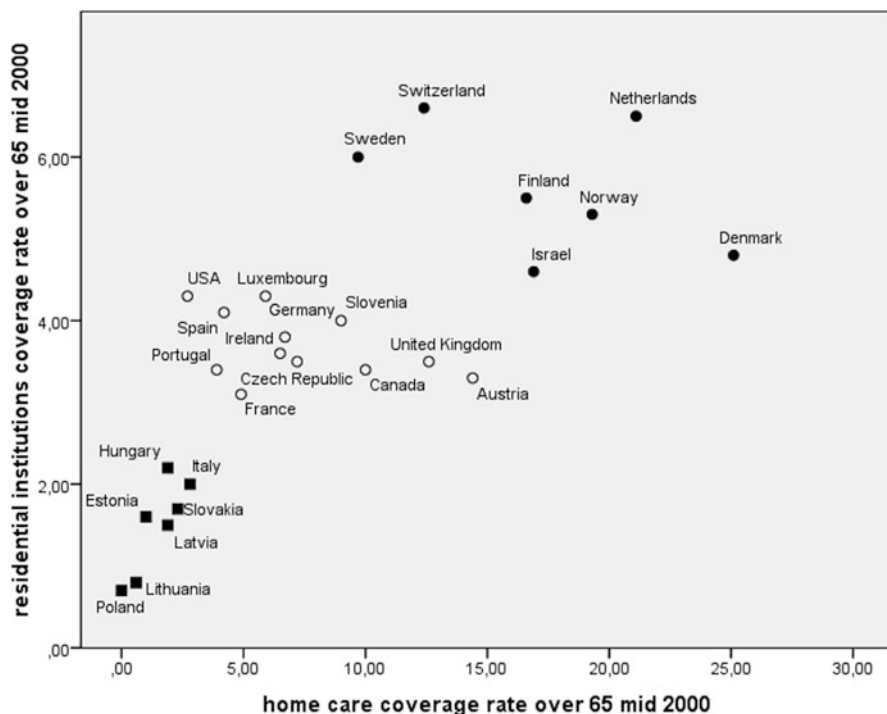


Fig. 2.9 Rates of coverage for home and residential care services—mid-2000s. (Source: Authors' calculations based on ESSPROS data, Eurostat 2010)

The intermediate aggregate group includes countries, which are united by the fact that they have a rate of coverage of residential care services of around 4 %. What distinguishes them, however, is the rate of development of home care services: while some of these countries such as France, Spain, and Germany have a rate of coverage of about 5 % for home care services, other countries such as Austria and the United Kingdom had developed home care services offering coverage for up to 10 % of the older population. Finally, if we compare the situation of various European Union countries with others from the OECD, we can see how the United States can be inserted into the same group as France and Germany, while Israel and Canada have a better developed LTC services system.

Combining together data on expenditure and coverage, a substantial consistency between the different indicators emerges (see Fig. 2.11). Essentially three groups emerge. One group with a very high level of spending (more than € 1,000 per capita, adjusted for PPP) and coverage, which substantially meets demand (coverage rates higher than 15 % of the 65+ population), which includes the Nordic countries and the Netherlands: countries, which provide a universalistic model of LTC with significant levels of service provision. In contrast, a second group includes countries that provide a level of spending almost half that of the first group (not more than € 500 per

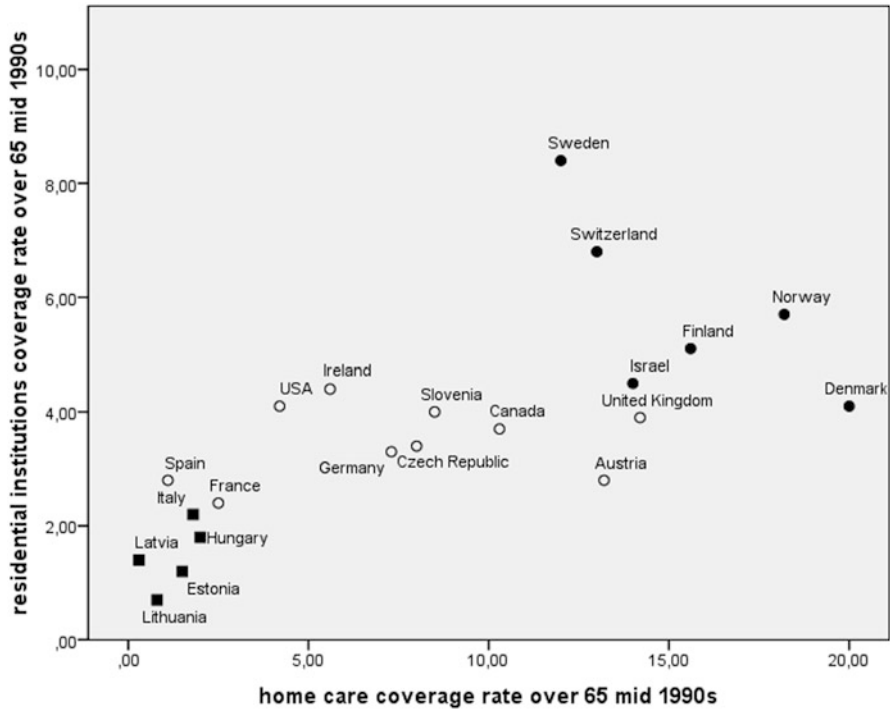


Fig. 2.10 Rates of coverage for home and residential care services—mid-1990s. (Source: Huber et al. 2009)

capita) and with rates of coverage of less than 5 %, in which LTC constitutes a residual and underdeveloped system: this group includes most of the Mediterranean and central-eastern European countries. The third, intermediate, group, includes several European countries that have made significant financial investments into LTC, at different times and following diverse institutional and organizational models, as we have already seen. In these countries, spending reaches an intermediate level of between 500 and € 1,000 (per capita), and, while the rates of coverage are variable, each provides coverage of at least 5 % of the older population. This group includes a set of very diverse countries, which, in one sense or another, have faced significant institutional reforms over the last 20 years. It includes France and Germany as well as countries such as Austria and the United Kingdom. These intermediate countries are those which have incurred the greatest developments over the course of the last 20 years.

2.4.2 Citizen’s Level of Satisfaction

Moving from the analysis of spending and coverage to citizen’s valuation and satisfaction with the LTC system, we can see some, albeit weak, congruence between the two sets of data. Figure 2.12 shows that the percentage of individuals that declare to

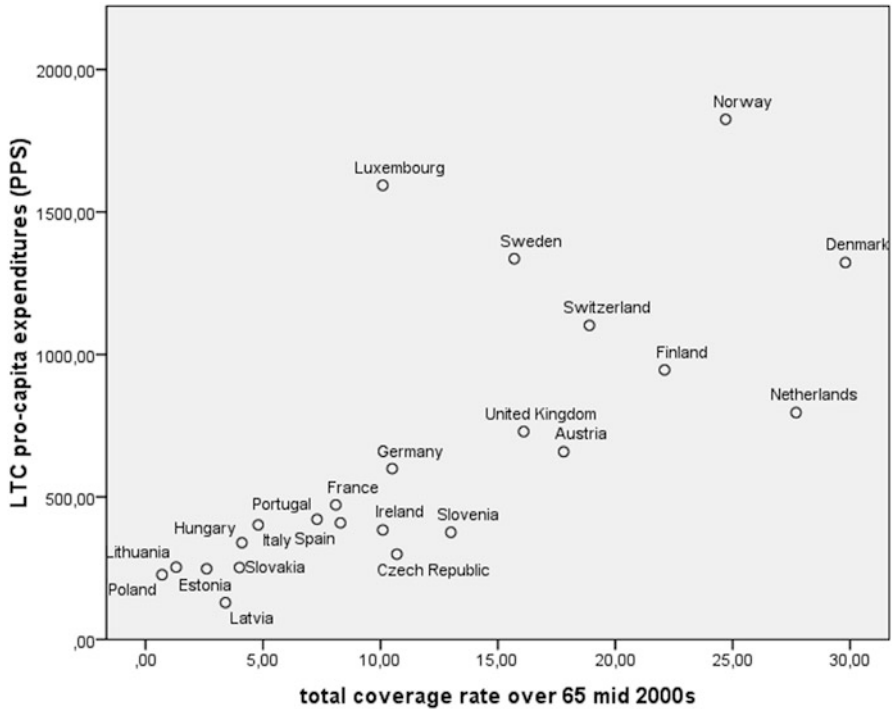


Fig. 2.11 Total rates of coverage for the older population (mid-2000s) and level of spending on LTC (GDP per capita—2008; ESSPROSS data, Eurostat 2010)

have paid for or who currently pay for care for their parents is highest in Italy (34.1 %), followed at some distance by Portugal, Austria, Belgium, Cyprus, and Malta, which all have values of between 25 and 28 %. In some of these countries (Italy and Austria, for example), private spending by the family is supported by particular public systems, which favor cash transfers over services. For other countries, including the Scandinavian countries, together with those from the Baltic region and the United Kingdom, the opposite can be found, namely, just 10 % of the population reported paying for care to support their older parents. Between these two extremes lie all of the other countries, including some, which are characterized by a less concentrated form of the phenomenon (for example, the western continental countries with values of around 20 %) and others with a relatively more limited spread (Mediterranean and central-eastern European countries).

If we examine the assessments of those who have had some experience of the public LTC systems both directly (either personally or through family members) and indirectly (through other relatives, neighbors, and friends), strong country variations emerge. Figure 2.13 synthesizes the average dissatisfaction ratings for each country, while Table 2.4 reports on how this dissatisfaction relates to specific aspects of care (quality, accessibility, and cost). The countries with the worst satisfaction ratings are

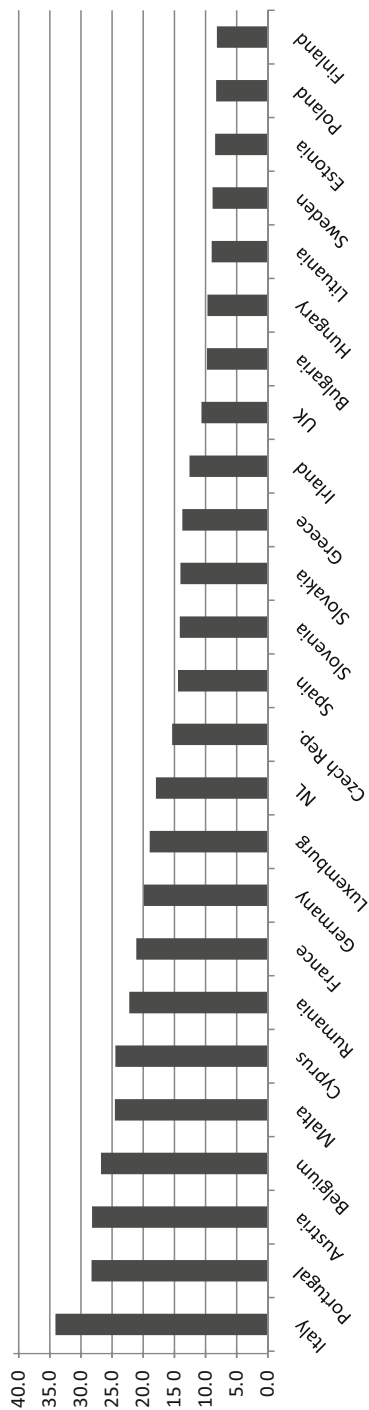


Fig. 2.12 Percentage of citizens who report that they currently pay, or have in the past paid, for care services for their parents (percentage calculated among respondents aged 40+), 2010. (Source: Authors' calculations based on Eurobarometer (2010) microdata)

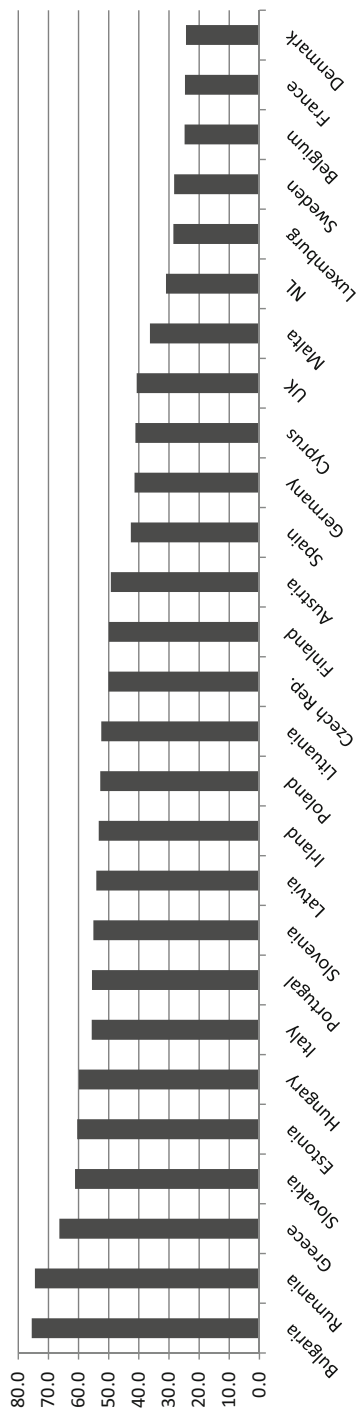


Fig. 2.13 Percentage of citizens dissatisfied with the performance of their LTC system. (Source: Eurobarometer 2007)

Table 2.4 Satisfaction ratings for various aspects of the public LTC system, 2007 (the data refer only to those with prior experience of the issues of dependency). (Source: Authors' calculations based on Eurobarometer (2007) microdata)

Country cluster	Country	Percentage of dissatisfaction with aspects of the LTC system						
		Quality of home care services	Quality of residential care services	Ease of access to home care services	Ease of access to residential care services	Costs of access to home care services	Costs of access to residential care services	
Complete satisfaction (sometimes with problems relating to the costs of residential care)	Belgium	7.1	12.6	13.1	36.2	22.2	57.7	
	Denmark	36.3	37.5	24.7	26.8	4.8	16.3	
	France	16.6	12.4	24.5	15.3	33.0	46.4	
	Luxembourg	12.2	23.2	8.8	61.9	12.9	52.3	
	Netherlands	26.2	31.1	37.5	43.5	23.8	23.8	
	Sweden	24.4	23.5	25.3	40.4	24.5	31.8	
	<i>Average</i>	20.5	23.4	22.3	37.4	20.2	38.1	
	Austria	26.4	34.5	45.9	54.8	63.5	70.8	
	Cyprus	33.3	41.5	24.1	21.8	57.5	68.6	
	Germany	26.5	40.1	14.9	35.2	54.9	77.1	
	Malta	11.5	13.6	22.4	34.3	61.4	74.9	
	United Kingdom	35.8	35.4	39.3	34.3	39.2	60.3	
	Spain	25.9	28.5	39.0	52.6	41.4	68.7	
	<i>Average</i>	26.6	32.3	30.9	38.8	53.0	70.1	
Partial satisfaction, (only with the quality of service provision)	Estonia	44.2	47.1	55.7	71.0	59.0	85.8	
	Finland	34.6	31.6	52.1	63.7	51.9	65.8	
	Ireland	45.0	39.3	49.7	54.8	57.6	73.5	
	Italy	58.0	48.2	59.7	47.9	55.1	65.1	
	Latvia	48.0	41.1	64.3	70.7	46.7	53.8	
	Lithuania	47.9	51.4	57.5	63.9	46.9	47.3	
	Poland	54.6	62.6	41.3	55.4	45.3	57.7	
	Portugal	52.9	35.0	55.2	45.5	70.4	74.3	
	Czech Republic	24.7	25.9	60.3	84.6	47.9	57.2	
	Slovakia	46.9	46.7	62.3	78.4	60.3	72.4	
	Slovenia	24.4	27.6	55.6	68.2	71.7	83.0	
	Hungary	47.0	45.5	60.2	74.7	61.3	70.3	
	<i>Average</i>	44.0	41.8	56.2	64.9	56.2	67.2	
	Complete dissatisfaction	Bulgaria	71.5	73.3	79.1	80.4	73.4	75.6
Greece		54.7	74.8	51.6	51.3	76.4	89.4	
Romania		68.7	75.1	66.8	73.7	81.6	80.9	
<i>Average</i>		65.0	74.4	65.8	68.5	77.1	82.0	

Bulgaria and Romania, followed by Greece, where almost two-thirds of respondents declare themselves completely dissatisfied. In a second group of countries, including many central-eastern European countries, together with Italy, Portugal, and Ireland, almost half of all citizens express negative opinions. However, the rates of dissatisfaction fall below 30 % in some Scandinavian countries, in the Benelux, and in France. In the middle can be found Spain, Germany, and the United Kingdom (with values reaching around 40 %).

The data presented in Table 2.4, which outlines citizen's level of satisfaction with the main aspects of residential and home care for dependent older people, helps to confirm these findings: the quality of services, ease of access, and the relative costs. Given the abundance of data reported in Table 2.4, the information on each country is organized into clusters.⁴ Altogether, four sets emerge:

1. In the first group of countries, comprising almost all the Scandinavian countries, together with France and the Benelux, a majority (often large) of citizens report being satisfied with their LTC system in all respects, apart from, in a few national cases, the issue of the costs associated with residential care for older people (in France, Belgium, and Luxembourg).
2. The second group of countries is largely similar to the first group, but the level of dissatisfaction with the costs of both residential and home care is stronger: in this group can be found Austria, Germany, the United Kingdom, and Spain, where there appears to be a relatively strong trade-off between, on the one hand, quality and access, and on the other, associated costs.
3. The majority of central-eastern European countries, together with Italy, Portugal, Finland, and Ireland fall into the third group, in a critical situation, in which citizens are partially satisfied with the level of service provisions, but are very dissatisfied with the level of access and the costs of LTC services.
4. The fourth, and arguably worst-off, group is composed of the Balkan-south-east of the European Union (Romania, Bulgaria, and Greece), where levels of dissatisfaction were the highest for every item.

The picture shows that there is a certain congruence between the level of public expenditure and the citizen's level of satisfaction with the functioning of the various aspects of their LTC system (costs, access, and quality).

2.5 The Impacts of Different Models of Care

Investigating the impact of the different models of LTC using quantitative data is, clearly, a complex issue. It is possible to do so with reference to different variables, which give an overall picture, as we do here. In particular, we aimed to evaluate the impact of these policies, as shown in the following paragraphs, examining in particular inequalities in access to services and the prospects of reconciling work and caring responsibilities.

⁴The allocation of the country clusters was carried out by using a hierarchical cluster analysis (Ward's method).

2.5.1 Inequalities in the Access to Health Services According to the Level of Disability

Prohibitive costs and limited supply can create barriers to individuals receiving acute healthcare treatment. To investigate whether this barrier also exists in the LTC sector in Europe, we used available data from Eurostat. The EU-SILC survey contains a variable, which identifies situations where it is not possible for individuals to obtain necessary treatment. We were able to investigate ease of access to LTC within Europe using this variable. Furthermore, we used three variables from the EU-SILC data (the subjective evaluation of health, the presence of chronic conditions, and the difficulty of performing tasks of daily living due to health problems), to form a summary variable of individual's health status, which distinguishes between those in good health, those with minor problems, and those with more serious health problems. Using data related only to older people, Table 2.5 summarizes the results of a probit regression analysis, which measured whether older people's health problems impact on their ability to access to health services. The regression analyses are controlled for other independent variables: age, gender, nationality, and level of education (which are not listed in the table).

Four groups of countries emerge from the analysis, which for the most part resemble the classification of countries according to their diverse ways of investing in LTC:

1. The Scandinavian countries, the Benelux countries, France, and Spain do not differ significantly in terms of access to services for older people in terms of their health status. In other words, those in need of LTC are not likely to experience any barriers in receiving treatment.
2. In the Germanic area and Slovenia, those with serious health problems are those most likely to experience some difficulties in accessing care. Germany is at the crux of this group and the first as it produces just marginal significant effects, which are very low compared with the other countries.
3. Both the Anglo-Saxon countries and the Czech Republic are characterized by the fact that health status has a significant negative impact on access to health services. In other words, even those with moderate health problems may experience difficulties in receiving access to care, for a variety of different reasons.
4. All of the rest of the countries, particularly in the south and central-east regions, including Italy, are characterized by the fact that health status (and the presence of disability) of older people has a strong negative influence on access to healthcare and services.

This analysis indicates that, paradoxically, dependency and health problems hinder individual's ability to access health and social care services in some southern and central-eastern Europe countries, rather than promoting access. This often depends on the fact that a lack of access to integrated health and care services is linked to the prohibitive costs, which individuals are often required to pay to obtain treatment (data not reported in Table 2.5). In many LTC systems, therefore, older people with disabilities or health problems are likely to be doubly penalized.

Table 2.5 Probit regression of the role played by the health status of older people on the lack of access to health services: marginal effects (category reference: individual in good health). (Source: Authors' calculations based on EU-SILC (2007) microdata (2008 for Romania and Bulgaria))

	Country	Older people with minor health problems	Older people with serious health problems
Countries in which different health statuses of older people do not reduce the probability of access to health services	Belgium	ns	ns
	Denmark	ns	ns
	Finland	ns	ns
	France	ns	ns
	Luxembourg	ns	ns
	Netherlands	ns	ns
	Spain	ns	ns
	Sweden	ns	ns
	Countries in which only the situation of major health problems of older people reduces the probability of access to health services	Austria	ns
Germany		ns	.018*
Slovenia		ns	.045***
Countries in which different health status of older people has a moderate negative effect on the probability of access health services	Czech Republic	.027**	.061***
	United Kingdom	.023***	.068***
	Ireland	.024***	.071***
Countries in which different health statuses of older people has a strong negative influence on the probability of access health services	Hungary	.063***	.102***
	Poland	.076***	.104***
	Portugal	.043***	.110***
	Cyprus	.032***	.111***
	Italy	.071***	.113***
	Estonia	.137***	.167***
	Lithuania	.088***	.191***
	Greece	.098***	.196***
	Bulgaria	.140***	.202***
	Latvia	.102***	.207***
	Slovakia	.128**	.260***
Romania	.176***	.288***	

ns not significant.

*sig. < 0.05; **sig. < 0.01; ***sig. < 0.001

Controlled for: age, gender, level of education, and nationality

2.5.2 *The Reconciliation of Caring Responsibilities and Paid Work*

A second dimension, which requires careful attention when considering the impact of LTC on families and on people with dependency needs, is in relation to the ability to reconcile paid work and caring responsibilities (Glendinning et al. 2009; Lamura et al. 2008). In Sect. 2.3 above, we discussed the attitudes of European citizens with regard to the balancing of caring “duties” with paid work. In this paragraph, we

analyze the frequency of the decision to renounce or reduce paid work in order to engage in informal care work.

In the countries of the European Union (EU-27, Eurostat data), the primary motivations for people of working age (15–64 years) for not participating in the labor force vary by gender. The weight of family responsibilities in a broad sense is a predominant motive for women to withdraw from the labor market. The highest percentages of nonparticipation (between 20 and 40 %) can be seen in the Mediterranean countries (Malta, Cyprus, Spain, Greece, Portugal); however, percentages elsewhere are also significant (Romania, Belgium, Croatia, Austria, Ireland, Germany, Slovenia, Bulgaria, Poland are between 10 and 20 %). However, caring responsibilities affect career choices to a lesser extent in Finland, France, Slovakia, Hungary, Sweden, and the Czech Republic (between 0.5 and 1.9 %).

The countries with the highest rates of inactivity in the labor force due to the need to care for dependent family members/friends are United Kingdom, the Czech Republic, Estonia, Slovakia, Ireland, and Hungary (between 18 and 28 %); followed by Finland, Italy, Austria, Germany, Cyprus, Poland, Holland, and Spain (14–16.5 %). Fewer individuals in Belgium, Croatia, Romania, France, Denmark, and Slovenia report withdrawing from the labor force for this reason (2.5–5 %).

Data analysis of the various reasons is complicated by the fact that the various rationales for inactivity are combined in unpredictable ways, and are related to the conditions of the labor market, the provision of welfare services, cultural models, and family traditions. The fact remains, however, that, among the reasons for inactivity, family responsibilities related to both children or adults with disabilities, is one of the most common, particularly in Ireland, Cyprus, Spain, Luxembourg, Austria, Germany, Greece, and Italy.

A total of 13 % of women who have a relative with a disability reported having to leave paid employment in order to assume caring responsibilities or had to reduce their (paid) working hours (see Fig. 2.14). The Scandinavian countries, Germany, France, the Benelux countries, various countries from central-eastern Europe, Greece, Cyprus, and Malta all fall close to, or less than, the average. However, the proportion of women affected is significantly higher in Austria, the area of the former Czechoslovakia, Hungary, Portugal, Ireland, and Spain. Italy and the United Kingdom have values slightly higher than the overall average, with values of around 15–18 %.

These figures, which relate to current labor market practices, are somewhat different from the information reported in Sect. 2.3 above in relation to cultural attitudes with regard to the acceptability of the decision to continue to work rather than caring for dependent family members (see Fig. 2.15): the correlation between the two variables, although positive and relatively strong (0.441), is not as strong as that reported earlier in relation to other trends. Figure 2.15 shows that, in a large group of Mediterranean (Italy, Spain, and Portugal) and eastern countries (Czech Republic, Romania, Hungary, Slovakia, Lithuania, and Estonia), the prevailing opinion is that caring responsibilities take precedence over work and career expectations, while in the Scandinavian and “Francophone” countries, work and career expectations are prioritized.

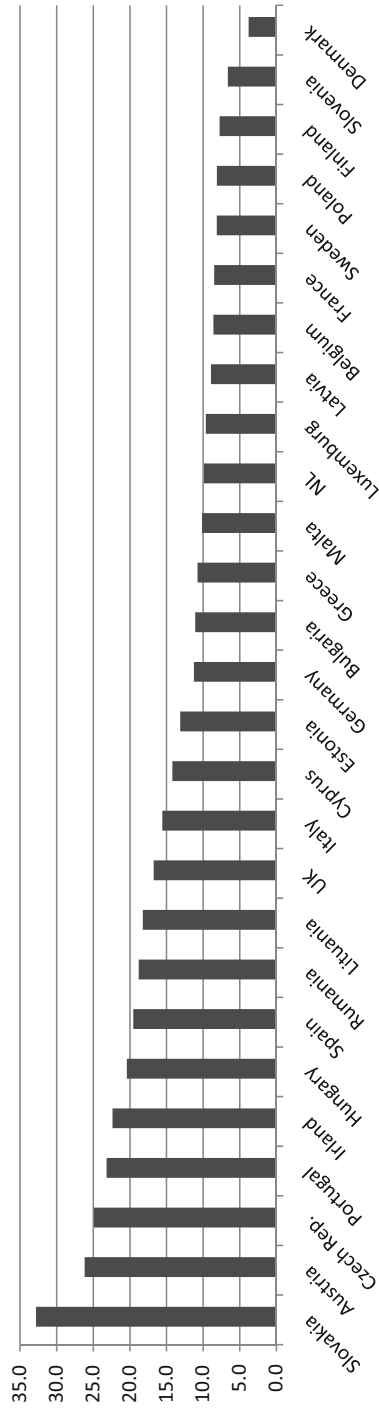


Fig. 2.14 Percentage of women who have withdrawn (partially) from the labor market to take up caring responsibilities (for disability) to close family members including older relatives—2007 (only women aged 40+ with an older or disabled relative). (Source: Authors' calculations based on Eurobarometer (2007) microdata)

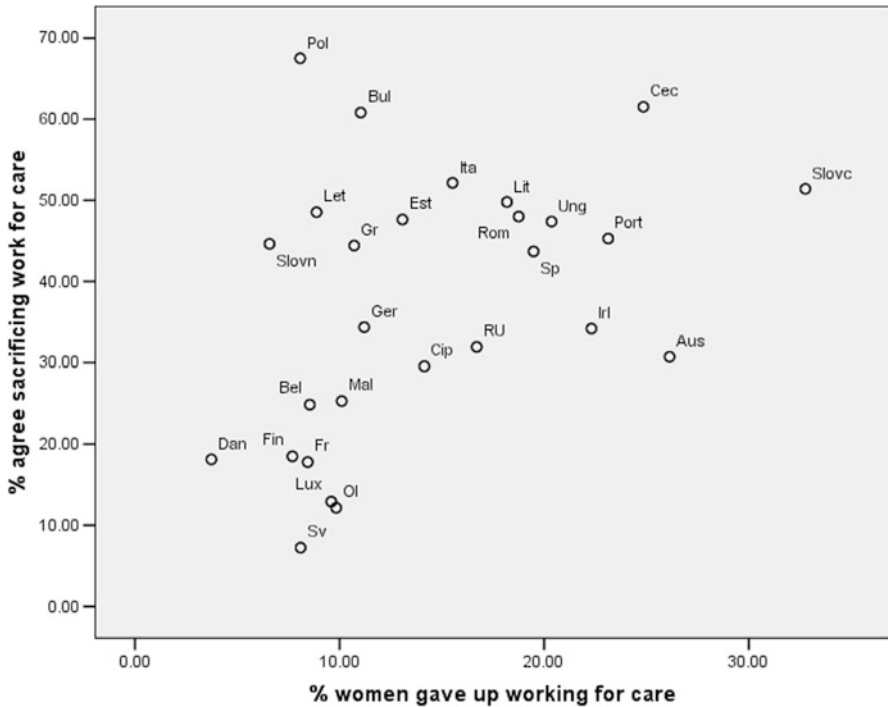


Fig. 2.15 Relationship between the percentage of women that have withdrawn (partially) from the labor market to take up caring responsibilities for a dependent family member (young adult or older person), and the percentage willing to sacrifice their career for caring responsibilities—2007 (sample made up of women more than 40 years with a dependent family member). (Source: Authors’ calculations based on Eurobarometer (2007) microdata)

Other sources help to provide some context for these findings. For example, a recent OECD study (2011) has found that caregivers are less likely to have been in paid employment before taking up caregiving duties and are 50 % more likely to have been homemakers (see Table 2.6). The gap between the occupations of caregivers and noncaregivers is small in northern European countries, but larger between those in the south (Greece, Spain, and also Poland). In Austria and Italy, a high percentage of caregivers are pensioners (48.9 and 36.2 % as compared with an OECD average of 20 %).

According to the analysis carried out by the OECD (2011), the repercussions on career choices are determined by the intensity of the care required by the dependent relative. Indeed, in northern Europe and in Switzerland, care requirements are less intense, with caregivers providing between 0 and 9 hours of care per week. Furthermore, less than 20 % of caregivers provide more than 20 hours a week. Unsurprisingly, in southern and eastern European countries, such as Poland and the Czech Republic, over 30 % of caregivers provide more than 20 hours of care a week.

Table 2.6 Difference between carers and noncarers according to employment status before taking up caregiving duties (percentages in relation to specific population groups). (Source: OECD 2011)

Country	Pensioner		In paid employment		Unemployed		Homemaker	
	Carer (%)	Noncarer (%)	Carer (%)	Noncarer (%)	Carer (%)	Noncarer (%)	Carer (%)	Noncarer (%)
Australia	16.8	16.2	53.1	66.2	1.6	1.8	21.7	6.9
Austria	48.9	44.0	31.8	38.9	3.3	4.0	11.6	9.8
Belgium	22.3	25.6	39.0	42.7	10.5	6.0	16.5	13.0
Czech Republic	34.7	43.4	44.7	48.1	11.2	5.6	0.3	0.0
Denmark	19.1	22.2	59.0	60.6	7.0	5.9	1.3	1.7
France	24.0	25.5	51.6	52.7	4.3	6.1	13.8	9.3
Germany	23.5	20.5	48.2	53.8	9.7	11.2	11.9	8.9
Greece	18.7	23.3	31.4	47.2	2.4	2.8	46.0	25.1
Ireland	11.1	17.0	55.6	51.9	1.7	4.0	24.7	17.8
Italy	36.2	35.5	33.5	35.8	3.2	4.0	24.5	22.3
Korea	7.0	10.6	45.0	48.9	3.8	3.0	36.9	33.2
Holland	6.5	11.0	52.4	5.1	2.9	3.0	27.0	17.6
Poland	37.6	36.2	33.6	60.3	3.4	7.9	9.8	5.3
Spain	10.0	13.8	33.0	45.1	5.9	7.5	43.9	25.7
Sweden	12.9	16.3	75.4	73.9	1.4	3.5	0.8	1.1
Switzerland	7.3	10.2	67.0	69.5	3.5	2.8	15.7	10.0
United Kingdom	10.6	7.3	77.9	80.9	1.4	0.9	5.3	5.0
United States	17.7	15.5	58.5	62.0	2.3	1.8	10.7	9.1
OECD (17)	20.3	21.9	49.5	52.4	4.4	4.5	17.9	12.3

Data refer to people aged between 50 and 65

Thus, the impact of care work on labor market participation becomes more apparent when the caring requirements are intense: every increment of 1 % in the hourly provision of care work increases the likelihood of labor market withdrawal by 10 %. The same figure was also found in a study carried out by Costa and Ranci (2010), who found that caregivers with relatively light responsibilities (less than 14 hours a week) have a higher than average income (per capita), while income reduces by 16 % for caregivers who provide a moderately higher level of care and reduces by 33 % for caregivers with intensive caregiving responsibilities (more than 28 hours a week). In general, intensive caregiving is a strong factor in creating financial risks, while caregiving offered only for a limited amount of time does not appear to have any significant negative economic consequences, especially in the case of families with a medium to high standard of living. Overall, these findings suggest that being a caregiver in northern Europe does not necessarily equate to an automatic reduction in employment opportunities, while in southern Europe, the likelihood of withdrawing, even partially, from the labor market, is more pronounced.

2.6 Conclusions

The findings presented in this chapter paint a picture of a highly differentiated Europe in terms of LTC policies and provision. In particular, in facing increased demand for services because of the ageing of the population, responses from families and the welfare state differ, which in turn have diverse consequences both for individuals with disabilities and their families.

With regard to LTC public provision, findings relating to expenditure and coverage highlighted two main findings. The first is that, even today, the information that is required for international comparison is lacking. This reflects, on the one hand, the complexity of national systems of LTC, the diverse forms of intervention, and institutional responses from the various sectors of the welfare state (for example, the often poorly defined barrier between the social and health sectors). On the other hand, the absence of reliable data can be seen as a reflection of the failure to prioritize the construction of a relevant database at the European level to facilitate independent analysis of comparative statistical data. The progressive increase in financial investment into the LTC sector, as confirmed by the findings presented in this chapter, demonstrates the importance with which national governments are now starting to see this issue, yet also highlights the need for basic statistics in order to determine expenditure requirements and gauge the effectiveness of various interventions. Such data are also imperative for the European Union, which over time is likely to start taking more responsibility, albeit indirect, in this field.

The second major finding is that in Europe, it is possible to identify two diverse LTC systems. The first is characterized by generous financing and a comprehensive set of services, as evidenced through high rates of coverage. In contrast, the second is characterized by low rates of funding and a strong dominance of cash support. These two models correspond, as will become evident in the following chapters, to

diverse forms of definition and extension of social rights in the field of LTC. Between these two extreme positions can be found various national systems, particularly those located in continental Europe, which operate according to a more intermediate model. Over the last 20 years, many of these mid-ranging countries have introduced major policy reforms into their national LTC systems. The available data, although scarce, duly highlight how these reforms have led to a greater convergence between the various European countries over the last 20 years, notwithstanding the significant weakness of specific LTC systems such as that of Italy, in which reform has not occurred in any shape or form. Furthermore, the institutional model adopted in each country is both broadly congruent with the attitudes and valuations of its citizens toward the overall welfare model. However, the operation of LTC policies in some countries diverges from attitudes toward individual's roles in providing direct care to dependent family members (of which countries in central-eastern Europe provide a clear example).

Furthermore, in terms of the growth of population ageing, the operation of LTC systems clearly has an impact on social inequality, particularly in terms of gender. In several European countries, older people's access to healthcare is negatively related to their health status; those with chronic health problems or disabilities experience greater access problems. Likewise, it appears to become more difficult for family members to reconcile their caring responsibilities with paid employment when their older relative has more extensive care needs. This in turn helps to highlight how less well-developed LTC models based around cash transfers, rather than in kind services, result in the relatively widespread penalization of women with caring responsibilities.

References

- Bajekal, M., & Prescott, A. (2003). *Health survey for England 2001: Disability*. London: The Stationery Office.
- Cambois, E., Clavel, A., & Robine, J.-M. (2006). L'espérance de vie sans incapacité continue d'augmenter. *Solidarité et Santé*, 2006(2), 7–22.
- Christensen, K., Doblhammer, G., Rau, R., Vaupel, J. W. (2009). Ageing populations: The challenges ahead. *The Lancet*, 374(9696), 1196–1208.
- Comas-Herrera, A., Wittenberg, R., Gori, C., Costa-i-Font, J., di Maio, A., Patxot, C., Pickard, L., Pozzi, A., Rothgang, H. (2006). Future long-term care expenditure in Germany, Spain, Italy and the United Kingdom. *Ageing and Society*, 26(2), 285–302.
- Costa, G., & Ranci, C. (2010). *Dependency as a factor of vulnerability in Europe*. Paper presented at the Transforming Care Conference. Copenhagen.
- Da Roit, B., Le Bihan, B., & Österle, A. (2007). Long-term care policies in Italy, Austria and France: Variations in cash-for-care schemes. *Social Policy and Administration*, 41(6), 653–671.
- De Hollander, A. M., Hoeymans, N., Melse, J. M., Van Oers, J., & Polder, J. (2006). *Care for health. The 2006 Dutch public health status and forecast report*. Houten: Bohn Stafleu Van Loghum.
- Eckholm, O., et al. (2006). *Health and morbidity in Denmark 2005 & trends since 1987*. Copenhagen: National Institute of Public Health.
- Eurobarometer. (2007). *Health and long-term care in the European Union* (Special Eurobarometer 283, 1–247). Brussels: European Commission.
- Eurobarometer. (2010). *Eurobarometer 71: Future of Europe*. Brussels: European Commission.

- Eurofamcare. (2006) *Services for supporting family carers of dependent older people in Europe: The trans-European survey report*. <http://www.ukc.de/extern/eurofamcare/deli.php>.
- European Commission, Directorate-General for Employment and Social Affairs. (2002). *Definition of disability in Europe: A comparative analysis*. Brussels: Brunel University.
- European Commission. (2011). *The 2012 ageing report: Underlying assumptions and projection methodologies*. European Economy 4/2011, Joint Report prepared by the DG ECFIN and the Economic Policy Committee (AWG), Brussels.
- Eurostat. (2010). *ESPROSS database*. Brussels: Eurostat.
- Eurostat. (2011). *Europe in figures: Eurostat yearbook 2011*. Brussels: Eurostat.
- Fernandez, J. L., Forder, J., Trukeschitz, B., Rokasova, M., & McDaid, D. (2009). *How can European states design efficient, equitable and sustainable funding for long-term care for older people?* (European Observatory on Health Systems and Policies, Policy Brief No. 11). Copenhagen: WHO Regional Office for Europe.
- Fries, J.F. (1980). Aging, natural death, and the compression of morbidity. *New England Journal of Medicine*, 303(3), 130–135.
- Glendinning, C., Arksey, H., Tjadens, F., Moree, M., Moran, N., & Nies, H. (2009). *Care provision within families and its socio-economic impact on care providers across the European Union*. York: Research Works, Social Policy Research Unit, University of York.
- Gruenberg, E. M. (1977). The failures of success. *Milbank Memorial Fund Quarterly Health*, 55(1), 3–24.
- Huber, M., Rodrigues, R., Hoffmann, F., Gasior, K., & Marin, B. (2009). *Facts and figures on long-term care*. Wien: European Centre.
- Kraus, M., Rieder, M., Mot, E., Willemé, P., Röhring, G., & Czypionka, T. (2010). *Typology of systems of long-term care in Europe—Results of work package 1 of the ANCIEN Project* (ENEPRI Research Report No. 91). Brussels: CEPS. <http://www.ancien-longtermcare.eu/node/27>.
- Lafortune, G., & Balestat, G. (2007). *Trends in severe disability among elderly people: Assessing the evidence in 12 OECD countries and the future implications* (OECD Health Working Papers No. 26). Paris: OECD.
- Lagergren, M., & Batljan, I. (2000). *Will there be a helping hand? Macroeconomic scenarios of future needs and costs of health and social care for the elderly in Sweden, 2000-30*. Stockholm: Fritzes offentliga publikationer.
- Lamura, G., Döhner, H., & Kofahl, C. (2008). *Services for supporting family carers of older people in Europe: Characteristics, coverage and usage. A six-country comparative study*. Hamburg: Lit Verlag (EUROFAMCARE Consortium).
- Manton, K. G. (1982). Changing concepts of morbidity and mortality in the elderly population. *Milbank Memorial Fund Quarterly: Health and Society*, 60(2), 183–244.
- OECD. (2005). *Long-term care for older people*. Paris: OECD.
- OECD. (2006). *Projecting OECD health and long-term care expenditures: What are the main drivers?* (OECD Economics Department Working Paper No. 477). Paris: OECD.
- OECD. (2011). *Help wanted? Providing and paying for long term care*. Paris: OECD.
- Oliveira Martins, J., de la Maisonnette, C., & Bjørnerud, S. (2006). *OECD health and long term care expenditures: What are the main drivers?* (Economics Department Working Paper No. 477). Paris: OECD.

Part II

Country Analysis

Chapter 3

Long-Term Care in Sweden: Trends, Actors, and Consequences

Gabrielle Meagher and Marta Szebehely

3.1 Introduction

In the 1970s and 1980s, Sweden had a well-developed system of tax-funded, mainly publicly provided services for older people, and some development of services for people with disabilities aged less than 65 years old. This system has changed significantly during recent decades. There has been some *retrenchment* in eldercare, evident in falling coverage and stronger targeting on people with higher levels of need. This development has led to *informalization* of care for some groups of older people as services, which would have been available as public services for previous generations must now be provided by family members. In disability care, there has been considerable *expansion* of services, perhaps most notably in the introduction of a personal assistance scheme for people with severe disabilities. These divergent trends in services for older people and people with disabilities have coincided with a convergent development across both care fields: the *marketization* of services and the emergence of large, corporate, for-profit providers.

The focus of this chapter is to explain how and why these changes have happened, and to discuss their consequences for service users and for the possible future of social care in Sweden. We explore the roles of different social, political, and economic actors in the change process, and identify which changes were intended and unintended by policy makers. In addition to the dynamic interaction of state-steering and municipal response that are typically important in explaining change in patterns of social service in countries with multilevel government, we identify “invasive displacement” and “layering” as processes transforming the institutions that directly and indirectly organize care service provision.

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3.2 Sweden's Care Regime: Institutional Structures and Governance Processes

In comparative perspective, care for both older people and people with disabilities in Sweden is provided within a universalistic care regime, underpinned by a publicly or collectively oriented “care responsibility culture.” The system is organized within a strongly decentralized political structure that has been dominated at the national level by the Social Democratic Party, punctuated by short periods of right-wing government. Within this broad framework, the roles that the family, the public sector, and the private sector each play in providing and funding care have evolved over the years. It is possible that the trajectory along which care provision seems to be evolving is threatening the traditional universalistic care regime, a theme to which we return later. However, this section first sets out the formal institutional structures and governance processes through which the tasks of funding and providing care are distributed and overseen.

One defining feature of the Swedish care regime is that families do not have a legal responsibility to provide for the care needs of their adult members, even though in practice families play a considerable (and, in eldercare, increasing) role. Furthermore, and important to note for readers of this book, “long-term care” is not a concept used in Swedish policy or political debate. Rather, care for frail older people, including nursing homes, and care for people with disabilities are framed as two separate fields of *social care* (rather than health care).

Another feature of Sweden's care regime is the strong tradition of municipal autonomy: municipalities have primary responsibility for organizing publicly funded care services, both home-based and residential. Municipalities also have the substantial taxing powers required to fund much of the total public budget for formal care for older people (85 %) and for people with disabilities (around 70 %). Municipalities are also free to decide on the distribution of different types of care (for example, between homecare and residential care in eldercare services) and between services that meet the needs of different social groups (for example, eldercare, childcare, and disability services).

However, the primary role that municipalities take in funding and providing care services does not mean that the state is unimportant: the national government may currently fund only 10 % of the costs of eldercare (the remaining 5 % is covered by user fees), but it has a considerable impact on municipal care practice, via three steering mechanisms: legislation and regulation; financial incentives; and oversight and guidance. Sometimes, state actions are aimed specifically at reform of one branch of care services (such as the Disability Act of 1993); sometimes they are decisions with a general remit, directed at a wider span of activities, or indeed the whole of municipal activity (such as the Municipal Act of 1991).

Through the mechanisms of legislation and regulation, the Swedish state stipulates which populations municipalities are required to provide care for, how much they can charge for services, and what kind of organizations are allowed to offer services. The needs of both older people and people with a disability are recognized within

the Social Services Act (SSA) introduced in 1982, which regulates home-based care services and residential care including nursing homes. The SSA is a goal-oriented legislation ensuring a general right to claim support “if the needs cannot be met in any other way,” so that the individual can have a “reasonable level of living.” The legislation does not specify “needs” but there is a right to appeal to court if the individual is not satisfied with a decision.

In addition to entitlements established by the SSA, people with severe disabilities have further entitlements under the Disability Act of 1993 (consisting of the Act Concerning Support and Service for Persons with Certain Functional Impairments, LSS, and the Assistance Benefit Act, LASS; the latter has been part of the Social Insurance Code since January 2011). In contrast to the SSA, this legislation confers specific and absolute rights to persons with certain extensive functional impairments¹ (not caused by normal ageing), and sets out the measures that local authorities are obliged to provide to ensure these persons “good living conditions” (a more ambitious goal than in the SSA). Disabled people who qualify for the services under the Disability Act, and who need extensive help with basic needs, may also be entitled to personal assistance, in which case the state covers the municipality’s costs for assistance exceeding 20 hours per week. Thus, an important difference between the SSA on one hand and the Disability Act on the other is that the SSA leaves the municipalities to define or interpret who is entitled to services and what their entitlements are, while the Disability Act prescribes quite specifically who is entitled and what support they should receive, thereby constraining municipal discretion.

The state also steers municipal activity using financial incentives, both via the *scale* of state subsidies, and their *structure*. Over recent decades, financial steering measures that affect care services have changed several times. In 1993, special purpose grants for key service areas were replaced with block grants that could be allocated between different purposes by municipalities themselves. Later, a range of special earmarked funds were introduced alongside block grants, to give municipalities incentives to change their organization or activities in line with the national government’s goals. One example of earmarked project funds that is crucial to our account has been their use as an incentive for municipalities to introduce customer choice models (in effect since 2009); other examples include incentives to introduce support for family carers since 1999, and funds for training on dignity in eldercare since 2011.

Oversight and guidance is the third major category of steering mechanisms, and in Sweden, these activities are largely delegated to the National Board of Health and Welfare, NBHW (Socialstyrelsen). The main trend here is the increasing intensity of soft regulation via such measures as benchmarking, open comparison of data on expenditure and quality in care services, and the development of practice guidelines and assessment tools.

¹ Three groups are specified in the Disability Act: (1) persons with an intellectual disability, autism, or a condition resembling autism; (2) persons with a significant and permanent intellectual impairment after brain damage in adulthood; and (3) persons with other lasting physical or mental disabilities (not due to normal ageing) if these disabilities cause significant difficulties in daily life requiring extensive support.

3.3 Trends in Long-Term Care: Changing Coverage, Spending, and Organizational Forms

We began this chapter by noting that there has been significant change in the scope and organization of services to older people and people with disabilities in Sweden in recent decades. This section briefly describes these changes in order to provide evidence of the trends, which this chapter seeks to explain, including falling coverage in eldercare; the emergence and growth of new programs providing care to people with disabilities; and the marketization of different kinds across both forms of care.

In contrast with most other European countries, provision of eldercare services has declined in Sweden, relative to the share of older people in the population. Thirty years ago, 16 % of people 65 and over received public homecare, while approximately half as many were in residential care (Szebehely 2005). By 2000, the proportion receiving homecare had fallen to 8 %, while the proportion in residential care remained more or less stable. Over the last decade, there has been a significant decrease in residential care, which has only partially been compensated by an increase in home-based care. Thus, according to the most recent national statistics, in 2011, 9 % of the older population (65 years and over) received homecare, while 5 % were in residential care, including sheltered housing (NBHW 2012a). Declining coverage can only partially be explained by improved health among older people; hence the probability of receiving publicly funded homecare is now clearly lower than it was 30 years ago (Larsson 2006; Szebehely and Trydegård 2007).

The trend in service provision for people with disabilities aged less than 65 years has been quite different from that in eldercare. Coverage rates cannot be calculated for people with disabilities in a way analogous to older people, so here we rely on absolute numbers of recipients. Available data show that the number of disabled people receiving any form of public social care increased by 29 % between 2000 and 2009 (Szebehely 2011). Yet informal care also remains important for people with disabilities, especially for those who fall outside the scope of the Disability Act. As for older people, the majority of care for those with disabilities is provided by family members, even though Sweden is a country with comparatively well-established formal long-term care services. In fact, since the end of the 1980s, there has been an increase of family care for people with disabilities with fewer care needs as well as among older people with all levels of need. Only among people with extensive disabilities, in particular those covered by the personal assistance scheme, has there been an increase of formal care services and a decrease of those receiving informal care only (Szebehely and Trydegård 2007).

Spending trends mostly reflect this changing profile of service provision in long-term care. Public spending on eldercare increased during the 1980s (from 55 to 64 billion SEK between 1985 and 1990) despite falling coverage, for reasons we explain in the following section. Between 1990 and 2000, spending increased by only 5 %—in relation to the number of people aged 80 years and older in the population, this corresponds to a decrease of 14 % (Government Report 2004). Between 2002 and 2009, spending declined in absolute terms by 4 %, from 93.4 to 89.6 billion

SEK in 2009 prices (NBHW 2011a). By contrast, between 1993 and 1999, public spending on provision for disabled people increased by 68 %, with most of the increase occurring between 1993 and 1995 with the introduction of the disability reforms LSS and LASS, mentioned earlier (Palme et al. 2003). Between 2000 and 2009, public spending on disability services increased a further 66 %, from 37 to 61 billion SEK in 2009 prices.² As a result, spending on disability services as a share of public spending on long-term care has increased significantly and was 41 % in 2009 (Szebehely 2011).

Despite these changes to the long-term care profile, public resources flowing to eldercare services remain generous in Sweden, from a comparative perspective. Although comparable data on spending on social services are difficult to come by, available evidence suggests that Sweden remains one of the most generous countries in the OECD when it comes to services for older people. Public spending amounted to around 2.4 % of GDP in Sweden in the mid-2000s, compared to 1.7 % in Denmark, 1.1 % in Italy, and 0.9 % in the United States. Indeed, of the 14 countries for which data are available, only the Netherlands spends a higher proportion (2.5 %; Huber et al. 2009). The same data source put spending on long-term care (including care for both older and disabled people) in Sweden at 3.9 % of GDP, higher than any other of the 24 European and North American nations analyzed (Huber et al. 2009).

If the care needs of Sweden's elderly have changed less than formal care offerings, the question arises: who is helping them now? Evidence suggests that the gap is being bridged by family members, especially daughters (Johansson et al. 2003; Szebehely and Trydegård 2012) and it has been estimated that, between 1994 and 2000, families' share of all community care increased from 60 to 70 % (Sundström et al. 2002). Privately funded, privately provided services purchased on the open market, outside the needs assessment and oversight processes of the formal care system, have also come to play a greater role in the overall arrangements for support for older people. Since 2007, the state has sought to promote such private purchases with a tax rebate; thereby blurring the boundary between the private market and publicly funded care services. While those with lower education are likely to rely on family carers, those with higher education often turn to the market to buy services (Szebehely and Trydegård 2012). Thus, the decline of tax-funded services has had different consequences for older people from different social groups as well as for their families.

Informalization and privatization through the increased use of privately purchased services are not the only developments of note in the Swedish care system. Private service *providers* have also come to play a significant role, *inside* as well as outside the publicly funded, publicly organized care system, as a result of a range of policy changes since the early 1990s. In 1993, only 2 % of publicly funded hours for older people receiving homecare were privately provided (NBHW 2003); by 2010, this

² Childcare is another area where increased government ambitions have reduced the municipal resources available for eldercare: with the implementation of the School Act 1995, municipalities became obliged to offer childcare to all children 1–12 years of age. As a result, between 2000 and 2009, the public resources for childcare increased by 67 % (National Agency for Education 2011).

proportion had increased to 19 %; in 2010, a similar proportion, 19 %, of older people in residential care lived in privately run facilities (NBHW 2011b). Among disabled people less than 65 years receiving services, the rate of private provision is higher: in 2010, 23 % of homecare hours and 28 % of the places in residential care were privately provided (NBHW 2011b), while among those using the personal assistant scheme, just more than half (55 %) received services from a private provider (Swedish Social Insurance Agency 2011). Significantly, the entire increase in private provision has been among *for-profit* providers; the share of cooperatives and other nonprofits has remained stable since the early 1990s. Furthermore, large corporate providers are dominant among for-profit private providers. The two largest players, Carema and Attendo, both owned by international private equity companies, controlled half the eldercare market in 2008 (Meagher and Szebehely 2010).

3.4 Explaining the Changing Profile of Long-Term Care in Sweden

The combination of falling coverage of public eldercare in Sweden with the emergence of new, well-funded measures to support certain groups of people with disabilities means that the profile of long-term care recipients in Sweden has changed substantially in recent decades. Although shaped by the consolidation of market-oriented ideas and “New Public Management” (an ideology that signifies suspicion toward traditional public sector ways of working by the policy-making elite), the changes we explain in this section are somewhat separate from the marketization policies discussed later. Much can be explained in terms of the normal cost-shifting strategies that governments in multilevel systems use. Another significant factor is the emergence and impact of a strong disability rights movement in Sweden during the 1980s. We argue that the Disability Act, which fundamentally changed both the scale and scope of services available to people covered by it, is an example of what Streck and Thelen (2005) call “layering.”

3.4.1 *Rationalizing Eldercare*

After the oil shocks of the 1970s, Sweden entered the 1980s with the world’s largest proportion of older people in its population and a fiscal deficit that was to worsen before it eventually improved. At this time, economists who were critical of the size and dominance of the public sector came to hold a much more central place in public and policy discourse, and pressure on public budgets intensified. However, as we noted in the previous section, resources in eldercare did not fall, but rather increased; in fact, the number of hours worked in homecare services doubled over the 1980s. What changed, in the new economic and policy climate, were the kind of needs recognized by the system, the kinds of services delivered to older people, and the

organization of care work and the care workforce, as previous research has firmly established (Sundström and Malmberg 1996; Szebehely 1995; Thorslund 1991). In homecare, services became more targeted at those with larger care needs, so that a smaller proportion of older people received more intensive care. Furthermore, an increasing proportion of care workers' time came to be taken up with personal care rather than domestic help (Sundström and Malmberg 1996). The policy priority of "deinstitutionalization" also contributed to the changing needs profile of homecare clients.

Not all of the increase in measured hours in the homecare service was spent in caring for this proportionally smaller and absolutely frailer cohort. Supported by the Municipal Workers' Union, work in homecare became more professionalized as workers gained rights, which other professionals had long enjoyed (Liljeström and Özgalda 1980). Between the mid-1970s and the mid-1980s, contract staff (paid by the hour) were largely replaced by (mostly part-time) employees (Thorslund 1991). These employees were also paid for time spent traveling between clients, rather than just the time they spent with them. Furthermore, homecare workers began to attend meetings and receive training and supervision, for which they were also paid. Overall, the "indirect" working hours (paid hours not spent with clients) increased from 3 to 34 % between 1970 and 1987 (Szebehely 1995). Funding arrangements reduced municipalities' incentive to contain the growth of indirect working hours: between 1964 and 1993, the state subsidized 35 % of the wages of homecare workers with an earmarked grant, and from 1984, hours for training could be included. Under the influence of New Public Management ideology, there was a related shift from a more person-centered organizational model, under which each care worker was responsible for a small number of clients, toward a Taylorized "assembly-line" model, under which a number of care workers jointly provided specific tasks to a larger number of clients. An unexpected consequence of this rationalization of care was that a larger proportion of working time was required for tasks other than helping, such as planning and coordinating the work (Szebehely 1995).

During the 1990s, eldercare provision came under further pressure from general developments in municipal finance and from specific developments in health and social care policy. The economic crisis of the early 1990s squeezed resources for eldercare, as municipal tax revenues fell and unemployment, which rose from 1.7 % in 1990 to 8.3 % in 1993, increased demand for social assistance benefits. But more active policy changes also affected municipal finances in general, and eldercare funding and regulation in particular. As part of its deficit reduction strategy, a newly elected right-center national government legislated in 1991 to cut grants to local government and to stop municipalities raising their own taxes to compensate for the loss of state funds (Loughlin et al. 2005). This effective tax-freeze was not lifted until 1993.³

³ Also, after the actual tax-freeze several government initiatives have imposed restrictions on the municipalities' decision latitude in raising tax rates. For instance, between 1997 and 1999, municipalities that raised their tax forfeited government grants equivalent to half of the increase in revenue (Palme et al. 2003).

Furthermore, in 1993, the same national government changed the structure of state grants to the municipalities, merging earmarked grants for specific activities (such as wages of homecare workers) into a single block grant to each local authority. The “Principle of finance,” also adopted in 1993, obliged the state to ensure that municipalities had the means (without raising taxes) to fulfill any new tasks they might be delegated. As Loughlin et al. put it, “this principle has not always been respected, at least according to the municipalities” (2005, p. 357). These changes became particularly significant for eldercare provision, because the ambitious new Disability Act would be legislated in the following year.

Measures aimed at financial regulation of various kinds certainly put new pressure on municipal eldercare, but so did policies directed squarely at the organization of care services. Passed by a Social Democratic parliament in 1990 and in operation from the end of 1992, the Ädel reform shifted the responsibility for nursing homes from the *health* care sector, administered and funded at the county council level, to the *social* care sector, administered and funded at the municipal level. This reform was the result of a long process of contention within and between the right and left political blocs and of “clear conflict” between the county and municipal levels of government over more than a decade (Lakomaa 2009). Ultimately, it involved the work of two committees over more than a decade. Under the reform, municipalities were required to pay for hospital care for older people considered medically ready for discharge. Given the relative cost of a hospital and a nursing home bed, this created a strong incentive to move older people out of hospital. The primary stated aim of the reform was to increase quality of life for older people by “demedicalizing” their care. However, the reform was implemented just as Sweden fell into deep recession, and focus shifted to its cost-saving potential as fiscal strictures tightened. Certainly, the number of so-called “bed-blockers” decreased sharply (as did the number of hospital beds). However, this change also meant that older people were more likely to be leaving hospital with higher care needs, and these people came to use an increasing share of the municipalities’ already squeezed resources. This was yet another factor pushing groups of older people with smaller (but existing) care needs outside the system.

By the early to mid-1990s, municipal finances were squeezed by the combined effect of the recession (which reduced tax revenues), the Ädel reform (which increased demand for eldercare on the municipalities by decreasing the number of hospital beds), and the disability reforms (which made new demands on municipal funds). In this context, many municipalities relied on user fees to steer demand for services and some used fees to increase their income. Income-related fees became a handy instrument to discourage older people with higher incomes from using public services, while low-income pensioners refrained from using services because they were not guaranteed the right to retain a reserved amount of their income. Considerable differences between the municipalities became evident, and along with lack of fairness in the system and inequality of access meant that these problems came increasingly onto the political agenda in the 1990s—put there not least by pensioners’ organizations (Feltenius 2007). However, it was not until 2002 that a remedy, in the form of the “max-fee” reform, was legislated by a Social Democratic government

with the explicit goal of strengthening universalism (Government Bill 2000/01:149). This policy protects older people on low incomes by specifying a reserved amount for users of homecare as well as of residential care, such that fees charged could not reduce their income below a specified level: 4,967 SEK (€ 565) per month plus rent for a single person in 2012. The reform also protects older people with higher incomes with a maximum fee: 1,760 SEK (around € 200) per month in 2012. Nevertheless, municipalities continue to have an incentive to use fees as rationing devices for homecare services, particularly to steer away more affluent groups of older people with fewer care needs (Szebehely and Trydegård 2012).

3.4.2 Disability Support: Redressing the Balance?

One of the most important legislative changes for both older people and disabled people in Sweden was the introduction of the Disability Act in 1993. The need for reform to enable full participation of disabled people in social, cultural, and economic life had been recognized in the mid-1960s (National Insurance Board 2002). However, during the 1970s and 1980s, a range of actors inside and outside the social service system argued that the standard of welfare for disabled people, particularly those with severe disabilities, had not kept pace with developments for the general population. Different groups of actors represented different groups of disabled people, specifically those with learning disabilities on one hand and those with severe physical disabilities on the other.

The National Association for Persons with Intellectual Disabilities (FUB), primarily a parents' organization, played a critical role in promoting the prioritization of support for people with learning disabilities (NBHW 2009). By FUB's own account of its history, the principle of "normalization," according to which the "patterns and conditions of everyday life" for people with learning disabilities should be "as close as possible to the norms and patterns of the mainstream of society" (Nirje 1969), has been central to this organization's ideology. Nevertheless, FUB fought for the specific recognition of people with learning disabilities in the Disability Act, against opposition (including inside the disability movement) that considered the singling out of specific groups as potentially discriminatory (FUB 2007). Inside the social service system, Karl Grunewald was an important advocate for reform of services for people with learning disabilities. Grunewald held a range of key positions in the National Board of Health and Welfare, including as Director of Mental Retardation Care Services (as they were then called) in the 1970s. Similar to FUB, he advocated strongly for giving people with learning disabilities the opportunity to live "normal lives," and deinstitutionalization was a particular focus of his activism (Grunewald 1974). FUB's advocacy, in combination with Grunewald's, succeeded in having people with learning disabilities specifically recognized in the Disability Act.

Another extremely influential organization, with strong connections inside the political system, was the Independent Living Movement (ILM), which advocated primarily for adults with extensive physical disabilities. Founding member Adolf

Ratzka, a Germany-born Swede, severely disabled by polio as a young man, spent several years in the United States during the 1960s, where he came into contact with the Independent Living Movement and experienced self-directed personal assistance services at first hand. Ratzka brought the ideas of the ILM to Sweden, where he organized the first Nordic conference on Independent Living and established a pilot self-organized personal assistance scheme in Stockholm, both in 1983 (Ratzka 1986). In a manifesto published in 1984, Ratzka stated that the ILM was linked to other struggles for equal rights, and was influenced by the ideology of “consumerism,” which, when “applied to disability, postulates that we disabled people are experts on our own lives [and] that we have the right and responsibility of assuming control over our own lives” (1984, p. 3). Significantly, Ratzka’s manifesto goes on to state that “Independent Living subscribes to de-professionalization,” and his account of the history of the ILM in Sweden directly criticizes the Municipal Workers’ Union’s efforts to professionalize services for people with disabilities (Ratzka 1986).

In 1986, then leader of the Liberal Party in Sweden, Bengt Westerberg, met Ratzka for the first time. Addressing a conference celebrating 25 years of the ILM in Sweden in 2008, Westerberg reported being “very inspired by that meeting” (Westerberg 2008). Over the next few years, he was to be an important advocate for a personal assistance scheme for people with disabilities. In 1988, he put a motion to the parliament proposing a personal assistance scheme, but he was overtaken by events. Bengt Lindqvist, Minister for Health and Social Affairs in the Social Democratic government at that time, had recently established a commission to examine provision for people with disabilities, with a view to making recommendations about how support for this group could be improved (Dir 1988).⁴ Because disability policy was already under review, Westerberg’s motion failed.

Lindqvist’s original directions to the commission stressed that it should identify possibilities for increased efficiency, despite the stated ambition of improving support for people with disabilities; under the stringent fiscal disciplines imposed during the 1980s, all new proposals had to be financed within existing public monies. However, in 1990, he gave new instructions to the commission, allowing it to propose reforms that could cost more than existing programs for people with disabilities. The revised instructions were the result of three motions by members of parliament from the Center, Communist Left, and Liberal parties, the last signed by Bengt Westerberg, all arguing for the work of the commission to be unrestricted. The commission delivered its report in the early 1990s, by which time a right-center government was in power—with Bengt Westerberg as Minister of Health and Social Affairs. In 1993, when the country was still in a serious economic crisis, this government passed the Disability Act. A personal assistance scheme was a central element of the new provisions for certain people with disabilities.

⁴ In Sweden, a parliamentary commission usually is appointed to investigate an issue before a Government Bill is put to the Parliament. The commission presents one or more Government Reports, which are discussed widely during a consultation process designed to provide feedback to the Government. Bills are drafted after the consultation process has concluded (Ministry of Justice 2007).

3.4.3 *Competition Over Resources? Layering in Long-Term Care*

One logical possibility for the government to respond to the emergence of a strong disability rights movement in Sweden would have been to reform the Social Services Act to specify a right to support for all people with significant disabilities, whether congenital or acquired, of any age. Yet, this was not the approach the government took. Instead of revising a policy that takes in *all* citizens who might benefit from more extensive support, the government chose to make separate provision for specific groups of younger disabled people only, in what can be understood as a new “layer” in the social care system.

Streeck and Thelen (2005) define “layering” as a form of institutional change that occurs when policy creates new organizational structures and practices (or “layers”) on top of existing institutions, which are more difficult to change. They argue that, because the process of “layering” does not directly undermine existing institutions, it is less likely to “provoke countermobilization by defenders of the status quo,” even though the new forms may undermine support for the traditional system by offering alternatives to particular constituencies. Thus, Streeck and Thelen (2005) argue, to the extent that new institutions “operate on a different logic and grow more quickly than the traditional system, over time they may fundamentally alter the overall trajectory of development as the old institutions stagnate or lose their grip and the new ones assume an ever more prominent role in governing individual behavior.”

The Disability Act enabled policy makers to meet the needs of a particular social group (people less than 65 with specific significant disabilities). Because services under the Act are aimed explicitly at people less than 65,⁵ in the context of a growing population of older people, this approach also enabled the government to contain demand for costly services among another group with arguably similar needs (people with significant disabilities acquired after the age of 65). The new structures and practices established by the Act have different underlying logics from those under the SSA (the goals of the Disability Act are more ambitious than the SSA and the Disability Act confers rights to services, while the SSA confers the right only to assessment and appeal), and two systems have evolved divergently (the scale of provision under the Disability Act has grown, while provision under the SSA has shrunk). Moreover, there is evidence that increased expenditure on disability services is directly related to retrenchment in eldercare, through the mechanism of unbalanced growth identified by Streeck and Thelen (2005). Using data from 288 Swedish municipalities for the period 1998–2007, Birkelöf (2009) found that the rapid growth in spending on services to disabled people under the Disability Act (LSS) crowded out spending on services for older people and people with disabilities provided under the Social

⁵ People who begin to access services before they turned 65 are allowed to keep the (typically much higher) level of provision under the Disability Act, rather than be moved into the eldercare system. However, if they have personal assistance, they are not permitted any increase in the service offering, even if their needs change.

Services Act.⁶ Controlling for the age structure of the population, the size of the tax base and the municipalities' levels of long-term debt, Birkelöf's model showed that for every increase of 100 SEK in LSS spending, spending on SSA services to older and disabled people declined by 42 SEK.

In summary, within the long-term care system, layering in disability services has led to spending growth and reduced reliance on family among those eligible, while rationalization has led to declining spending and coverage in eldercare, resulting in off-loading of care to the family and the market sector⁷ (see also Szebehely and Trydegård 2012). While policy makers have intended the changes to disability services, they did not explicitly intend the informalization of eldercare or (before 2007) its purchase on the private market, outside the social service system.

3.5 Explaining Marketization of Swedish Long-Term Care

The rapid emergence and consolidation of a private sector is a particularly noteworthy phenomenon in the Swedish case, because the development of public services in Sweden has been so substantial in comparative perspective, and because these (public) services have been so central to the idea of Sweden as a universal or social democratic welfare state (see for example, Sipilä 1997). This section explains the introduction of competition and the growth of private providers within the tax-funded eldercare system as a process of *invasive displacement* of traditional public sector organization, with *layering* of market measures on top of existing public sector organizations, later amplifying marketization.

3.5.1 *Displacing the Public Sector: Early Market Reforms*

Streeck and Thelen (2005) explain displacement as a process of institutional change that occurs when “new models emerge and diffuse which call into question existing, previously taken for granted organizational forms and practices.” New models do not emerge by themselves—in the case of invasive displacement, Streeck and Thelen argue, change involves “active cultivation by enterprising actors,” who import and cultivate “‘foreign’ institutions and practices.” Using Streeck and Thelen’s concept, we seek to explain which forms and practices have been called into question in Sweden. We ask which “traditional arrangements” have been “discredited” and which “new institutions” and “behavioral logics” have been created, and by whom.

⁶ The study also found that LSS spending also crowded out spending on education, but did not crowd out spending on other municipal social responsibilities, including childcare, social assistance, and culture and leisure activities (Birkelöf 2009).

⁷ Younger disabled people with smaller care needs who are not eligible under the Disability Act rely, similar to older people, on services under the SSA, or on informal or market care, and they have been similarly affected.

The traditional arrangements of the postwar Swedish welfare state, before their partial displacement by competition and choice policies, are summarized by Blomqvist (2004) as publicly funded, publicly provided services aimed at offering high-quality services to all citizens. That the services were *public* was critical to social democratic reformers: “only by providing services *itself* could the state guarantee access to high quality social services for all citizens,” thereby achieving both equality and freedom from the market. Universality of high-quality services had a political goal, too, aiming to preserve “broad political support for the welfare system” by ensuring that offerings were attractive to *all* citizens—including the middle class (Blomqvist 2004, pp. 143–144). The behavioral logics of institutionalized public provision were based on high trust in the professionalism of public sector workers, and democratic steering and oversight of services at the local level. In practice, in homecare this meant that care workers had scope to negotiate with care recipients, which tasks would be performed and how (Eliasson-Lappalainen and Motevasel 1997; Szebehely 1995).

In elite discourse, public provision and the active citizen have been displaced as central to the goals of the Swedish welfare state since the 1980s, and a range of policies, proposed as “solutions” to the new “problems” that public provision posed for the Swedish economy and society, have since been enacted (Antman 1994; Blomqvist 2004; Green-Pedersen 2002; Montin and Elander 1995). Many of the reforms that have profoundly affected eldercare services targeted municipal activity in general, catching eldercare services up in their wake. Significantly, governments of both right and left have enacted market-oriented policies, although the intensity and intent of policy change under right and left governments has differed somewhat.

The process of legislating for market reform began in the mid-1980s under a Social Democratic government, which established initiatives to promote competition in the public sector, with the goals of increasing efficiency and quality. Both external (exogenous) and internal (endogenous) forces contributed to this shift in policy. Externally, what Streeck and Thelen (2005) call enterprising actors—in this case, the conservative party and the main employers organization, the Swedish Employers’ Confederation (SAF; today the Confederation of Swedish Enterprise) and neoclassically oriented academic economists—had begun to cultivate and import policy ideas foreign to the traditional arrangements. Inspired by British Prime Minister Margaret Thatcher, the 1980 SAF congress expressed the strongest neoliberal attack on the welfare state since the Second World War, arguing for market mechanisms and privatization of public services (Antman 1994; Svallfors 1989). A new, low-trust behavioral logic underpinned the proposed new institutional forms, which included contracting relationships between public purchaser and private providers. The behavioral logic of competition, rather than trust and professionalism, would drive efficiency and quality gains, ideally leading to a shrinking of the public sector.

Over the coming years, SAF consolidated its invasion strategy, significantly increasing resources devoted to propaganda activities while completing its defection from the previous tripartite (state, labor, and capital) consensus on the economy and the welfare state (Blyth 2001; Ryner 2002). SAF’s propaganda efforts included sponsoring market-oriented think tanks such as SNS and Timbro. Through publications

and seminars, which drew in academic economists, other opinion-makers, and senior figures from state agencies, especially the Ministry of Finance (MoF) and the Bank of Sweden, these think tanks became “vital agents in promoting change” (Blyth 2001; see also Ryner 2002). Actively promoted by Timbro, criticism of the public sector got a strong foothold in the media (Blyth 2001). The welfare state was described as wasteful, overly bureaucratic, and, above all, depriving the Swedish people of their right to choose freely which services they preferred (Montin and Elander 1995).

These efforts fostered a milieu in which economists, policy makers, and opinion leaders cohered into an epistemic community, centered around the ideas of neoclassical economics and New Public Management. This epistemic community provided intellectual authority to the private interests of Swedish big business, effectively constituting an “invading force,” seeking to discredit the traditional institutions of the Swedish welfare state.

This epistemic community had members inside the Social Democratic government as well as outside in SAF, SNS, Timbro, and the universities. Indeed, Streeck and Thelen (2005) argue that “exogenous change is advanced by *endogenous forces pushing in the same direction but needing to be activated by outside support*” (2005, p. 32, emphasis added). In this case, economists within the (Social Democratic) government acted as an endogenous force, activated by exchanges with academic economists, within international organizations (such as the OECD) and forums organized by SNS and Timbro (Ryner 2002). The key role of economists within the Social Democratic Party became evident in 1980—the year of the SAF congress—when the Social Democrats established an internal “crisis commission” to analyze the party’s loss of a second election in 1979. The crisis group was strongly dominated by economists, and its work arguably marks a starting point of the marketization of Swedish social policy. The Social Democrats were returned to power in 1982, and Kjell-Olof Feldt, a neoclassically trained economist and prominent advocate of public sector reform, was appointed Finance Minister (1982–1990; Ryner 2002). Among his other actions, Feldt “trebled the number of academically trained economists among top advisors within the Ministry of Finance” (Korpi 1996, p. 1729). Over the next few years, economists in and around the Ministry of Finance published several reports arguing for reorganization of the public sector—in a market direction (Antman 1994). Indeed, during the second half of the 1980s, virtually all publications from the Ministry of Finance came to advocate the introduction of various types of so-called “quasi-markets” in the social services sector (Blomqvist 2004).⁸

One example of the impact of Ministry of Finance economists on welfare policies is the Competition Commission, appointed in 1989 by the Ministry of Civil Affairs under a Social Democratic government. The commission focused initially on the private sector, but in 1991 received further instructions from the Minister to investigate how increased efficiency through competition would stimulate the development of

⁸ Particularly important was the 1987 Long-Term Survey, which suggested both limits on taxation and the introduction of market mechanisms such as a division between purchaser and providers and that private companies should be able to compete with public providers. The argument was that “the consumers’ free choice will show under which organizational forms an activity is best provided according to the consumer’s wishes” (Government Report 1987, p. 178).

the public sector. The market-oriented voice of MoF economists entered the commission via the Minister's instructions, which referred to the recent budget proposal that argued for increased competition and "market-type solutions by dividing between purchaser and providers" (Government Bill 1990/91:100, Appendix 2, pp. 33–34). This idea was acted on even before the report of the Competition Commission was published, in the new Municipal Act passed by the Social Democratic majority in 1991. The act allowed municipalities to introduce a division between purchasers and providers, and to outsource the provision of services to private companies.⁹

The report of the Competition Commission (Government Report 1991) was published in November 1991, just after the Social Democrats had lost the election, and the new conservative-led government had proclaimed a "Freedom of choice revolution." In 1992, the government presented a proposal (Government Bill 1992/93:43) based on the Commission's report, proposing further clarifications regarding the municipalities' right to outsource services. This proposal and its reception by the Social Democrats reveal something about the politics of privatization. The Social Democrats did not oppose either competition or for-profit companies in welfare service provision. Rather, they argued that the clarifications were not necessary for marketization, since the Municipal Act—passed by the Social Democrats—already allowed municipalities to contract out welfare services. They only expressed a fear that the suggested amendments might lead to private monopoly rather than competition. As Montin and Elander (1995, p. 38) argue, "A pragmatic and apolitical view of privatization was dominant in the government just before the election of 1991. When the non-socialist majority took their seats in government after the election, the former government had already partly paved the way for further privatization."

Comparison with Denmark sheds further light on the politics of market reform in Sweden. In Denmark, the impact of NPM or market reforms has been much more muted than in Sweden, even though Denmark has had longer periods of non-social democratic government. Green-Pedersen (2002) attributes this to the position the Swedish Social Democratic party has taken on marketization. As Green-Pedersen puts it: "Right-wing parties can be expected to be proponents of NPM reforms" (2002, p. 274), making support among Social Democrats critical to the enacting market reform—and in need of explanation. In the 1980s, under the influence of the epistemic community discussed above, the Swedish Social Democrats (by contrast with the Danes) had begun to view the public sector as part of the problem, not the solution (Antman 1994). Once Social Democratic parties positively embrace NPM reforms, Green-Pedersen concludes, "they will find it hard to change to a negative response" (2002, pp. 274–275). Having started down the marketization road, Swedish Social Democrats found themselves without strong arguments to combat the "freedom of choice revolution" proclaimed by the right-center government in 1991. The market-type reforms implemented by the nonsocialist government between 1991 and 1994 followed a path that the Social Democrats had laid down (Green-Pedersen 2002), and "the Social Democrats resumption of office at the election of 1994 . . . did

⁹ The same Minister was responsible for both issues, the Minister of Civil Affairs, Bengt K.Å. Johansson, former Assistant Minister of Finance.

not spell a return to the previous system to any appreciable extent” (Palme et al. 2003, p. 82). Thus, between 1994 and 2006, when the right-center coalition next regained power, there was a slow but steady introduction of market principles and private provision into tax-funded welfare services. A purchaser–provider model had been introduced by 10 % of municipalities in 1993, the year after the possibility had been opened up; by 2003, more than 80 % had introduced the new institutional model (Gustafsson and Szebehely 2009), and the proportion of for-profit private providers had begun its growth trajectory.

The fact that marketization in Swedish long-term care began as competitive tendering for large nursing homes and geographical areas of homecare, rather than with a customer choice model, is important in explaining the oligopolistic structure of private sector provision, with its two dominant providers. During the recession of the early 1990s, competition over price (rather than quality) dominated (Edebalk and Svensson 2005). This gave an advantage to larger for-profit companies, with their greater capacity to manage the bidding procedure, over small companies or not-for-profit organizations. Larger organizations could also underbid, if necessary, to enter the market (Government Report 2007). Once a larger company is established, further growth by acquisition is relatively easy.

3.5.2 Consolidating the Market Model: New Layers, New Behavioral Logics, New System Dynamics?

The pace of marketization increased with the change of government in autumn 2006, when new behavioral logics and new system dynamics were introduced through a process of layering. The new right-center government did not proclaim a “Freedom-of-choice revolution,” but its intentions in this direction became clear in spring 2007, when the Assistant Minister of Health and Social Affairs appointed a Freedom-of-choice commission. The commission’s task was to suggest new legislation to make it easier for municipalities to introduce consumer choice models in care for older and disabled people. The process was quick: the commission’s report (Government Report 2008) was published in February 2008; half a year later the Government Bill 2008/09:29 was presented to the parliament, and the new legislation *Act on Free Choice Systems*, came into effect on January 1, 2009. As argued by the commission, and echoed by the Minister, the goal of the legislation was to “move power from politicians to citizens, to increase the choice and influence of users and to promote a diversity of providers” (Government Report 2008).

The new law encourages municipalities to introduce customer choice models, with a quasi-voucher system. Legislative change was combined with financial incentives to municipalities to introduce the customer choice model. We characterize the introduction of this act as “layering,” because the stated intention is not to *replace* the old system with the new; rather, the new was to “function as a voluntary tool” to develop the market model. “In-house” (public) provision by municipalities remains one of the “alternatives open to a public authority” under the act, alongside purchaser–provider

arrangements introduced in 1992 (Government Report 2008) and the new customer choice “layer.” Although the new system has not yet replaced the old, a primary goal of the act is to promote the “differential growth,” which Streeck and Thelen argue is central to the system-changing dynamics established by institutional layering. Two aspects of the new legislation are designed to have this effect. One is that barriers to entry for private providers into customer choice systems should not be too high, to encourage entry of a diverse range of private providers; as the commission argues: “the higher the requirements set, the fewer the companies that will be interested in an agreement with the authority” (Government Report 2008, p. 29). The second is that, within the customer choice model, only private providers are allowed to offer additional services, with which customers “top up” the needs-assessed publicly funded offering. An explicit goal of this preferential treatment for private providers is to encourage the growth of “small enterprises” and to allow them to “increase their operation and reach a higher profitability” (Government Bill 2008/09:29, p. 123). The commission considered but ruled out allowing public care providers to offer “extra services”: “An option for a municipality to provide extra services can have negative consequences for small enterprises, including women’s enterprise, something that the Act on free choice systems is intended to encourage instead” (Government Report 2008, p. 34).

The behavioral logic of the new legislation is quite different from that of the earlier market reform, which introduced a purchaser–provider split. The logic of the earlier reform operated entirely on the supply side—to mobilize the discipline of competition within the public sector and/or between private providers. The new law seeks to bring the *demand* side into the competitive process, by enabling consumers, as well as local authority purchasers, to control which organizations offer services. The commission, as well as the Minister, expressed high expectations that the quality of services will be enhanced by the introduction of this new, demand-side, market mechanism: “It is the individual’s opportunity to choose and choose again that is the very core of the system and that is intended to help to maintain and further develop the quality of the services included” (Government Report 2008, p. 32).¹⁰

Evidence suggests that the Minister’s faith in customer choice as the core quality driver may be misplaced, not least because most service users are reluctant to change providers. A recent study found that only 4 % of the older homecare users in municipalities with choice models actually changed their provider during 2009 and one in five changes were because the provider closed down (Svensson and Edebalk 2010). Another frequent reason for changing homecare provider is that the older person’s ordinary homecare worker had moved to another employer (Fried 2007).

In practice, the ambition to empower older people by giving them the right to choose may have had the obverse effect—at least for those with fewer resources. The eldercare “ombudsman” in Stockholm (where customer choice and private provision are highly developed) notes that older people who complain to the city officials are advised to choose another provider. But what the older people want is for their

¹⁰ In contrast to the “real” market, the price is set in advance; thus the providers are expected to compete only with quality.

complaints to be properly attended to, without needing to change provider; they feel that the local authority is not taking responsibility for guaranteeing all individuals high-quality care (Stockholms stad 2010). Furthermore, while a customer choice model fits reasonably well with the aspirations and demands of the Independent Living Movement, especially for personal assistance schemes, there is no evidence that older people and their organizations have advocated for this service model (Edebalk and Svensson 2005). Research finds that although some older people appreciate being able to choose a provider, many find that choice stressful, and most find the ability to affect the actual tasks carried out to be more important (Hjalmarson 2003; Hjalmarson and Norman 2004).

The increased focus on consumerism and choice may, therefore, have different consequences for different social groups. Compared with young, physically disabled persons, frail older people are, in general, less prepared to act as customers. Therefore, there is an obvious risk for increasing inequalities when Swedish municipalities introduce choice models and tend to leave part of the quality control to these frail older “customers” by relying on them to make active choices and to complain (Svensson and Edebalk 2010; Swedish Competition Authority 2009; Winbladh et al. 2009). Individuals with more resources, such as higher education, will probably have an advantage in navigating the new landscape of care markets (NBHW 2011c).

The introduction of a customer choice model in publicly funded services combines with another measure introduced 18 months earlier as another “layering” reform that promotes the development of private sector provision in eldercare. In July 2007, the right-center government introduced a *tax deduction on household services and personal care*. Under this reform, taxpayers are entitled to deduct 50 % of the price of household services up to 100,000 SEK (close to € 11,000) per person per year if the service company has a business tax certificate. The services may be carried out in the purchaser’s own home or, significantly, in a parent’s home. The government expressed several goals when introducing the tax deduction, including gender equality (reducing the burden of domestic work and care for parents that falls primarily on women), bringing the gray economy “on to the books,” and promoting small business (Government Bill 2006/07:94, p. 94).

This deduction is available for all age groups and is not part of the eldercare services. Yet it clearly interacts with the eldercare system. In the vast majority of municipalities, older people with relatively small care needs and medium-high incomes would find it cheaper to use the deduction to purchase services on the private market, rather than use municipal care services. (These citizens receive a state subsidy for assistance via the tax system rather than a municipal subsidy via the social service system.) For those who choose a private provider for their needs-assessed homecare service, the deduction halves the cost of “extra services.” In practice, the combination of customer choice models and the deduction creates an incentive for well-to-do older people to choose private providers for their tax-funded and needs-assessed homecare 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 people but with fewer care needs, the tax rebate serves as an incentive to entirely refrain from the tax-funded homecare and buy private services instead.

Evidence shows growing use of privately purchased household services in Sweden, now further encouraged by the introduction of the tax deduction. However, compared to tax-funded homecare services, the deduction is still used by fewer older persons (by 6.3 % of people 65 and older in 2010—up from 1.7 % in 2008—compared to 9 % using the needs-assessed homecare services from public or private providers).¹¹ The income profile also differs: the deduction is used mainly by older people with high incomes while the homecare services are (so far) used by all social groups (NBHW 2012b). In 2010, 14 % of older people with high annual incomes (more than 500,000 SEK) used the deduction, compared to 5 % of those with low incomes (less than 120,000 SEK). Furthermore, although average annual deductions were rather small (at an average of 2,800 SEK, which would purchase around 20 hours of help per year), older people with higher incomes deducted twice as much as those with lower incomes. This measure is also becoming increasingly costly: the figures for 2010 report expenditure of 1.3 billion SEK, up from 440 million SEK in 2008 (Statistics Sweden 2012).

A key feature of the “layering” of customer choice and the tax deduction is that older people with good incomes and larger care needs can use the deduction to top up with extra services from the same staff that provide their municipally funded care—if they choose a private provider. As Streeck and Thelen (2005) point out, citing Rothstein on the Swedish case, the risk is the loss of the middle class as a constituency for, and user of, public services. Although publicly provided, publicly financed services have neither been abolished, nor declared residual, the layering of customer choice and the household rebate promotes dualization within the eldercare system, such that they risk becoming residual services for the poor.

3.6 A Turning Point for the Swedish Model of Long-Term Care?

From one perspective, the Swedish model of long-term care, with generous, publicly funded, publicly provided services looks more or less intact; spending remains high, and less than a fifth of publicly funded eldercare services are in private hands. Yet, behind the national average of 19 % private provision of publicly funded eldercare services, there is wide variation between the municipalities. In more than half (54 %), there is no private residential care at all and in two-thirds (65 %) of the municipalities, all homecare services are publicly provided. In contrast, more than half of the homecare services and more than half of the residential care beds are privately provided in close to 5 % of the municipalities (NBHW 2011b).

Our account of the marketization of Swedish eldercare has emphasized the top-down push from the national government. The wide variation in the level of private

¹¹ As the deduction is offered to all purchasers of domestic and care services, without needs assessment, it is not possible to determine whether these purchases are a direct substitute for publicly subsidized services offered via the formal care system.

provision of tax-funded services in municipalities raises questions about why this top-down push has been only partially successful, and about the likely future trajectory of marketization of long-term care, in Sweden. We cannot predict the future, of course. However, we can point to some of the processes that have been set in train by, and the interests that have emerged under, marketization policies.

Part of the explanation for local variation is the political color of governments in the context of strong municipal autonomy. Although Social Democratic national governments have been market-oriented, right-wing governments at both national and municipal levels have been more so. For example, in Stockholm, which has a conservative political majority, 60 % of the publicly funded homecare was privately provided in 2010 (NBHW 2011b), up from 37 % in 2006 (NBHW 2007). In Sweden's second biggest city, Gothenburg, which has a Social Democratic majority, all homecare was still in public hands in 2010 (NBHW 2011b). The cases of Stockholm and Gothenburg show that Social Democratic and right-wing politics do diverge, and that the combination of a right-wing coalition both at central and local level can make a difference. More comprehensive modeling has found that municipalities that are more middle class¹² and which have right-wing majorities tend to have more private eldercare (Stolt and Winblad 2009).

But this is not the end of the story. Cutting across this political pattern is evidence of a kind of geographical "contagion" of privatization. Stolt and Winblad (2009) found that privately managed eldercare was pioneered in metropolitan areas where right-wing majorities dominate, but that "surprisingly, neighboring municipalities tended to follow these pioneers *irrespective of their political colour or economic situation*" (Stolt and Winblad 2009, p. 903, emphasis added). This process of diffusion has meant that, even in municipalities with stable Social Democratic majorities, there has been privatization of eldercare. Sometimes, the municipality's economic situation is a precipitating factor, as the "seducing power in the neo-liberal process of privatization" (Stolt and Winblad 2009, p. 910) conquers the ideological hostility of Social Democratic municipalities in straitened financial circumstances. But the idea of "what worked for others must also work for us" (Stolt and Winblad 2009, p. 911) was in itself also important, and once introduced, privatization is rarely reversed. Furthermore, there is a real possibility that municipalities' capacity to choose to resist marketization may be legislated away in the future. In 2010, unhappy with the slow pace of change, the national government introduced further incentives for municipalities to introduce customer choice models during 2011–2014 (Government Bill 2010/11:1, p. 163). The Bill included the warning that "compulsory legislation would be considered" if all municipalities had not responded by 2014. Finally, the emergence of large corporate providers in long-term care creates a powerful interest in further privatization (Meagher and Szebehely 2010).

Over 30 years, a range of somewhat disparate reforms have rationalized eldercare, expanded provision for people with severe disabilities, and opened up long-term care services to the market. Together, through a complex set of interactions, these policy

¹² As measured by a higher proportion of residents with university education and a higher tax base, both of which correlate to higher average household incomes.

changes have consolidated into a real threat to the universality of long-term care in Sweden. There are already signs of class differences in response to retrenchment of publicly funded eldercare services, as poorer people turn to family and richer to the market. There is not yet evidence of class differences *within* the publicly funded system. However, ongoing marketization may give incentives for more resourceful groups to leave the public system. If a class gap opens up *within* the publicly funded system, a vicious cycle of middle class flight and falling quality could become established. Over time, creeping selectivity could leave the poor with poor-quality services—precisely the outcome that universal services enable societies to avoid.

References

- Antman, P. (1994). Vägen till systemskiftet—den offentliga sektorn i politiken 1970–1992 [The road to the system shift—The public sector in politics 1970–1992]. In R. å. Gustafsson (Ed.), *Köp och sälj, var god svälj? Vårdens nya ekonomistyrningssystem i ett arbetsmiljöperspektiv* [Buy and sell. Work environment perspectives on NPM in Swedish health care services] (pp. 19–66). Stockholm: Arbetsmiljöfonden.
- Birkelöf, L. (2009). *Do local public expenditures for functionally impaired crowd out other local public expenditures?* [Umeå Economic Studies No. 797]. Umeå: Umeå University.
- Blomqvist, P. (2004). The choice revolution: Privatization of Swedish welfare services in the 1990s. *Social Policy and Administration*, 38(2), 139–155.
- Blyth, M. (2001). The transformation of the Swedish model: Economic ideas, distributional conflict, and institutional change. *World Politics*, 54(1), 1–26.
- Dir. (1988). *Samhällets stöd till människor med funktionshinder* [Social support for people with disabilities]. Instructions for the disability commission of 1989. Stockholm: Ministry of Health and Social Affairs.
- Edebalk, P. G., & Svensson, M. (2005). *Kundval för äldre och funktionshindrade i Norden. Konsumentperspektivet*. [Customer choice for elderly and disabled persons in Scandinavia: The consumer perspective] (Tema Nord No. 507). Copenhagen: Nordic Council of Ministers.
- Eliasson-Lappalainen, R., & Motevasel, I. (1997). Ethics of care and social policy. *Scandinavian Journal of Social Welfare*, 6(3), 189–196.
- Feltenius, D. (2007). Relations between central and local government in Sweden during the 1990s: Mixed patterns of centralization and decentralization. *Regional and Federal Studies*, 17(4), 457–474.
- Fried, R. (2007). *Hemtjänsten i Stockholm—en enkät till brukarna hösten 2006* [Home-care services in Stockholm: A survey of users 2006]. Stockholm: Stockholms stads utrednings- och statistikskontor AB.
- Government Bill 1990/91:100 *Förslag till statsbudget för budgetåret 1991/92* [Draft state budget for 1991/92].
- Government Bill 1992/93:43 *Ökad konkurrens i kommunal verksamhet*. [Increased competition in municipal services].
- Government Bill 2000/01:149 *Avgifter inom äldre- och handikappomsorg*. [User fees in eldercare and in disability services].
- Government Bill 2006/07:94 *Skattelättnader för hushållstjänster, m.m.* [Tax deductions on household services etc.].
- Government Bill 2008/09:29 *Lag om valfrihetssystem* [Act on Free Choice Systems].
- Government Bill 2010/11:1 *Förslag till statsbudget för 2011. Hälsovård, sjukvård och social omsorg* [Draft state budget for 2011: Health and social care].
- Government Report. (1987). *Långtidsutredningen 1987* [The Long Term Survey 1987]. SOU 1987:3. Stockholm: Allmänna förlaget.

- Government Report. (1991). *Konkurrensen inom den kommunala sektorn* [Competition in the municipal sector]. SOU 1991:104. Stockholm: Allmänna förlaget.
- Government Report. (2004). *Sammanhållan hemvård* [Integrated Homecare] SOU 2004:68. Stockholm: Fritzes.
- Government Report. (2007). *Vård med omsorg—möjligheter och hinder* [Careful care: Possibilities and obstacles]. (Betänkande från Delegationen för mångfald inom vård och omsorg [Report from the Delegation for diversity in care]). SOU 2007:13. Stockholm: Fritzes.
- Government Report. (2008). *LOV att välja—Lag om valfrihetssystem*. (LOV—[Legislation on choice] Betänkande av Frittvalutredningen [Report from the Choice Commission]). SOU 2008:15. Stockholm: Fritzes.
- Green-Pedersen, C. (2002). New public management reforms of the Danish and Swedish welfare states: The role of different social democratic responses. *Governance: An International Journal of Policy, Administration, and Institutions*, 15(2), 271–294.
- Grunewald, K. (1974). The guiding environment: The dynamic of residential living. In D. Boswell & J. M. Wingrove (Eds.) *The handicapped person in the community: A reader and sourcebook*. (pp. 10–18). London: Taylor and Francis.
- Gustafsson, R., & Szebehely, M. (2009). Outsourcing of eldercare services in Sweden: Effects on work environment and political legitimacy. In D. King, & G. Meagher (Eds.), *Paid care in Australia: Politics, profits, practices*. (pp. 81–112). Sydney: Sydney University Press.
- Hjalmarson, I. (2003). *Valfrihet inom äldreomsorgen—en reform som söker sin form* [Choice models in eldercare]. Stockholm: Stockholm Gerontology Research Center.
- Hjalmarson, I., & Norman, E. (2004). *Att välja hemtjänst* [To choose homecare]. Stockholm: Socialstyrelsen.
- Huber, M., Rodrigues, R., Hoffmann, F., Gasior, K., & Marin, B. (2009). *Facts and figures on long-term care: Europe and North America*. Vienna: European Centre for Social Welfare Policy and Research.
- Johansson, L., Sundström, G., & Hassing, L. (2003). State provision down, offspring's up: The reverse substitution of old-age care in Sweden. *Ageing and Society*, 23(3), 269–280.
- Korpi, W. (1996). Eurosclerosis and the sclerosis of objectivity: On the role of values among economic policy experts. *The Economic Journal*, 106(439), 1727–1746.
- Lakomaa, E. (2009). The “Ädel Reform”: An economic-psychological analysis of the transfer of government activities from counties to municipalities. In E. Lakomaa (Ed.), *The economic psychology of the welfare state*. Stockholm: Economic Research Institute, Stockholm School of Economics.
- Larsson, K. (2006). Care needs and home-help services for older people in Sweden: Does improved functioning account for the reduction in public care? *Ageing and Society*, 26(3), 413–429.
- Liljeström, R., & Özgaldal, E. (1980). *Kommunals kvinnor på livets trappa* [Women in the Municipal Workers' Union]. Stockholm: Svenska Kommunalarbetarförbundet.
- Loughlin, J., Lidstrom, A., & Hudson, C. (2005). The politics of local income tax in Sweden: Reform and continuity. *Local Government Studies*, 31(3), 351–366.
- Meagher, G., & Szebehely, M. (2010). *Private financing of eldercare in Sweden: Arguments for and against* (Working Paper 1/2010). Stockholm: Institute for Futures Studies.
- Ministry of Justice. (2007). *The Swedish law-making process. Factsheet Ju 07.06e*. Retrieved from <http://www.sweden.gov.se/sb/d/8589/a/84861>.
- Montin, S., & Elander, I. (1995). Citizenship, consumerism and local government in Sweden. *Scandinavian Political Studies*, 18(1), 25–51.
- National Agency for Education. (2011). *Kostnader för förskoleverksamhet, skolbarnsomsorg, skola och vuxenutbildning 2009* [Costs for childcare and education 2009]. Stockholm: Skolverket.
- National Association for Persons with Intellectual Disabilities [FUB]. (2007). *Historik: Från idiot till medborgare—en sammanfattning av FUB:s historia* [History: From idiot to citizen—A summary of FUB's history]. Retrieved from <http://www.fub.se/fub/historik/>.
- National Board of Health, & Welfare [NBHW]. (2003). *Konkurrensutsättning och entreprenader inom äldreomsorgen. Utvecklingsläget 2003* [Competition and out-sourcing in eldercare. Status report 2003]. Stockholm: Socialstyrelsen.

- National Board of Health, & Welfare [NBHW]. (2007). *Äldre—vård och omsorg år 2006* [Care and services to older persons 2006]. Stockholm: Socialstyrelsen.
- National Board of Health, & Welfare [NBHW]. (2009). *Swedish disability policy—Service and care for people with functional impairments*. Stockholm: Socialstyrelsen.
- National Board of Health, & Welfare [NBHW]. (2011a). *Lägesrapport 2011. Hälso- och sjukvård och socialtjänst*. [Status report 2011. Health care and social services]. Stockholm: Socialstyrelsen.
- National Board of Health, & Welfare [NBHW]. (2011b). *Äldre och personer med funktionsnedsättning—regiform m.m. för vissa insatser år 2010* [Management forms in services for older persons and for persons with impairments in 2010]. Stockholm: Socialstyrelsen.
- National Board of Health, & Welfare [NBHW]. (2011c). *Valfrihetssystem ur ett befolknings- och patientperspektiv*. [Choice models from population- and patient perspectives]. Stockholm: Socialstyrelsen.
- National Board of Health, & Welfare [NBHW]. (2012a). *Äldre—vård och omsorg den 1 april 2011* [Care and services to older persons April 1, 2011]. Stockholm: Socialstyrelsen.
- National Board of Health and Welfare [NBHW]. (2012b). *Tillståndet och utvecklingen inom hälso- och sjukvård och socialtjänst Lägesrapport 2012*. [Trends in health care and social services. Status report 2012]. Stockholm: Socialstyrelsen.
- National Insurance Board. (2002). *Ideals and reality in disability policy, social insurance in Sweden 2002*. Stockholm: RFV.
- Nirje, B. (1969). The normalization principle and its human management implications. In R. Kugel & W. Wolfensberger (Eds.), *Changing patterns in residential services for the mentally retarded*. Washington: President's Committee on Mental Retardation.
- Palme, J., Bergmark, Å., Bäckman, O., Estrada, F., Fritzell, J., Lundberg, O., Sjöberg, O., & Szebehely, M. (2003). A welfare balance sheet for the 1990s. *Scandinavian Journal of Public Health*, 31(60 suppl.), 3–143.
- Ratzka, A. (1984). *The prerequisites for independent living* (GLADNET collection: Paper 427). Retrieved from <http://digitalcommons.ilr.cornell.edu/gladnetcollect/427>.
- Ratzka, A. (1986). *Independent living and attendant care in Sweden: A consumer perspective*. Retrieved from <http://www.independentliving.org/docs1/ar1986spr.html>.
- Ryner, J. M. (2002). *Capitalist restructuring, globalization and the third way: Lessons from the Swedish model*. London: Routledge.
- Sipilä, J. (Ed.). (1997). *Social care services: The key to the Scandinavian welfare model*. Aldershot: Avebury.
- Statistics Sweden. (2012). *Statistical database. Final income and tax statistics 2010*. Retrieved from <http://www.ssd.scb.se/databaser/makro/produkt.asp?lang=2&produktid=HE0110>.
- Stockholm stad. (2010). *Äldreombudsmannens årsrapport för 2010* [Report from the Eldercare Ombudsman for 2010]. Stockholm: Stockholm stad.
- Stolt, R., & Winblad, U. (2009). Mechanisms behind privatization: A case study of private growth in Swedish elderly care. *Social Science and Medicine*, 68(5), 903–911.
- Streeck, W., & Thelen, K. (2005). Introduction: Institutional change in advanced political economies. In W. Streeck & K. Thelen (Eds.), *Beyond continuity: Institutional change in advanced political economies*. Oxford: Oxford University Press.
- Sundström, G., Johansson, L., & Hassing, L. (2002). The shifting balance of long-term care in Sweden. *The Gerontologist*, 42(3), 350–355.
- Sundström, G., & Malmberg, B. (1996). The long arm of the welfare state shortened. *Scandinavian Journal of Social Welfare*, 5(2), 69–75.
- Svallfors, S. (1989). *Vem älskar välfärdsstaten? Attityder, organiserade intressen och svensk välfärdspolitik* [Who loves the welfare state? Attitudes, organised interests and Swedish welfare politics]. Lund: Arkiv Förlag.
- Svensson, M., & Edebalk P. G. (2010). *Kundval i äldreomsorgen—Stärks brukarens ställning i ett valfrihetssystem?* [Customer choice in eldercare—Is the user's position strengthened in a choice model?]. Stockholm: Swedish Association of Local Authorities and Regions.

- Swedish Competition Authority. (2009). *Konkurrensutsättning inom hemtjänsten och primärvården* [Competition in home care and primary health care]. Stockholm: Konkurrensverket.
- Swedish Social Insurance Agency. (2011). *Statistics: Assistance allowance*. Retrieved from http://statistik.forsakringskassan.se/portal/page/portal/intstat/funk/assers/assers_offstat4.
- Szebehely, M. (1995). *Vardagens organisering. Om vårdbiträden och gamla i hemtjänsten* [The organisation of everyday life—On home helpers and elderly people in Sweden]. Lund: Arkiv förlag.
- Szebehely, M. (2005). Care as employment and welfare provision—Child care and eldercare in Sweden at the dawn of the 21st century. In H. M. Dahl & T. Rask Eriksen (Eds.), *Dilemmas of care in the Nordic welfare state*. Aldershot: Ashgate.
- Szebehely, M. (2011). Insatser för äldre och funktionshindrade i privat regi [Privately provided care services for older and disabled persons]. In L. Hartman (Ed.), *Konkurrensens konsekvenser. Vad händer med svensk välfärd?* [The consequences of competition. What happens to welfare in Sweden?]. Stockholm: SNS—Center for Business and Policy Studies.
- Szebehely, M., & Trydegård, G. B. (2007). Omsorgstjänster för äldre och funktionshindrade: skilda villkor, skilda trender? [Services for elderly and for disabled persons: Different trends, different conditions?]. *Socialvetenskaplig Tidskrift*, 14(2–3), 197–219.
- Szebehely, M., & Trydegård, G. B. (2012). Home care in Sweden: A universal model in transition. *Health and Social Care in the Community*, 20(3), 300–309.
- Thorslund, M. (1991). The increasing number of very old people will change the Swedish model of the welfare state. *Social Science and Medicine*, 32(4), 455–464.
- Westerberg, B. (2008). *Speech at the conference celebrating 25 years of independent living in Sweden, 28 November*. Retrieved from <http://www.independentliving.org/25years/westerberg>.
- Winbladh, U., Andersson, C., & Stefansson, K. (2009). *Kundval i hemtjänsten—erfarenheter av information och uppföljning* [Customer choice in home care—experiences of information and follow-up]. Stockholm: Sveriges Kommuner och Landsting.

Chapter 4

Trajectories of Change in Danish Long Term Care Policies—Reproduction by Adaptation through Top-Down and Bottom-Up Reforms

Viola Burau and Hanne Marlene Dahl

4.1 Introduction

The literature often sees universalism and local autonomy as the key tenets of Nordic care regimes (Burau et al. 2007); the former refers to substantive aspects of long term care policies, while the latter refers to procedural aspects. Against this background, the case of Denmark is interesting in two respects. Firstly, among the Nordic countries, long term care policies remain the most universal in terms of coverage, which is reflected in the level of public expenditure. Secondly, Denmark combines institutional change from below (nonlegislative change) with institutional change from above (legislative change).

Although Denmark, like most of the OECD countries, has been exposed to New Public Management (NPM) reforms, understood as a drive for a retreat of the state, cost containment and consumerism (Dahl 2005; Glendinning 2008), long term care policies have not been characterized by retrenchment. Yet the absence of retrenchment does not necessarily mean an absence of change. Therefore, in this chapter, we will first investigate whether there has been a change in long term care for older people in Denmark in the period 1994–2007, and if so, we will seek to identify the characteristics of this change. We will do this by investigating how any changes relate to existing institutions. Indeed, as described below, our analysis indicates that change has occurred through restructuring (Pierson 2001). Specifically, long term care policies since the 1990s have included elements of both control/standardization and flexibility/choice, which has led to substantial changes in terms of the organization of long term care (Dahl 2005). In procedural terms, reforms represent a

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form of reproduction by adaptation, whereby new elements are attached to existing institutions which gradually change as a result (Streeck and Thelen 2005; Thelen 2000). Taking a broad concept of reform from neoinstitutional theory (Streeck and Thelen 2005) as our point of departur, we analyze two reforms that encompass elements of control and flexibility, and which in procedural terms point to legislative and nonlegislative forms of incremental transformation.¹

4.2 The Structures of Opportunities and Constraints for Reforms

In many ways, the long term care system in Demark is a classic example of the Nordic welfare state, combining universalism with local autonomy. While services are uniform and are both designed for and used by all (Anttonen 2002), services are largely controlled locally (Kröger 1997). Services are publicly funded and coverage is highly universalistic, the provision of services is public, and the organization of both funding and provision is largely the responsibility of local authorities, which also enjoy considerable powers in relation to the regulation of services.

Long term care includes both institutional and home care; although for more than five decades there has been a focus on the latter (see Sect. 4.3). Home care has a clear social care orientation and encompasses personal care as well as practical help. Access to services is based on the principle of citizenship and, by law, citizens have the right to get help if they experience difficulties with activities of daily living; in comparison, the provision of services is needs based. Home care is free at the point of use and is funded by local authorities; they are also responsible for providing services and for conducting needs assessments. Taken together, this puts local authorities in a highly influential position in terms of shaping long term care. Here, the provisions of the Social Services Act are key factors, as they offer the basis for a unified yet decentralized long term care system (Doyle and Timonen 2007). While the Act requires local authorities to provide the necessary services for its citizens, it is up to the individual authorities to determine the substance, level and organization of services. More specifically, the Act distinguishes between what local authorities have to do and what they can do (Nielsen and Andersen 2006). In practice, the long term care system in Denmark is not only highly universalistic but also generous (measured in terms of the percentage of older people receiving services) when compared with other Nordic countries (Szebehely 2003).

The decentralized nature of the long term care system means that the policy process in relation to reform occurs within the context of central–local relations. This makes the central government and the local authorities two of the key players in the policy field. Through the Association of Local Authorities (*Kommunerne Landsforening*,

¹ The case studies are based on analyses of secondary sources together with selected primary sources such as parliamentary debates, evidence submitted by stakeholders to the minister, reports of the parliamentary select committee together with grey literature from relevant stake holders.

KL), local authorities have significant resources and are in an influential position by virtue of their responsibility for funding and providing long term care (Blom-Hansen 2002). Their interest in relation to long term care is twofold, namely to retain/expand existing funding and to safeguard the autonomy local authorities enjoy concerning a wide range of governing issues.² In contrast, the resources of central government are connected to setting the overall policy framework and to allocating additional funds to long term care. For the period we are investigating, the overall interest of central government was to develop its steering capacity vis-à-vis long term care, both in relation to containing costs and determining the substance of services. As in other Nordic countries, the balance between the central and the local level has been subject to change. While the 1980s were characterized by decentralization, detailed regulation replaced the earlier legislative framework from the 1990s onwards (Hansen and Vedung 2005). The tighter regulation of details resulted in tensions between the two levels, whereas the Association of Local Authorities has tried to actively resist the decreasing autonomy at the local level (Dahl 2011). Nevertheless, Denmark's policy style is broadly consensus-oriented and there are multiple formal and informal channels which allow a wide range of policy actors to influence the policy process. Of these, the yearly budget negotiations between the central government and the local authorities are particularly prominent.

The other two main actors in the policy field are the Trade Union of Occupation and Work (*Fag og Arbejde*, FOA), which mainly organizes care workers, and the major interest organization of older people, called 'DaneAge' (*Ældresagen*). Occupation and Work is a specialized trade union for care workers, that is, home helpers and auxiliary nurses, and it has a total of approximately 200,000 members.³ With its history as a trade union for public employees, the trade union also includes other professions. Indeed, there is no other trade union for care workers, only one for nurses. The trade union has traditionally had a middle-of-the road social-democratic orientation, but over the last five years has gradually become more radicalized, also defending welfare rights more broadly. The trade union has successfully put issues of work conditions—including the organization of work and the gender wage gap—on the political agenda. The membership of DaneAge is even bigger (about 600,000; DaneAge 2011), which seems to defy the dictum that the interests of older people as such are difficult to organize. Dane Age accepts members below the retirement age and thereby also lobbies on behalf of those sympathetic to the needs of the elderly, such as relatives. However, even without these additional members the organization's membership among the older population is significant. Together with extensive fundraising activities, this also makes for significant financial resources

² KL is also an employer organization, but its autonomy in collective negotiations is severely limited by the Ministry of Finance. KL negotiates pay and work conditions for home carers on behalf of the municipalities and this requires taking into account the consequences for both expenditure and staff retention.

³ We have no specific number for the percentage of employees that are organized in trade unions. The Nordic countries have traditionally scored very high, although the level of trade union membership has fallen over recent decades. Nevertheless, it remains high compared to other countries.

and this gives the organization the possibility for a strong media presence as well as for conducting its own research. Not surprisingly, DaneAge is especially visible as a watchdog for older people, who encounter unfair, bureaucratic treatment or who experience a fall in their home help entitlements; indeed, the organization has several times threatened to summon a local authority. DaneAge also lobbies against retrenchment. In short, the interests of DaneAge are to promote, safeguard and expand the welfare and user rights of older people.

What are the current pressures for reform? These are best understood in the context of the historical development of the long term care system. This goes back to the period after the Second World War and the introduction of publicly funded but means tested 'home makers' providing temporary support to families in times of crisis (Dahl 2000; Petersen 2008). This offered a springboard for a substantial expansion of long term care over the next three decades (Hansen and Vedung 2005; Nielsen and Andersen 2006). Legislation introduced in 1958 marked a shift to homecare as both the permanent, time unlimited service and the legislation in 1964 explicitly required local authorities to offer assistance to older people, so that they could live at home as long as possible. This extended the responsibilities of local authorities and so personal care became a distinct focus of home care. The Social Services Act in 1974 brought together different provisions under one legal framework and further underlined the importance of personal care, by highlighting the need for training for care workers. Services were typically centered on the home and the principle 'at home as long as possible' became an entrenched principle of long term care policies in Denmark early on (Lewinter 2004). In contrast, policy developments since the early 1980s have been characterized by restructuring (Hansen and Vedung 2005).

While, in a cross country comparative perspective, the system of long term care in Denmark emerges as the relatively cheapest and best (Sarasa and Mestres 2007), from the domestic point of view, the total amount of public funds spent on long term care is seen as the key reference point and the reason that the State is interested in influencing the provision of long term care (Nielsen and Andersen 2006). Further, with the neo-liberal turn, high public expenditure is also seen as a problem in Denmark, and concerns for containing expenditure, value for money, and responding to individual needs have become predominant (Dahl 2004, 2009). The same applies to healthcare, although shifting costs from health to social care is not an explicit issue. In addition, several factors are all seen to put more demand on long term care services (Hansen and Vedung 2005): besides rising numbers of older people and processes of urbanization, the higher labor market participation of women is especially prominent compared to other countries. For example, the percentage of women in paid labor (the employment rate) rose from 43.5 % in 1960 to 74.4 % in 2009 (Danmarks Statistik 2010a; Hansen and Vedung 2005, p. 54).

Given these conditions, especially the institutional settings outlined above, what are the opportunities and constraints for reform? Denmark has a universal, institutionalized system of long term care, which makes any form of material retrenchment—such as reducing existing entitlements—difficult. The interests of older people and care workers are also well organized. This is compounded by a 'care ideal' that sees long term care first and foremost as a public rather than a private responsibility, and

an ideal that privileges care in the private home over institutional care.⁴ For example, family members are neither in practical nor in financial terms expected to support an elderly relative (Doyle and Timonen 2007). Concurrently, long term care has over the years become increasingly professionalized, with formal training of care workers at both basic and advanced levels. The training of home care workers has been extended from a couple of weeks to a whole year based in vocational schools (Dahl 2005). Home care workers have become social and health workers, and after graduating, they can qualify to become social and health assistants by attending 2 years of additional vocational training. Home care workers also perform some nursing functions and can take on leadership positions in care for older people or work in hospitals.

Similarly, political decision making based on consensus puts constraints on making radical reform, as the wishes of local authorities, the trade unions of care workers (FOA) and interest groups for older people (particularly DaneAge) have to be taken on board. More specifically, in relation to the parliamentary process, the consensus orientation is partly counterbalanced by the fact that, since 2001, Denmark has had a (centre-right) minority (coalition) government with a permanent support party that has not shied away from using its majority.⁵ Further, the existence of a well-institutionalized and highly integrated policy arena (for a more detailed discussion, see the following section) also means that there is considerable administrative capacity at both national and local government levels. It is indicative, for example, that in 1998 the government took the initiative to get in touch with its citizens in a more direct way through the ‘preventive home visit’ (*forebyggende hjemmebesøg*). This allows for a more explicit codification of universalism, which otherwise tends to be defined in loose terms.

4.3 The Process of Reform

As outlined above, long term care policies go back to the late 1950s and have been subject to systematic expansion over a period of three decades. This makes for a policy arena that is well institutionalized, not least because the policy arena is firmly embedded in the structures of central–local relations, a feature which is one of the cornerstones of the political system in Denmark.

The policy arena is also characterized by a clear focus on homecare. This is typical of Nordic care regimes and can be seen in the policy practice: ‘at home as long as possible’. In Denmark, this has its early beginning in the late 1950s when ‘older people at home’ emerged as a distinct user group, while the concrete policy practice goes back to the late 1960s and was motivated by both financial and policy considerations. In the context of the expansion of long term care, homecare was seen

⁴ An ideal of care is defined by Arlie Hochschild as country or region specific understandings of ‘good enough caring’ (1995).

⁵ This ended an 8 year period of centre–left governments, where the Social Democrats were in shifting coalitions with smaller parties forming mostly minority governments. In contrast, between 1990–1993, Denmark was governed by a centre–right minority coalition government.

as less expensive than institutional care. This coincided with a widespread societal critique of care in institutions, from which home based care emerged as the ‘better’ option (Dahl 2000). Care in institutions was increasingly demonized and portrayed as an antithesis to freedom. In this dichotomous thinking, freedom in the private home was the preferred policy option. In concrete policy terms, this led to the expansion of home-based long term care together with the closing down of nursing homes from early on; legislation introduced in 1987 even prohibited the building of new nursing homes and thereby consolidated the principle of ‘at home as long as possible’ (Dahl 2000; Rostgaard 2007). Not surprisingly, the number of nursing homes has fallen dramatically, whereas the number of places in assisted housing has risen significantly (Doyle and Timonen 2007).

More recently, there have been boundary issues in relation to health care, reflecting the fact that both policy arenas have shifted towards a reform paradigm of restructuring and thereby a greater concern for public expenditure and value for money (for health care, see Strandberg-Larsen et al. 2007). Boundary conflicts are particularly centered around discharge from hospitals. Through a range of measures, hospitals were put under considerable pressure to reduce patients’ length of stay, which has had repercussions for the demand on long term care provided by the local authority (Strandberg-Larsen et al. 2007). The local authorities need to have suitable long term care services ready on discharge, as they otherwise will be penalized financially; they have to cover any additional hospital charges that patients incur because of a lack of care facilities at the local level (Dahl 2008).

As mentioned above, the substance of policy change has focused on restructuring, which Pierson (2001) defines as reforms that aim to make the welfare state more compatible with contemporary goals and demands. This can occur either through rationalization, where welfare programs are brought in line with new ideas of how to achieve existing goals, or updating, where welfare programs are adapted to changing demands and needs. The long term care reforms in Denmark have included both types of restructuring: the introduction of market mechanisms is an example of rationalization, where long term care is brought in line with neoliberal ideas about the superiority of market mechanisms for delivering welfare services; the tailoring of services to individual needs is more of a hybrid, as it is about both creating consumerism and responding to the complex needs of a more individualized society. Restructuring has occurred through a process of institutional change based on reproduction by adaptation. We look now at two reforms that are typical of this type of institutional change, but which show that institutional change can occur both through legislative and nonlegislative means.

4.3.1 A ‘Common Language’ for Home Care

Common Language is an example of a bottom-up, nonlegislative policy change which originated from the Association of Local Authorities (KL) in 1998 (Hansen and Vedung 2005; Højlund 2004). *Common Language* can be seen as an attempt to define

in a more objective way the level of ability of the older person and to link the levels to categories of service provision. The policy change consisted of a new initiative in which older care users were allocated to one of four newly developed categories of care needs, ranging from independence (level 1) to total dependency upon others (level 4; Petersen and Schmidt 2003). Each of these categories systematically linked individual needs with specific types and with a specific level of service. The initiative addressed concerns about securing the welfare rights of citizens, but at the same time rendered other less formalized aspects of care services invisible (Højlund 2001, 2004). The initiative also tightened the control over the delivery of care services by professionals and as such fit with the central government's aim of introducing quality standards and preparing for the introduction of a purchaser-provider split.

The Association of Local Authorities, as an umbrella organization, also provides consultancy to its members in case of administrative and organizational problems. It is in this servicing capacity that KL in the early 1990s discovered that the field of care for older people lacked a coherent system of resource management and service provision (Højlund and Højlund 2000, p. 24). The municipalities were frustrated and within that context, KL suggested that something needed to be done. Based on a belief about the potential of technology for solving organizational problems, local authorities believed that governance problems (i.e. poor management and organization) could be resolved through the development of new information technologies. Driven by the concerns of the municipalities, KL began to investigate the more specific nature of these steering problems. In 1994, it published a report arguing that the long term care sector suffered from an extremely weak system of governance. At that time, no statistics on the costs of long term care were available, and the relationship between needs and help provided remained incomprehensible. KL decided that the introduction of new information technology could solve this problem, and initiated a developmental project. However, in 1995, KL realized that the software firms commissioned to design the new technology could not deliver the requested product, as there was no common understanding of the work delivered by home care workers available (Højlund and Højlund 2000, p. 25). There was, in short, no common language to describe what work was being done in the home with and for the older care recipient.

Consequently, the strategy was revised and the development of a common understanding of care services (*Common Language*) began. The new language was supposed to provide a catalogue for the needs of older people and the corresponding services of home care workers. *Common Language* was launched in 1996 and represented a particular form of codification of most of the hitherto tacit knowledge and also offered a standardization of the services provided. *Common Language* was developed in several stages through a process based on ongoing dialogue with selected local authorities, which took part in pilot programs (Hansen and Vedung 2005). Version II was developed to improve the earlier version by adding additional dimensions, including the experienced needs and motivation of users as well as the training

activities, and also expanded the applicability of *Common Language* to enable communication with hospital staff (Kommunernes Landsorganisation 2002a).⁶

Common Language initially emerged as a purely bureaucratic and supposedly neutral tool, but soon became politicized, whereby different professional groups together with users demanded influence over its development (Kommunernes Landsorganisation 2002b). KL had to revise the decision making process and grant these groups some influence. In 2001, *Common Language* also became a topic in the local and national media. In the beginning, the initiative was portrayed positively as a tool that enabled better quality and comparability, but soon critical views were being voiced relating to the governance of details, the tyranny of time and the standardization of help provided (Dahlgaard 2001; Ib 2001; Pedersen 2001). In a rather atypical move, KL issued a warning that *Common Language* should not be misused as a control instrument. Instead, the Association argued that it should be used solely to improve the quality of care and to support the work of home helpers (Thye-Petersen 2001).

The controversy surrounding *Common Language* led to it becoming one of the several key issues in the national election campaign of 2001. The leader of the opposition Anders Fogh Rasmussen criticized the incumbent Prime Minister Poul Nyrup Rasmussen on national television and blamed him for the way in which home help was governed by a “tyranny of time”. The issue was further politicized both by the media and DaneAge. This politicization was subsequently used in the electoral campaign to create an image of the government as the one favoring bureaucracy and the tyranny of time, which was contrasted with Fogh Rasmussen’s concern for freedom.

The Association of Local Authorities considered leaving the project to the National Ministry of Social Affairs, but subsequently decided against this move (Kommunernes Landsorganisation 2002c). In the process of developing *Common Language*, the Association became self-reflective about the system’s uses and abuses (Kommunernes Landsorganisation 2002c; Thye-Pedersen 2001) and even explicitly acknowledged some of the inherent problems, such as the dominance of nursing language and the stereotypical nature of the initiative, particularly in Version II (Kommunernes Landsorganisation 2002b).

In short, *Common Language* was not initiated by the state; the Ministry of Social Affairs merely provided some initial seed money for supporting the development of the project. Instead, KL developed *Common Language* as an administrative tool for its members; the local authorities were free to choose, or to reject, the tool. As such, the initiative was formally voluntary. However, KL was indirectly setting a norm for good governance when it advised its members to link *Common Language* to new information technologies (Kommunernes Landsorganisation 1999, pp. 3–4). Today, the initiative remains part of the software package offered to local authorities, and is therefore difficult to avoid (Nielsen and Andersen 2006, p. 41).

⁶ One of the interesting aims of *Common Language II* was to break down the strict boundaries between social care in the local authorities and the health care in hospitals by training hospital staff in understanding categories of *Common Language*. This is an ambitious goal, and there have not been any evaluation of the concrete effects.

4.3.2 *The Introduction of ‘Free Choice’ in Home Care*

In 2003 Denmark witnessed the introduction of *Free Choice* (*frit valg*), which can be seen as an example of top down, legislative change (Højlund 2004, 2006; Rostgaard 2006). The legislation allowed citizens greater choice of service provider and extended the choice to the range of services to be provided. The legislation required local authorities to act as purchasers and to contract services not only from public but also from private providers; local authorities also have to define quality standards.

Where did *Free Choice* come from and why was it introduced? Free choice was not a new instrument in Danish welfare policies. There had been a long tradition for free choice of schools in Denmark, which goes back to the 1824 People’s Schools Act (*Folkeskoleloven*). This legislation required children to be educated, but did not specify where; thus, education could also be delivered outside of publicly funded schools. Importantly, for the present context, free choice was further extended under the Social Democratic government in the late 1990s, notably in relation to hospitals and home care itself. This was embedded in the notion of putting users at the center stage (Petersen 2008, p. 171), but the basic acceptance of the principle as such also made it difficult for the Social Democrats to turn their back on free choice under the subsequent center-right government (for more information on this point, see Green-Pedersen 2002). The free choice of hospital was introduced in 1993 and allowed patients to choose among public hospitals, not only limited to their own county (Vrangbæk and Østergren 2006). The approach to free choice was pragmatic and cautious, as reflected in a number of significant safeguards and restrictions; hospital choice could therefore best be characterized as ‘extended’ rather than ‘free’. The same applies to so-called ‘flexible home care’ (*fleksible hjemmehjælp*), introduced in 2000, which allows the older people to have more say about the type of services they receive, although the concrete procedures are heavily prescribed: choice is confined to practical help and does not include choice of provider; the adjustments have to remain within the original time frame and ‘necessary services’ cannot be replaced; the local authority also retains the overall and final responsibility for the delivery of services (Højlund 2004).

Yet, there were two things which were new: first, to connect the principle of free choice to the marketization of welfare services—more specifically, to use free choice as a mechanism to stipulate competition; and second, to substantially extend free choice from a possibility that existed in individual local authorities to a general right across local authorities. On the one hand, this reflects the fact, that the introduction of *Free Choice* was part of the modernization program of the new conservative centre-right government, which came into power in 2001. The program emphasized the centrality of freedom and promised to put citizens at the centre in public services, by combining existing responsibilities of society with new responsibilities of the individual (Petersen 2008). The notion of ‘free choice’ is based on two conditions (Højlund 2004): transparency, in that users need to be able to know precisely what they choose among; and competition, in that free choice only makes sense if there are multiple providers to choose between. The program can be seen as a clear ‘ideological marker’ of the policies which were to come later. On the other hand, the government

was also driven by budgetary considerations. As mentioned above, the long term care system is both highly universal and generous and competition was seen as a welcome measure of cost containment (Hansen and Vedung 2005). In this respect, the emergence of a strong budgetary discourse treating care as a commodity was also indicative of the new conservative government's ideological slant (Dahl 2005).

With the top-down nature of the policy initiative, the policy process leading to the introduction of *Free Choice* was mainly concentrated within the parliamentary arena (Politiken 2001). The decision making process stretched from late February 2002, when the government presented the first draft legislation to parliament, to May 2002, when the parliament passed the revised legislation, which came into force in January 2003. During this period, the draft legislation was debated in Parliament twice, when a wide range of institutional interests submitted evidence, and the Parliament's Select Committee on Social Affairs met four times.

The parliamentary decision making process progressed smoothly, for a number of reasons. The basic principle of free choice remained largely uncontroversial in the political debate, which instead focused more on issues relating to curtailing the autonomy of local authorities as well as to technical issues concerned with implementation. Furthermore, the strong majority held by the new center-right government, the main actor driving the reform was a significant factor contributing to the successful passage of the initiative through the Parliament. Indeed, the phenomenon of a significant majority was rather unusual in modern Danish political history. The coalition included the Liberal Party (*Venstre*) and the smaller Conservative Party (*Konservative*) and, thanks to the support of the extreme right wing Danish People's Party (*Dansk Folkeparti*), the government had the majority in parliament; old age care policies were also a central policy for the support party.

This may also highlight the fact that the decision making process was in fact not very consensus oriented. The draft legislation was formally negotiated with the Association of Local Authorities as the subcentral level of government and beyond that, only the Social Democratic Party (*Socialdemokraterne*) succeeded in getting some of its concerns addressed; in contrast, the criticisms from other stakeholders were ignored. However, the Social Democrats also supported the need for greater choice. Both local authorities, as the funders and providers of care services, and the interest groups of older people supported the initiative. Nevertheless, all parties also expressed concerns in relation to the reform, but had little weight in the ensuing decision making process.

For the Social Democratic Party, a major concern was that the legislation required all local authorities to implement free choice and thereby to forcefully intervene in local autonomy (Petersen 2008, p. 200). The more specific fear was that this would undermine the coordination of services, resulting in unnecessary and costly bureaucracy (Folketingsdebat 2002). Similarly, in relation to the extension of choice of the range of service, the Social Democrats criticized the fact that increased flexibility did not necessarily translate into more time for care (Petersen 2008, p. 199) and that it was precisely the time that was lacking in home care (Folketingsdebat 2002). Significantly, the party succeeded in addressing only some of these concerns in later drafts of the legislation (Jyllands-Posten 2002): the number of private providers per

local authority was restricted to between 2 and 5; the implementation of the law was postponed to 1 January 2003; and the legislation was set to come up for review after operating only for a short period of time (in the autumn in 2004).

The concerns of the Association of Local Authorities mirrored those of the Social Democrats. The Association criticized not only the fact that introduction of free choice was to be imposed from the top-down but also about a range of practical implications (Høringssvar 2002; Socialudvalget 2002). This included the costs associated with defining quality standards and price levels as well as with contracting private providers (Ritzau 2002); there were additional concerns about how best to organize the entry of new providers into the sector and also about competition between providers.

For their part, the interest organizations of older people, from large umbrella organization DaneAge, to smaller organizations related to specific diseases such as the *Alzheimersforening*, saw free choice as part and parcel of strengthening the rights of older people (Kristeligt Dagblad 2001). They specifically demanded greater transparency and a stronger professional orientation of the needs assessment by local authorities; that local authorities would retain ultimate responsibility for ensuring that services are delivered; and the introduction of minimum quality standards. Significantly, however, the evidence submitted by the organizations to the parliamentary subcommittee did not seem to be taken into consideration in the subsequent decision making process.

At the same time, only a few actors rejected the reform outright. This included the Social Liberal Party (*Socialistisk Folkeparti*) and the left wing Unity Party (*Enhedslisten*). Indeed, the Unity Party argued that it was paradoxical to use public funds to open private businesses (Petersen 2008, p. 199), while the Social Liberal Party accused the government of introducing privatization through the back door (Folketingsdebat 2002). However, both were small opposition parties without much influence or power. In addition, the trade union of care workers was outspoken in its opposition to the principle of free choice (Høringssvar 2002). The organization expressed a view that the provision of home care was best kept in public hands to safeguard the coordination of services and also to maintain a high standard of care. From this perspective, the central problem in homecare was the lack of resources, which put care workers under undue pressure. Compared to the small opposition parties, the trade union was potentially more influential, but the absence of a consensus orientation within the decision making process gave it little leverage.

In short, the centre-right minority government was the clear “winner” of the reform, as it succeeded in pushing through its own agenda. Thus, the small opposition parties and the trade unions, with their outright rejection of the legislation, can arguably be seen as the clear “losers” of the reform. The position of the Social Democratic Party, the Association of Local Authorities and the interest organizations of older people is more ambivalent. They emerged well out of the process in that they supported the basic principle of free choice, though at the same time, their concerns, especially about safeguarding local autonomy, went unheeded. The overall picture of the reform process was similar when it came to the revision of the legislation in 2004/2005, which was concerned with spelling out the procedures for free choice (Petersen 2008).

4.4 The Substance and the Result of the Reforms: Substantial Change through Restructuring

In 2003, the percentage of older people over 67 receiving home care in Denmark was 25 %; by far the highest percentage compared to other European countries (Nielsen and Andersen 2006, p. 57). The picture was similar in relation to the extent of the help provided (Nielsen and Andersen 2006, p. 63). Significantly, the percentage of older people over 65 receiving home care has remained at a high level since the mid-1990s (Nielsen and Andersen 2006). Analyses even suggest that the absolute rise in the number of older people receiving home care since the mid-1990s mostly reflects an increase in coverage, as demographic factors played a minor role (Indenrings- og Sundhedsministeriet 2004, 1). The picture is similar when looking at more recent figures, though no direct comparison is possible because of data problems; between 2005 and 2008, the coverage of home help remained at around 22 % for those aged 65 and more (Danmarks Statistik 2010b). The most recent figure (based on our own calculations) for home help use for people 65 years or older is 20 % (Danmarks Statistik 2011a, b). The typical recipient obtains 4 h per week if he lives in his own home, and approximately 20 h of help if in institutional care or sheltered dwellings. Those in institutional care are typically older and more fragile; approximately every second person above 80 lives in a nursing home (Danmarks Statistik 2008).

The figures above strongly demonstrate that there has been no retrenchment. We therefore need to look more closely at the specific type of restructuring associated with the reforms. The reforms we analyze were aimed at increasing efficiency, quality, and participation, and we thus need to connect any change to specific tools of implementation, such as the type of regulation of service provision. As is typical of Nordic care regimes, citizens are at the centre of such regulatory activities (Højlund 2004, 2006). Yet, regulation has two potentially contradictory sides; it is concerned with both ‘securing’ and ‘extending’ the welfare rights of citizens and, as a consequence, encompasses both measures of control and measures of choice/flexibility. In the following section, we argue that these contradictory building blocks have offered a springboard for gradual, yet substantial change through adaptation, which significantly alters the organization of long term care.

4.4.1 *Common Language*

As noted earlier, *Common Language* was a nonlegislative change that was both initiated and implemented by the Association of Local Authorities, while the Ministry of Social Affairs only provided financial support for some of the initial development of the system. *Common Language* added a new element (the needs assessor) to existing institutions, namely the home care worker and the policy principle of ‘as long as possible at home’. This has gradually led to a change in the way in which care is delivered, altering the status of the home care worker and, unintentionally, changing the overall goal of care work, as well as the routines of the home care worker, as outlined below.

The effects of *Common Language* are manifold and complex as implementation varies locally. However, the literature clearly identifies the more general effects of the reform: increasing bureaucratization and less time for concrete care (Nielsen and Andersen 2006, p. 45), the standardization of care for users resulting in less flexibility and responsiveness to individual needs (Petersen and Schmidt 2003) and more transparency for older people and their relatives in relation to the care services provided. These impacts reflect the ambivalence of restructuring through both control and flexibility.

The policy principle of ‘at home as long as possible’ thus remains, but the basis on which it is implemented has been significantly transformed. The standardization encapsulated in *Common Language* reduces the autonomy of home care workers and, thus, also changes their status. More specifically, their flexibility is limited as they are not able to respond to emergent and unassessed needs. Further, the time available for hands on care is being limited as more time is being used for assessing needs and documenting the care delivered. This is an unintended effect which changes the goal of care work from providing care responsive to the immediate needs of the user to provide care based on standardized packages, and from a focus on delivering care to a focus on documenting care. From the user’s point of view, an equally substantial change has occurred in the direction of greater autonomy; *Common Language* has strengthened the position of the user through the introduction of a written assessment specifying what they can expect (and demand). In this sense, *Common Language* reflects the consumerism inherent in NPM (Glendinning 2008) together with a Nordic institutional context, where the welfare state secures services through rights, rather than exclusively relying on administrative practices and discretion.

4.4.2 *Free Choice*

The introduction of *Free Choice* also represents a gradual yet substantial change through adaptation. More specifically, universalism and localism, the institutional cornerstones of Nordic care regimes, are complemented by the new elements of free choice, standards and centralism; the reform actively sponsors the shift from “citizens” to “consumers”; the redefinition of the role of local authorities as purchasers; and the expansion of the regulative power of the central level. Taken together, this substantially changes the organization of long term care, although the change itself has occurred rather gradually. The possibility of contracting out as part of *Free Choice* has existed since 2003, but started out rather slowly. However, a major organizational reform of central–local relations in 2007 meant that local authorities grew in size and as a result the market for long term care services has become more attractive for private providers (Dahl 2008). Between 2008 and 2010, the number of private providers rose by 34 % (Danmarks Statistik 2011c) and private providers are no longer marginal in the delivery of home help. Now, every third recipient of home help chooses a private provider, although this applies exclusively to practical help such as cleaning; only 4 % of older people receiving personal care choose private providers (Danmarks Statistik 2010b).

Again, in substantive terms, restructuring occurs through both control and flexibility (Højlund 2004, 2006). On the one hand, to stipulate competition among providers of home care, the local authorities are required to develop a purchasing function, which is separate from the provider function. This means splitting up two formerly integrated functions, which also offers a basis for breaking the local authorities' monopoly over the provision of services. Yet, since homecare services remain publicly funded, this requires a 'controlled market entry'. The local authorities define quality standards. In addition, local authorities have to define procedures to ensure the due process of law, in relation to choosing providers, conducting needs assessment and to stepping in when providers fail to deliver. Taken together, this involves ceding the provider monopoly of local authorities and encouraging a more mixed provision of homecare services, while strengthening the organizational controls on the part of local authorities.

The picture is equally ambivalent when it comes to giving individual older people greater choice. On the one hand, users can now freely choose among providers, yet choice is combined with control. The user can only choose between the providers approved by the local authority and in relation to the services which the local authority has allocated as part of the preceding needs assessment. Similarly, users have to some extent the option to choose precisely which services they would like to receive. However, choice is conditional: the choice of individual users has to be approved by a care worker as a professionally sound and practical help cannot be exchanged for personal care tasks if these are not included in the initial needs assessment. Further, if an individual user persistently rejects a task, the local authority may decide to conduct a new needs assessment.

4.5 Discussion

From the analysis above, reform of long term care policies in Denmark can be seen as a case of substantial change through restructuring rather than retrenchment. The supposed need for restructuring originates from cost containment which is related to the dominant, transnational discourse of NPM. Reforms draw on elements of both control and flexibility, and this is gradually yet substantially changing the organization of long term care. More specifically, the existing institutions of universality, localism, the home helper and the principle of 'at home as long as possible' are re-defined with the introduction of new elements, including free choice, standards, and centralism. In procedural terms, reforms draw on both legislative and nonlegislative change.

While the system of long term care in Denmark continues to perform favorably in comparison with other countries (Sarasa and Mestres 2007), the number and extent of reforms over the last 20 years have left the system strained. The redefined institutions often exist uneasily and individual elements draw into different directions. In relation to both points, the ambivalent interplay between control/standardization and flexibility/choice is central (Hansen and Vedung 2005; Højlund 2004, 2006); this

is associated with a number of tensions, which potentially impact negatively on the effectiveness of the system of long term care. The tensions between control and flexibility become visible especially in two areas: the relations between central and local levels, and the interactions between users and professionals. *Free Choice* encapsulates a radical form of decentralization; it focuses on individual service providers rather than merely the local authorities. Yet, the flexibility inherent in microlevel market interactions is severely limited by public control of the emerging market. In addition, central government also regulates the activities of local authorities in an increasingly detailed way (Dahl 2011). Here *Common Language* adds further mechanisms for control, as it helps to standardize services. The tensions between control and flexibility are equally strong in the interactions between users and professionals. The standardization inherent in *Common Language* limits the possibility of care workers to exercise their professional judgment and to react to needs in a flexible way. However, the very same standards give more flexibility to the care users, as standards increase the transparency of the care system and thereby help to enable user choice. Nevertheless, user choice is severely ring fenced; it is limited in scope and depends on an initial needs assessment by professionals in the purchaser–provider model.

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References

- Anttonen, A. (2002). Universalism and social policy: a Nordic-feminist reevaluation. *NORA*, 10(2), 71–80.
- Blom-Hansen, J. (2002). *Den fjerde statsmagt? Kommunernes Landsforening i dansk politik*. Aarhus: Aarhus Universitetsforlag.
- Burau, V., Theobald, H., & Blank, R. H. (2007). *Governing home care: a cross-national comparison*. Cheltenham: Edward Elgar.
- Dahl, H. M. (2000). *Fra kitler til eget tøj—Diskurser om professionalisme, køn og omsorg*. Aarhus: Politica.
- Dahl, H. M. (2004). A view from the inside: recognition and redistribution in the Nordic welfare state from a gender perspective. *Acta Sociologica*, 47(4), 325–337.
- Dahl, H. M. (2005). A changing ideal of care in Denmark: a different form of retrenchment? In H. M. Dahl, & T. R. Eriksen (Eds.), *Dilemmas of care in the Nordic welfare state. Continuity and change*. Aldershot: Ashgate.
- Dahl, H. M. (2008). Strukturereform og ældreomsorg. *Gerontologi*, 24(2), 4–7.
- Dahl, H. M. (2009). New Public Management, care and struggles about recognition. *Critical Social Policy*, 29(4), 634–654.
- Dahl, H. M. (2011). Who can be against quality? In C. Ceci, K. Björnsdóttir, & M. E. Purkis (Eds.), *Home, care and practices—Critical perspectives on frailty*. London: Routledge.
- Dahlggaard, S. (2001). Oprørende—Hjemmehjælp i København ødelagt af dårlig ledelse. *Ekstrabladet*, August 6, p. 6.

- Dane Age. (2011). Retrieved from <http://www.aeldresagen.dk/Medlemmer/detgoervivfordig/omos/english/Sider/Default.aspx>
- Danmarks Statistik. (2008). *Nyt fra Danmarks statistik: varig hjemmehjælp*. (Report No. 194). København: Danmarks Statistik.
- Danmarks Statistik. (2010a). *RASIF1Erhvervs- og beskæftigelsesfrekvenser*. Retrieved from <http://www.statistikbanken.dk/statbank5a/default.asp?w=1280>
- Danmarks Statistik. (2010b). *Nyt fra Danmarks statistik: Varig hjemmehjælp*. (Report No. 187). København: Danmarks Statistik.
- Danmarks Statistik. (2011a). *Folketal*. Retrieved from www.statistikbanken.dk/FOLK1
- Danmarks Statistik. (2011b). *AED06. Modtagere af varig hjemmehjælp (frit valg)*. Retrieved from www.statistikbanken.dk/1565
- Danmarks Statistik. (2011c). *VH 33Leverandører af privat hjemmehjælp*. Retrieved from <http://www.statistikbanken.dk/statbank5a/default.asp?w=1280>
- Doyle, M., & Timonen, V. (2007). *Home care for ageing populations. A comparative analysis for domiciliary care in Denmark, the United States and Germany*. Cheltenham: Edward Elgar.
- Folketingsdebat. (2002). *Første behandling af lovforslag, L 130, 2001–02 (2. Samling)*, L 130. København: Folketinget.
- Glendinning, C. (2008). Increasing choice and control for older and disabled people: A critical review of new developments in England. *Social Policy and Administration*, 42(5), 451–469.
- Green-Pedersen, C. (2002). New Public Management reforms of the Danish and Swedish welfare states: the role of different Social Democratic responses. *Governance*, 15(2), 271–294.
- Hansen, M. B., & Vedung, E. (2005). *Fælles sprog i ældreplejens organisering. Evaluering af et standardiseret kategorisystem*. Odense: Syddansk Universitetsforlag.
- Hochschild, A. R. (1995). The culture of politics: traditional, postmodern, coldmodern and warmmodern ideals of care. *Social Politics*, 2(3), 331–345.
- Højlund, H., & Chresten H. (2000). Velfærdsparadoks og kommunikation: 'Fælles sprog': En anden ordens strategi på hjemmehjælpsområdet. *GRUS*, 21(61), 18–39.
- Højlund, H. (2001). Kvalitetsudvikling og velfærdsparadokser. In D. Høeg, E. Prose, A. Brockenhuus-Schack, & L. Milkær (Eds.), *ældreomsorg—management eller menneskelighed?* Hellerup: Videnscenter på Ældreområdet.
- Højlund, H. (2004). *Markedets politiske fornuft. Et studie af velfærdens organisering i perioden 1990–2003*. Copenhagen: Copenhagen Business School.
- Højlund, H. (2006). Den frit vælgende ældre. *Dansk Sociologi*, 17(1), 41–65.
- Høringssvar. (2002). *Høringsnotat vedrørende L 130, L 130, 2001–02 (2. Samling)*, L 130. København: Folketinget.
- Ib, H. (2001). Ansvar til tilbage til hjemmehjælperne. *Jyllands-Posten*, August 9, p. 3.
- Indenrigsog Sundhedsministeriet. (2004). *Ældreområdet*. (Strukturkommissionens betænkning, Bind III). Copenhagen: Indenrigsog Sundhedsministeriet. Retrieved from http://www.im.dk/publikationer/strukturkom_bind_III/kap35.html
- Jyllands-Posten. (2002). Ældre pakken: Ældre kan først vælge hjemmehjælp fra nytår. *Jyllands-Posten*.
- Kommunernes Landsorganisation (1999). *Nyhedsbrev*, April, No. 2.
- Kommunernes Landsorganisation. (2002a). *Nyhedsbrev*, November, No. 3.
- Kommunernes Landsorganisation. (2002b). *Nyhedsbrev*, June, No. 2.
- Kommunernes Landsorganisation. (2002c). *Nyhedsbrev*, February, No. 1.
- Kristeligt D. (2001). Ældre skal selv bestemme over hjemmehjælpen. *Kristeligt Dagblad*, December 8.
- Kröger, T. (1997). Local government in Scandinavia: autonomous or integrated into the welfare state? in J. Sipilä (Ed.) *Social care services: the key to the Scandinavian welfare model* (pp. 95–108). Aldershot: Avebury.
- Lewinter, M. (2004). Developments in home help for elderly people in Denmark: the changing concept of home and institution. *International Journal of Social Welfare*, 13, 89–96.
- Nielsen, J. A., & Andersen, J. G. (2006). *Hjemmehjælp. Mellem myter og virkelighed*. Odense: Syddansk Universitetsforlag.

- Pedersen, I. K. (2001). Det ser du for godt ud til. *Weekendavisen*, May 18, p. 2.
- Petersen, J. H. (2008). *Hjemmehjælpens historie. Idéer, holdninger, handlinger*. Odense: Odense Universitetsforlag.
- Petersen, L., & Schmidt, M. (2003). *Projekt fælles sprog*. København: Akademisk forlag.
- Pierson, P. (2001). Coping with permanent austerity welfare restructuring in affluent democracies. In P. Pierson (Ed.), *The new politics of the welfare state* (pp. 410–455). Oxford: Oxford University Press.
- Politiken. (2001). Foghs velfærdsmarked. *Politiken*, December 2, p. 1.
- Ritzau. (2002). Citathistorie fra Jyllands-Posten: ældrepleje kan ende i bureaukrati. *Ritzau*, August 28.
- Rostgaard, T. (2007). *Begreber om kvalitet i ældreplejen. Temaer, roller og relationer*. Copenhagen: Socialforsknings Institutet.
- Rostgaard, T. (2006). Constructing the care consumer: free choice of home care for the elderly in Denmark. *European Societies*, 8(3), 443–463.
- Sarasa, S., & Mestres, J. (2007). Women's employment and the adult caring burden. In G. Esping-Andersen (Ed.), *Family formation and family dilemmas in contemporary Europe*. Bilbao: Fundacion BBVA.
- Socialudvalget. (2002). *KLs brev to Folketingets Socialudvalg vedr. ændringsforslag til L 130, 17. maj 2002*, L 130, 2001–02 (2. Samling), L 130. København: Folketinget.
- Strandberg-Larsen, M., Nielsen, M. B., Vallgård, S., Krasnik A., & Vrangbæk, K. (2007). *Denmark. Health system review*. Copenhagen: WHO Europe.
- Streeck, W., & Thelen, K. (2005). Introduction: Institutional change in advanced political economies. In W. Streeck, & K. Thelen (Eds.), *Beyond continuity: institutional change in advanced political economies* (pp. 1–39). Oxford: Oxford University Press.
- Szebehely, M. (2003). Den nordiske hentjænsten—baggrund och omfattning. In M. Szebehely (Ed.) *Hemhjälp i Norden—illustrationer och reflektioner*. Lund: Studentlitteratur.
- Thelen, K. (2000). Timing and temporality in the analysis of institutional evolution and change. *Studies in American Political Development*, 14(Spring), 101–108.
- Thye-Pedersen, C. (2001). Styrsredskaber erstatter nemt sund fornuft. *Jyllands-Posten*, August 11, p. 4.
- Vrangbæk, K., & Østergren, K. (2006). Patient empowerment and the introduction of hospital choice in Denmark and Norway. *Health Economics, Policy and Law*, 1(4), 371–394.

Chapter 5

Long-Term Care Reforms in the Netherlands

Barbara Da Roit

5.1 Introduction

During the “golden age” of the welfare state, the Netherlands developed a hybrid social protection system, encompassing both universalistic and conservative–corporatist features (Arts and Gelissen 2002; Esping-Andersen 1999; Goodin and Smitsman 2000). In the field of care policy, this mixed approach is particularly evident. While care services for children have long been neglected by the Dutch welfare state, which assumed that (mostly nonworking) mothers would take care of their children, policy developments in the area of care for older people and people with disabilities have been strikingly different. A comprehensive and universalistic scheme aiming to offer support for long-term care (LTC) was started as early as 1968, when a national compulsory social insurance aimed at covering the costs of “exceptional medical expenses” (AWBZ, *Algemene Wet Bijzondere Ziektekosten*) was introduced. This LTC insurance scheme, together with basic pensions and family allowances, represents the core of the “universalistic” features of the Dutch welfare system.

With the introduction of the scheme, the Dutch welfare state assumed most of the financial and organizational responsibilities in supporting (older) people in need of continuous care, leading to the defamilization of care to a considerable extent.

The early development and universalistic features of the AWBZ are reflected in comparatively high coverage rates of services with respect to the target population and the high level of social expenditure for LTC. According to OECD data from 2006, around 20 % of people aged 65 or above in the Netherlands were in receipt of either homecare (13 %) or residential care services (7 %), one of the highest proportions in the OECD together with Norway (21 %). This can be juxtaposed with lower coverage rates in Italy (3 %), the United Kingdom (11 %), Germany (10 %), France (13 %), Denmark (14 %), Austria (16 %), and Sweden (17 %; OECD 2009, p. 115).

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In 2008, expenditure on LTC programs as a percentage of GDP reached 3.5 % in the Netherlands and 3.6 % in Sweden, in contrast with between 1 % and 2 % in most of the countries mentioned above (OECD 2010).

As a result, the distinct and possibly conflicting objectives of guaranteeing accessible and good quality care and keeping costs under control have both been at the core of the political debate and of policymaking in the field of LTC in the last 30 years in the Netherlands.

It has been argued that specific features of the Dutch political system make radical reforms somewhat challenging (Schut 1995); the relative weakness of successive governments and the relative strength of one set of actors would together make it difficult to pass substantial reforms. No political party has had an absolute majority in parliament since Second World War and so all governments have been coalition cabinets, where compromises between political parties are the key. At the same time, strong interests tend to crystallize around existing policies, particularly in a nationally structured and integrated policy field such as LTC. However, as outlined below, the LTC system has been undergoing a continuous process of “incremental” reform over the past 20 years.

5.2 The AWBZ as the Pillar of the Dutch LTC System

As mentioned above, the foundation of the current Dutch LTC system dates back to the end of the 1960s. LTC policies in the Netherlands have subsequently developed around the AWBZ, the national insurance for “exceptional medical expenses.” It is worth noting that, in the Dutch debate, the AWBZ is usually seen as part of the “care” (*zorg*) system, which encompasses (acute and nonacute) health and social care.

A brief reconstruction of the rise and development of the LTC system within the healthcare system will help to provide an understanding of the original logic of the policy and the stakes in the later reforming process.

5.2.1 The Original Logic of the Dutch “Care” System and the LTC Policy Field

Despite several government projects, the Netherlands did not have a comprehensive collective health insurance system before the Second World War: while most of the working population participated in voluntary sickness funds, the poor were taken care out of municipal funds and the better off relied on private insurance. In 1941, the German-occupying forces introduced a Bismarkian type mandatory health insurance scheme for employees (with the exception of civil servants, for whom insurance remained voluntary) and their families below a certain income threshold. At the same time, insurance companies continued to offer private insurance to citizens whose income exceeded the income ceiling (Van der Velden 1996).

After the war, a debate on the transformation of social policy toward a Beveridgean orientation took place in the Netherlands. This did not lead to an encompassing transformation of the Dutch welfare state, but the emerging program obtained some success in the pension system with the introduction of “people’s insurances” (including a flat rate basic citizen’s pension and child benefits) and a national social assistance scheme, alongside so-called “worker’s insurances” (Van Oorschot 2006). The dual acute healthcare system emerged during the war period was confirmed with the 1964 Sickness Fund Act (*Ziekfondswet*, ZFW), ratified in 1966. Finally, the debate about the need to cover “exceptional” health care risks also led to the development of a universal citizenship-based system through a national compulsory social insurance scheme.

It should be considered that the Dutch LTC system has been traditionally characterized by the intertwined development of housing, health and social care policies (De Boer 1999). The postwar period was a crucial time for the development of both care and housing policies. As a solution to an acute housing shortage caused by the war’s devastations, new housing for older people—namely, care homes (*verzorgingshuizen*)—was built so that younger families could live on their own (Van den Heuvel 1997). This development was a combination of national government action and that of nonprofit housing organizations (*woningcorporaties*). In order to properly supervise the care homes, regulations on housing and care for the elderly were subsequently released:¹ houses that met the criteria were entitled to public funding. In the 1960s, nursing homes (*verpleeghuizen*) began to develop, aimed at providing care for people with intensive (health) care needs and, at the same time, reducing the hospitalization of the chronically ill. It was at that time that insurance companies—the key element of the Dutch healthcare system—manifested a refusal to cover the care expenses of the chronically ill patients.

The introduction of the AWBZ, in 1968, settled this controversy. The social insurance basis of the healthcare system clearly exerted an influence in defining the institutional solution to the funding of LTC: instead of relying on general taxation, which would entail progressive income-related payments, the choice was made for a public insurance system, based on contribution proportional to income. However, a straight-forward extension of the acute healthcare insurance system to LTC-related risks was considered unviable. As mentioned above, acute health insurance was compulsory only for workers below a certain threshold: it therefore covered only two-thirds of the population, excluding the highest income group. This feature was seen as a limit for the new LTC coverage. The governmental proposal of extending the existing mandatory healthcare insurance to the entire population and the subsequent enlargement of its scope to LTC was rejected on the basis of resistance opposed by different stakeholders. Private insurance companies foresaw the restriction of their market possibilities; employers feared an increase in labor costs; and the medical profession feared the extension of governmental controls on professional fees for the privately insured. The alternative solution was represented by a separate mandatory insurance scheme for LTC (AWBZ) for the entire Dutch population (Schut and Van den Berg 2010).

¹ The “Homes for the Elderly Act” (WBO) of 1963 established national regulations for care homes for older people.

Consequently, LTC has been financed since 1968 by a specific national compulsory insurance.² The latter provides coverage for the “exceptional health risks” of older people, who need nursing and care, and also for people with mental health problems and those with disabilities. The Dutch LTC system has subsequently developed around the AWBZ. Until the early 1970s, services covered by the AWBZ were mainly residential. The proportion of institutionalized older people grew considerably over the years. In fact, the Netherlands had the highest institutionalization rates of older people in Europe during the 1970s and 1980s (OECD 1996a, b). However, the AWBZ, which was originally created for funding care in nursing homes, was progressively expanded to cover the expenses of residential care and homecare services for older people. Moreover, since the 1980s, psychiatric care and other services, aids and appliances were all taken out of the insurance package covered by the Sickness Fund Act (ZFW) and placed within the scope of the AWBZ.

As a result of these developments (and until the 2006 healthcare reform), the healthcare system in the Netherlands was usually seen as structured in three “compartments” (Van Ewijk and Kelder 1999). The first compartment, the AWBZ, provided coverage for the costs of LTC for all Dutch residents, regardless of age and citizenship. Statutory public health insurance and private insurance for those excluded from the public fund constituted a second compartment, providing coverage for acute healthcare-related costs. The third compartment consisted of supplementary care insurances. In the early 2000s, the AWBZ absorbed approximately 43 % of total healthcare expenditure (Stolk and Rutten 2005).

5.2.2 *Reforming the Acute Healthcare System*

A committee named after its chairman, Dekker, former Chief Executive Officer of the Philips Company, was set up in 1986 to analyze and propose a reform of the structure and financing of the healthcare system. The Dekker Report proposed a set of measures aimed at reducing costs and improving the efficiency of the system through the introduction of market mechanisms, together with the unification of the acute healthcare insurance scheme under a single scheme (Commissie Dekker 1987). Despite the fact that several governments endorsed the proposal, it was, in reality, only very partially implemented in the 1990s. However, in 2001, the ideas of the Dekker plan reemerged in a later governmental plan (Helderman et al. 2005), which was the basis of the 2005 acute healthcare reform that came into effect at the beginning of 2006. The governmental decision was preceded by an influential report of the Social and Economic Council (*Sociaal Economische Raad, SER*)—a tripartite body composed of representatives of the employers, employees, and

²The employer withholds the employees’ contributions from their wages and pays them to the tax authorities. Nonemployees liable for tax and national insurance contributions pay the AWBZ contribution based on an assessment made by the tax authorities. Insured people under the age of fifteen, and above fifteen with no personal income, are not liable to pay contributions.

experts nominated by the government—which recommended the introduction of a general mandatory insurance scheme for acute care. The report also urged the government to move away from the direct control of supply, prices, and budgets to a system based on regulation through demand, competition and market mechanisms, both on the side of the insurance companies and on the side of the suppliers. With respect to the AWBZ, the SER supported the maintenance of a unique social insurance provider. However, based on an assessment of the inefficiencies of, and lack of satisfaction with, the current system, the SER proposed that the AWBZ should focus on providing coverage for serious and long-term illness. It also suggested that market mechanisms should be introduced (SER 2000).

In fact, the 2005 reform eliminated the dualism in the second compartment by introducing a unique compulsory scheme for all residents. The government opted for risk coverage by private insurance companies, while maintaining the social nature of the health insurance system. In this compartment, the insured can freely choose an insurance company. The insured person pays a flat rate for normal care, while the employer's share is calculated in relation to the employee's income. Each insurer sets the premium, which should be identical for all of its insured clients, for the same health basket, regardless of the person's age or health status. Insurers cannot refuse to insure a client, whatever his or her risk profile, and must offer a basic insurance without extra benefits. The insurer is therefore expected to generate competition between care providers so as to obtain the best price.³ On the supply side, the system for financing hospitals is being modified, moving from an overall budget to a system of DRG reimbursements to allow competition between hospitals, which had previously been very limited.

The reform that came into effect in 2006 neither eliminates nor radically transforms the AWBZ. The competitive mechanisms introduced in the acute healthcare system are not extended to the AWBZ. However, following the SER's advice, the scope of the insurance is now limited to serious and chronic illnesses, often considered as uninsurable. For instance, short-term psychiatric care, which over the years came under the coverage of the AWBZ, has been moved to the second healthcare compartment (see the following section).

5.2.3 Reforming LTC: Actors, Discourses, Stakes, and Modus Operandi

The fact that the 2006 reform has only marginally interested, the AWBZ does not mean that LTC has not undergone a reform process throughout the years. On the contrary, considerable transformations took place either within the existing broad framework of the AWBZ or due to the interaction and shifting boundaries between

³ There is only one exception allowed regarding this rule for equal premiums for all under the same insurer: the case of collective insurance by employers for all their employees. The reduction, however, cannot exceed 10 %.

the AWBZ and new or reformed schemes in other policy areas. The debate that has been the basis of the reform of the Dutch LTC system has been dominated by different intertwined discourses since the late 1980s.

First, the theme of cost containment has been central and still is evident in the government's policies. This emphasis on the need to contain social spending in the field of LTC has been accompanied by two distinct trends. On the one hand, cost containment met the spreading ideas (well beyond the care sector) of "new public management" (NPM) and of the need to introduce individual choice and market principles as a way to foster efficiency. On the other hand, the idea that people should be made more responsible for their own care, and for each other, gained popularity. In the political arena, combined discourses about individual choice, individual responsibility and general financial sustainability have been supported by the neoliberal right and (liberal) left alike in the past 20 years (Kremer 2006). Social partners represented in the SER also fostered the idea of managed competition in healthcare and of the reduction in scope of insurance for LTC in order to ensure its long-term sustainability (see Sect. 5.2.2). At the same time, a neocommunitarian ideology among the Christian Democrats further supported the idea of horizontal subsidiarity, namely, participation as responsibility for one's own and others' wellbeing. The purported need to shift from a "welfare state" (*verzorgingstaat*) to a "welfare society" (*verzorgingsmaatschappij*; Kuiper and Bremmer 1983, 1987) dates back to the 1980s among the Christian Democrats and was increasingly emphasized until it became the conceptual basis for an all-encompassing reform of social welfare in the mid-2000s. The WMO (*Wet Maatschappelijk Ondersteuning*) or Social Support Act was ratified by a coalition government led by the Christian Democrats and the Social Democrats. The reform was specifically aimed at fostering individual responsibility within the "community," informal care and the decentralization of care policies, also in order to ultimately reduce the LTC budget. Similar to other contexts (Pennings 2010), even if liberal and conservative parties started supporting market-oriented and other retrenchment-based reforms much earlier, these principles were soon embraced by the Social Democrats as well. It has been argued that this type of welfare reform in the Netherlands has been highly consensual because of the key role played by the centrist Christian Democratic Party: political consensus was built around cost saving, individualization of risks and choice. Furthermore, party competition made the Labour Party accept the welfare reforms as a means to regain government power (Green-Pedersen 2001).

Second, organizations representing people with disabilities (and later older people) have been demanding greater independence, empowerment and choice for the users of LTC services since the 1980s (Kremer 2006). From that time, users' movements grew considerably in membership—they counted far more than one million members by the early 2000s (Sociaal en Cultureel Planbureau (SCP) 2002)—and in organizational capacity. The core idea put forward by these organizations under the strong influence of the "American Independent Living Movement" is that people in need of (health) care should be able to make decisions about their own lives and exert the same rights as any other citizen. Thus, organizations for people with disabilities in the Netherlands campaigned for people with disabilities to determine and choose

their own care arrangements. They aimed to override a burdensome bureaucracy, which was making decisions about people's care needs and offering solutions with limited transparency and inadequate consideration of individuals' wishes and self-determination. The increasing visibility of users' organizations represents one of the most important developments in the structure of organized interests in the field of (health) care in the Netherlands in the last 20 years, together with the decline of the power of trade unions. It has been shown that successive—differently colored—governments have explicitly supported users' organizations as a strategy to reduce the influence of professionals (Trappenburg 2005). Governmental support for users' rights started in the 1970s and was fully expressed in several laws passed in the 1990s. As health and social care users can experience challenges in advocating on their own behalf, users' organizations have also progressively assumed an important role in representing the user at the level of care institutions, hospitals, etc. At the same time, users' organizations have been asked by the public administration to "collect data on professional performance and hospital output and to translate these data in accessible information (quality rankings and option menus), so as to enable future patients to choose between healthcare providers" (Trappenburg 2005, p. 233).

Interestingly enough, it appears that these organizations have been far more concerned with the introduction of demand-driven and choice-based interventions than with the changing degree of universalism of the LTC system. According to this logic, users' organizations have become the most important allies of the government in the attempts to restructure the LTC system and reduce its costs, via deprofessionalization, enhancement of informal care and the introduction of customer-driven interventions.

It is at the intersection of these different claims, strengthened by the alliance between successive governments and users' organizations, that the Dutch care model began undergoing significant reform. Indeed, since the early 1990s, there has been a continuous process of reform of LTC policies in the Netherlands, which has resulted in a series of policy innovations and retrenchments (De Boer 1999; Knijn 2001). In what follows, we shall trace the most important reform trends, highlighting how the different reforms followed different logics and instruments.

We distinguish between three types of reforms. First, a set of innovations was aimed at redefining the eligibility criteria for accessing LTC services and the allocation of various resources with the explicit aim of cost containment (Sect. 5.3). Second, a set of reforms has introduced transformations in the governance of LTC interventions (Sect. 5.4). Third, the most recent set of reforms is aimed at redefining the boundaries of LTC policies (Sect. 5.5).

5.3 Direct and Indirect Cost Containment

The first type of reforms we distinguish aimed to reduce the costs of the LTC system by restricting access to collectively funded care. Switching from more to less costly forms of care, providing incentives to access informal and privately paid care were seen as less costly alternatives to formal care. These instruments are also largely

consistent with other goals, such as responding to the wishes of the cared for, who are assumed to prefer specific types of care to others (homecare to institutional care, informal care to formal care, commercial care to formal care).

5.3.1 *Deinstitutionalization*

The deinstitutionalization process represents the first and, by now, more traditional challenge to the Dutch care system. The first signs of change in Dutch LTC policies can be traced to concerns about the large proportion of older people and those with disabilities living in institutional settings. The process of “extramuralization” (i.e., the replacement of institutional settings with community-based settings) was predicated on arguments that disabled people preferred to live independently for as long as possible. While this idea became explicit in the policy arena in the mid-1970s, it was only in the late 1980s that new policies affecting the independence of older people and people with disabilities began to be implemented and affect the living circumstances of the former (Van den Heuvel 1997). In 1965, institutional settings housed 6.7 % of the population of those aged 65 and more; the figure rose to 8.8 % in 1970 and 9.7 % in 1975. Moreover, if we add the capacity of nursing homes, the total institutionalization rate rises to over 12 % in 1975. Ten years later, the rate was still 10 % of people aged 65 and more; however, this figure had dropped to 6 % by 2003 (de Boer 1999, p. 30).

Besides the argument that people prefer homecare, deinstitutionalization is also based on the assumption that homecare services are less costly than institutional services. However, there are some crucial implications of this assumption. Although deinstitutionalization plays a considerable role in cost reduction strategies, it also represents a major challenge, as increased support for homecare has to be provided somehow (Jacobzone et al. 1999). Community care may appear to be less expensive when a vast range of informal services are called upon to replace much more expensive professional care, yet it may be as expensive as institutional care if all of the costs are taken into account (Weissert and Cready 1989). This sharp deinstitutionalization trend therefore challenged the organization of homecare services and required more involvement of informal caregivers.

New forms of homecare services evolved, including round-the-clock and weekend support. The expansion of the homecare sector throughout the 1990s can be seen in the increasing number of homecare employees: 126,000 in 1995 and 580,000 in 1999 (Arts 2002, p. 10). The development of homecare services uncovered an even greater population of dependent older people living at home who were eligible for these services. This put even more strain on homecare services (and informal caregivers) and led to increased calls for further cost containment and measures to increase productivity such as the “Taylorisation” of tasks (Knijn 2001) or the introduction of competition among the providers (see Sect. 5.4). These contradictions were made evident by cutbacks on the one hand and labor shortages in the homecare sector on the other (Arts 2002).

5.3.2 *Direct Cost Controls*

The struggle to keep costs under control has a long history in the Netherlands and has been characterized by alternate periods of stringent direct cost containment (with consequent waiting list expansion and perceived “quality” problems) and of removed controls. This tradeoff is still on the agenda.

Direct mechanisms for budget control were already implemented in the 1970s, especially with respect to the number of “beds” in residential care: authorizations were needed in order to start new investments in the sector. As a result, the level of expenditure was controlled through the direct definition of the capacity of nursing homes. However, it was only in the 1980s that a comprehensive budgeting system for residential care was introduced, which was later extended to the homecare sector. With respect to other service sectors, the productivity of labor in the care sector has quite exceptionally increased on a continual basis since the early 1990s. This is thanks to both wage moderation and the introduction of tight budgets for care organizations, which were compelled to reduce managerial and organizational costs and to introduce systems of time management aimed at increasing the efficiency in service delivery (Eggink et al. 2008).

In the 1990s, this strategy was extended to the homecare sector and so the real costs of the AWBZ were effectively contained (Schut and Van den Berg 2010). However, the side effect of this strategy was the increase in waiting lists and a general perception of the deterioration of the quality of care, which became a wide public concern.

An important court decision concerning waiting lists in 1999 paved the way toward the suspension of this strategy: as Dutch residents were entitled to a “right to care” (which was also supposed to be timely) based on the social insurance legislation, the government was held responsible for ensuring this right, also against budgetary considerations. As a consequence of public and political pressure together with the court decision, the direct cost containment mechanisms were lifted in 2000: over the next few years the waiting lists were considerably reduced (Van Gameren 2005) at the cost of a steep increase in the AWBZ expenditure (Schut and Van den Berg 2010).

New attempts to put the AWBZ budget under control were introduced starting from 2005. Together with the increase in users’ copayments (see the following section), regional budgets for the AWBZ were imposed based on past expenditure: regional care offices were responsible for administering these budgets, negotiating the tariff levels and the maximum production level with care providers. This strategy is, again, at risk of producing waiting lists and the deterioration of quality.

5.3.3 *Limiting Access*

One indirect way of restricting access to care services is through the introduction of users’ copayments. While they were virtually nonexistent in the traditional health and social care sectors (De Boer 1999), copayments by homecare recipients (income-related tariffs per hour of homecare received) developed rapidly in the 1990s. Some

argued that these developments would limit the use of homecare by both the low- and high-income groups, as, although low income earners have the right to social assistance when they cannot afford the individual payments themselves, they would increasingly attempt to access informal care (therefore free of charge) instead of requesting social assistance. High income earners, on the other hand, would try to solve their care problems via the market (Knijn 2001, p. 172). According to government advisory boards, these developments threatened to alter the nature of the AWBZ as a general collective insurance (Commissie Sociaal-Economische Deskundigen (CSED) 1999).

A more direct way of achieving the same objective is to restrict the eligibility criteria themselves. One of the features of the universalistic approach of the Dutch LTC system is that the assessment of needs and the attribution of care resources do not depend on the (economic or care) resources of the claimant. However, several attempts of formalizing and enlarging what should be expected from the coresident family members in terms of informal care have been put in place (Landelijke Vereniging van Indicatieorganen (LVIO) 2003; Centrum Indicatiestelling Zorg (CIZ) 2005).

5.3.4 Effects of the Cost Containment Strategy

If we look at expenditure developments over the long term, the above-mentioned cost containment strategy has shown some limited effects. Real costs (nominal costs adjusted for inflation) almost doubled between 1985 and 2005: the increases are evident in homecare (25 % over 20 years), but are more apparent in the residential care sector (more than a 100 % growth; Eggink et al. 2008, p. 21). However, the direct cost containment strategy did have the effect of limiting yearly growth of expenditure until the early 2000s, since most of the growth took place in the period 2001–2005. The consequences produced by lifting the direct cost controls previously imposed in order to reduce the waiting lists are quite clear in the development of the overall costs. While the AWBZ-related costs as a percentage of the GDP were relatively stable at the level of 3.5 % between 1985 and 2001, this proportion subsequently increased to 4 % over a 2-year period. Only a quarter of this steep increase in such a short period of time can be explained by a slowdown of the economy in the same period (Eggink et al. 2008, p. 22).

It is important to note, however, that the increase in cost has affected the various subsectors of the LTC system in different ways. Most of the increase in costs in the homecare sector can be attributed to the increasing volume of services produced rather than to the increase in prices for these services. Yet the opposite has happened in the residential care sector, where the volume of production has increased much less (care homes) or even decreased (nursing homes); increasing prices are instead more responsible for the overall cost growth (Eggink et al. 2008, p. 24). This demonstrates that, particularly in the homecare sector, a strong cost containment of the labor costs (or an increase in productivity) is responsible for preventing the overall costs from increasing even more than they already have (Eggink et al. 2008, p. 31). This

labor cost containment might have had a considerable influence on the quality of the services provided.

It should be noted, moreover, that despite all the attempts to limit access to the AWBZ benefits, formal care provided through the national insurance system remains the key pillar of LTC in the Netherlands. The absolute number of homecare users remained stable around 260,000 per year in the period 1985–1997 and it increased to 410,000 in 2005. The number of care workers (expressed in fulltime equivalent) in the homecare sector grew from 50,000–60,000 between 1985 and 1997 and then to 80,000 in 2005 (Eggink et al. 2010, pp. 51–52). Therefore, the user–worker ratio remained relatively stable at around five to one, showing that there was no decrease in the average intensity of the services provided. There is no evidence—until the first half of the 2000s—about reduced access to the system and the substantial substitution of formal care with informal and market care (Da Roit 2010). However, there are signs that the introduction of formal protocols on “common care” and the recent steep increase in copayments may have an effect on, respectively, the recourse to informal care (Cardol et al. 2008, pp. 21–22; Cardol and Rijken 2010, p. 25; De Klerk et al. 2010, p. 215) and on the reduction of the access to formal care (Eggink et al. 2008, p. 23). Moreover, concerns about the quality of the services provided and the deprofessionalization of the care workers remain.

5.4 Changing Governance in the Dutch LTC in the 1990s: Users’ Empowerment and Market Arrangements

The second type of reforms we distinguish was aimed at changing the ways in which the resources for LTC were allocated and at modifying the relationships between the users, the professionals, the providers, and the collective funding system. These encompass mainly the introduction of consumer-directed care and of market-based principles.

5.4.1 *The Personal Budget (PGB)*

Until 1995, LTC was only provided in kind. In 1995, with the introduction of the “Personal budget” (*Persoonsgebonden budget*, PGB) a limited number of those eligible for homecare were provided with a cash allowance instead of in kind services. This allowance was not a direct cash payment, but rather a budget that beneficiaries could use to arrange their own care (Kraan et al. 1991). Since 1995, a limited but increasing proportion of the annual AWBZ budget has been going to PGB applicants for homecare. By 2001, everyone who had been approved for homecare for at least 3 months was declared eligible for a PGB. The number of budget holders rose steeply since the second half of the 1990s: from slightly more than 5,000 to 60,000 in 2003 (De Boer and De Klerk 2006, p. 151) and 80,000 in 2007 (Ministry of Health, Welfare, and Sport (VWS) 2007).

Since its inception, opting for a PGB seemed to be more popular among younger people with disabilities than among older dependent people (Miltenburg and Ramakers 1998). Estimates show that in 2007, the younger clients represented approximately 10 % of all those receiving AWBZ-compensated care and 5 % of older people in receipt of AWBZ-financed care (7 % of the elderly receiving AWBZ-reimbursed home-based care).⁴

PGB beneficiaries can spend the available resources to compensate nonprofessional caregivers, private professional services or traditional homecare services. Claimants who are entitled to care have a choice of receiving it 'in kind' or in the form of a personal care budget (or a combination of both). The value of the personal budget is set at about 75 % of the average cost of the corresponding care 'in kind', given the fact that at least part of the budget is expected to be spent on less expensive informal care or contracted privately paid care. An early study found that approximately 25 % of PGB holders purchased care from the traditional (not-for-profit) homecare organizations but they used commercial homecare services or self-employed caregivers more frequently. In about 20 % of cases, care was provided by informal caregivers (Miltenburg and Ramakers 1998). In 2007, one-third relied solely on informal care, one-third on formal care, and one-third on a combination of the two (VWS 2007).

Successive evaluation reports have highlighted the high level of satisfaction of the users (Miltenburg and Ramakers 1998; Ramakers et al. 2007; Van den Wijngaart and Ramakers 2004). On the other hand, the possible implications for informal caregivers (Grootegoed et al. 2010), for professionals and for the system of care delivery (Knijn and Verhagen 2007; Kremer 2006) have attracted little attention in the debate. At the same time, the PGB was long considered an effective strategy for cost reduction as the unitary cost of services is lower than that paid by the AWBZ for services in kind.

However, recent developments have shown the possible fallacy of this assumption. Despite the fact that the clients using a personal budget are still a small minority of the AWBZ users, the increase in both the number of clients opting for this form of care delivery and the relative budget have risen exponentially in the past few years. In 2010, for the first time, the government announced that from the second semester of the year it would not be possible to pay a personal budget to new clients of the AWBZ: new claimants could either opt for services in kind or would be put on a waiting list. This type of development unveils possible contradictions in the implementation of the PGB: a scheme implemented to reduce bureaucracy, empower the users and at the same time save collective resources, ends up not being viable because of budgetary overruns. From the perspective of the supporters of the cost containment strategy, the question is whether the recourse to a PGB is fostering the substitution of traditional formal care with (cheaper) informal and paid care or if it is increasing the overall demand for financial support. If the institutional design of the PGB ensures a reduction of cost *per user*, there is the risk that it increases the number of users by unveiling a demand that would not be there if only traditional

⁴ In 2007 840,214 people received AWBZ-financed care. 653,300 were aged 65 and above, 490,130 of which received extramural care (CBS 2008: 122–123)

services were available. In fact, research conducted on a sample of 700 PGB users shows that only one-third would have made use of traditional services if there was no possibility of accessing the PGB (25 % would have hired a privately paid caregiver; 18 % would have received no help at all, and 17 % would have held on to existing help; Ramakers et al. 2007, p. 117). At the same time, 38 % of respondents stated that they chose a PGB because the kind of help they needed could not be provided by traditional services, 33 % because they wanted to be able to pay for preexisting informal care, and 26 % because they wanted to be able to pay for existing informal care. This evidence suggests that the PGB only partly substitutes care in kind, while at the same time increasing demand for support, which would not otherwise arise. Moreover, the PGB only partly fosters increasing involvement of informal caregivers, while it seems to be used mainly for remunerating existing family carers. Even if this can be seen as a legitimate emergence of unexpressed demand and previously unsatisfied needs, it clearly contradicts the cost containment logic.

It is precisely for cost containment purposes and the prospect of a widespread misuse of the scheme that, in the summer 2011, the Cabinet announced a drastic reduction in the scope of the PGB. Despite the protests of the users' organizations, no new PGBs have been provided to homecare users from January 2012 and the existing budget holders should stop receiving the benefit in 2014. As soon as the PGB stopped being viewed as an instrument of cost containment, a 20-year-old alliance between the users' organizations and the government apparently ceased. Further developments are still unclear.

5.4.2 Making Assessment Independent from Delivery and Standardizing the Care Tasks

In line with NPM principles, organizational changes were introduced in order to separate the functions of assessment, funding and service provision on the one hand, and to make the "production" of care measurable and controllable on the other.

Until 1998, needs assessments and service delivery were both carried out by care providers. The separation of these two functions, which took place in 1998, was deemed as a solution to multiple problems. The assessment of needs would be more independent from the available services, enhancing the opportunities of the users and it would reduce the incentives of the care provider to overassess the clients' needs in relation to the organizations' interests. The assessment task was initially assigned to regional independent organizations (RIO, *Regionale Indicatie Organen*) under the responsibility of the municipalities (Algera et al. 2003), and, since 2005, to a single national organization (CIZ) with local branches.

This process was also associated with the progressive standardization of assessment procedures and of the system of attribution of care resources to the users. The further introduction of assessment "protocols" and "benchmarking" is also expected to play a role in making the AWBZ more efficient, sustainable and transparent in the future (SER 2008). The Dutch system also ensures a wide coverage of functions

and of time for homecare recipients. The most severe dependent people, in need of constant day and night care, tend to be directed to residential care, though it is not uncommon to find care users receiving 8 to 12 hours of support per day, 7 days a week. However, this support is commonly provided by a relatively high number of professional caregivers. The multiplication of the caregivers is largely because many work part time, but more so because their work tends to be task-based. Because it is often not undertaken by formal services, the coordination of high numbers of care workers tends to remain the responsibility of the user or of the informal caregiver (Knijn and Da Roit 2008).

5.4.3 Marketization of the Supply

The marketization or liberalization of public services is a trend that has been observable in several sectors in the Netherlands since the 1990s, not just in LTC. Childcare, unemployment, and activation services have all been reformed or expanded according to market-based principles as a way to reduce bureaucracy, enhance efficiency and improve quality.

In the (home) care sector, marketization has been implemented by means of two mechanisms: the introduction of the PGB as illustrated above and the introduction of competition between providers of in kind services.

However, the introduction of an actual care market had been more difficult than expected. The PGB did not produce considerable effects in this respect: its relative weight remained limited in spite of considerable growth, a relevant proportion of the beneficiaries used it to finance informal care only and it was recently repealed (see the section above). The introduction of competition between providers also remains rather limited. Most traditional homecare organizations still hold a quasi-monopolist position, mergers in the care sector have become quite common since the early 2000s, financed by the AWBZ (similarly and even more so than in the acute healthcare sector), and the entrance of new and small providers in the market has been restricted (Kremer 2006; Raad voor Volksgezondheid en Zorg (RVZ) 2003, 2008).

5.5 Redefining the Policy Boundaries: Hollowing the AWBZ as the New Reform Strategy?

The third type of reforms implemented in the Netherlands—more recent and still ongoing—comprises a redefinition of the boundaries of the AWBZ and taking important pieces of social protection away from the scope of the AWBZ and attributing them to other sectors of the welfare state.

5.5.1 Moving Psychiatric Care Out of the AWBZ to the Health Insurance System

As previously noted, at the time of the introduction of 2006 healthcare reform, it was stressed that the AWBZ should be restricted to the coverage of core LTC needs, while retaining its basic principles (SER 2000). This opened up the opportunity to transfer provisions previously offered through the national LTC insurance to different social protection schemes. The first effects of this change occurred in the psychiatric care sector; short-term psychiatric care, which over the years came under the coverage of the AWBZ, has been moved to the “second healthcare compartment.” Since 2008, the first year of a user’s psychiatric treatments has been financed through the acute care insurance system and any additional treatment is funded by the AWBZ.

In a similar way, the process of transferring rehabilitative homecare under the acute health care insurance system has recently started.

5.5.2 The Social Support Act and the Separation of Care from Household Assistance

The Dutch care system underwent a substantial transformation in 2007 with the implementation of the new Social Support Act (WMO). Some of the services that had traditionally been covered by the AWBZ—i.e., home help—have been handed over to the municipalities. The consequences have been twofold: on the one hand, citizenship rights have been transferred to a domain of social service provision—social assistance and care, which are locally managed—where discretionary power is more important; on the other hand, a service that was once integrated (health, social and household care) has been split into distinct provisions (health and social care on the one hand, and household care on the other), which respond to different logics.

An evaluation of the effects of the implementation of the WMO with respect to the newly organized delivery of household assistance at the municipal level has shown that, while the consequences of this change has hardly affected the users (in their own view), it has had consequences on the care organizations and their workers. The municipalities reassessed the needs of the AWBZ users receiving help with household tasks: the vast majority of them continued to receive the same amount and type of help, usually from the same care organization. Only 10 % of the users declared that the amount of support diminished and was no longer sufficient. By contrast, according to the care organizations, the shift from the AWBZ to WMO financed care meant a reduction in the hourly tariffs paid, with two consequences: financial problems for the organization themselves and the reduction in hourly wages for the care workers, which in turn represented an incentive for leaving one’s job (Plas et al. 2008). It seems, therefore, that the cost containment strategy embedded in the devolution of care responsibilities to the municipalities is based on the reduction of the labor costs, which in turn will produce further shortages and, as one can easily foresee, a decrease in the quality of the services provided.

5.5.3 *Hollowing out the AWBZ as a Reform Strategy?*

Similar proposals aimed at moving some risks currently covered by the AWBZ to the acute healthcare system or to other fields of social protection continue to be put forward. For instance, it has been proposed that “short-term (home) care” be taken away from the AWBZ coverage and financed by the health insurance system (Den Draak 2010; College van Zorgverzekeringen (CVZ) 2007, 2009). At the same time, the Social and Economic Council proposed a further removal of rehabilitation care and activation and supervision services from the AWBZ, which should be attributed, respectively, to the acute healthcare insurance and to the WMO (SER 2008). This would continue an ongoing trend of the revision of the boundaries between the AWBZ and the health insurance system from the point of view of the rehabilitation system (Eyck and Peerenboom 2006), similar to what has happened with parts of the psychiatric LTC system (Van Campen 2009).

5.6 Conclusion

The debate on LTC in the Netherlands is dominated by the tensions between ensuring universal, good quality services and maintaining the costs of this expensive social policy under control. Attempts to radically reform the AWBZ have proven to be difficult. By contrast, several incremental and partial reforms have been introduced: a set of different measures explicitly aimed at containing or reducing the costs of the LTC system, increasing the power of the users and redistributing the responsibility for LTC both between the public and private sector and also across the public sector more broadly.

As previously shown, despite all the attempts of limiting access to the AWBZ benefits, formal care provided through the national insurance system remains the pillar of the Dutch LTC system. There is no evidence of reduced access to the system and of the substantial substitution of formal care with informal and market care. Nonetheless, concerns about the quality of the services provided and the deprofessionalization of the care workers remain because of the direct and indirect cost containment strategy.

The new forms of governance introduced in the system, namely the cash-for-care scheme (PGB) and the introduction of market principles and NPM ideas seem to have had limited impact on the system. The PGB remained restricted to a small proportion of AWBZ users until its recent abrogation, while market mechanisms have entered the system to a limited extent.

Possibly the most disruptive transformation introduced into the system has been the shifting of some of the risks covered by the AWBZ to other fields of social protection. Since the early 2000s, the idea has become dominant that, in order to be sustainable, the AWBZ should go back to its “core business” and leave the coverage of complementary interventions to other policy domains. Not only have some “short-term” provisions been shifted to the acute healthcare system, but

long-term “noncore” activities (home help) have been removed from the AWBZ coverage to the municipal responsibility under the social support–social assistance framework. This trend represents a turning point in the pathway of reform in the field, as it involves the redefinition of the boundaries of LTC, outside of which the logics of social protection differ significantly. Interestingly enough, this appears to be a consensual development in the political arena.

In all, the tensions between responsiveness to needs, quality of care and expenditure are far from being settled and there is considerable uncertainty about the future of the AWBZ.

References

- Algera M., Francke, A. L., Kerkstra, A., & van der Zee J. J. (2003). An evaluation of the new home-care needs assessment policy in the Netherlands. *Health and Social Care in the Community*, 11(3), 232–241.
- Arts, S. E. J. (2002). *Caring as an occupation: Content and quality of working life among home helps*. Utrecht: Maastricht: Universiteit van Maastricht.
- Arts, W., & Gelissen, J. (2002). Three worlds of welfare capitalism or more? A state-of-the-art report. *Journal of European Social Policy*, 12(2), 137–158.
- Cardol, M., Marangos, A. M., & Rijken, M. (2008). Individuele ondersteuning in de periode 2004 tot en met 2007. In A. M. Marangos, M. Cardol, & M. de Klerk (Eds.), *Ondersteuning en participatie van mensen met een lichamelijke beperking. Een jaar na invoering van de Wmo. Tweede tussenrapportage WMO evaluatie* (pp. 21–34). Den Haag: Sociaal en Cultureel Planbureau.
- Cardol, M., & Rijken, M. (2010). Individuele ondersteuning in de periode 2004 tot en met 2008. In A. M. Marangos, M. Cardol, M. Dijkgraaf, & M. Klerk (Eds.), *Ondersteuning en participatie van mensen met een lichamelijke beperking. Twee jaar na invoering van de Wmo. Vierde tussenrapportage WMO evaluatie* (pp. 24–35). Den Haag: Sociaal en Cultureel Planbureau/NIVEL.
- Centrum Indicatiestelling Zorg. (2005). *Protocol gebruikelijke zorg*. Driebergen: Centrum Indicatiestelling Zorg.
- Commissie Structuur en Financiering Gezondheidszorg (Commissie Dekker). (1987). *Bereidheid tot verandering* (Willingness to Change). The Hague: Commissie Structuur en Financiering Gezondheidszorg.
- Commissie Sociaal-Economische Deskundigen. (1999). *Gezondheidszorg in het licht van de toekomstige vergrijzing*. The Hague: Sociaal-Economische Raad.
- College van Zorgverzekeringen. (2007). *Pakketadvies 2007*. Publicatie 248. Diemen: CVZ.
- College van Zorgverzekeringen. (2009). *Pakketadvies 2009*. Publicatie 274. Diemen: CVZ.
- Da Roit, B. (2010). Strategies of care. Changing Elderly Care Policies and Practices in Italy and the Netherlands. Amsterdam: Amsterdam University Press.
- De Boer, A., & de Klerk, M. (2006). Physical disabilities and Care. In A. de Boer (Ed.). *Report on the Elderly 2006. Changes in the Lives and Living Situations of the Elderly Persons in the Netherlands*. The Hague: Sociaal en Cultureel Planbureau.
- De Boer, A. (1999). *Housing and care for older people: a Macro-Micro perspective*. Nederlandse Geografische Studies 253. Utrecht: Urban Research Centre.
- De Klerk, M., Gilsing, R., & Timmermans, J. (Eds). (2010). *Op weg met de WMO. Evaluatie van de wet maatschappelijke ondersteuning 2007–2009*. Den Haag: Sociaal en Cultureel Planbureau.
- Den Draak, M. (2010). *Kortdurende thuiszorg in de AWBZ. Een verkenning van omvang, profiel en afbakening*. The Hague: Sociaal en Cultureel Planbureau.

- Eggink E., Oudijk D., & Woittiez, I. (2010). *Zorgen voor zorg ramingen van de vraag naar personeel in de verpleging en verzorging tot 2030*. The Hague: Sociaal en Cultureel Planbureau.
- Eggink, E., Pommer, E., & Woittiez, I. (2008). De ontwikkeling van AWBZ-uitgaven. Een analyse van awbz-uitgaven 1985–2005 en een raming van de uitgaven voor verpleging en verzorging 2005–2030. The Hague: Sociaal en Cultureel Planbureau.
- Esping-Andersen, G. (1999). *Social foundations of post-industrial economies*. Oxford: Oxford University Press.
- Eyck, A., & Peerenboom, P. B. (2006). *Revalidatie in nederland. De grenzen van AWBZ en ZVW*. Leusden: ETC Tangram.
- Goodin, R. E., & Smitsman, A. (2000). Placing welfare states: The Netherlands as a crucial test case. *Journal of Comparative Policy Analysis: Research and Practice*, 2(138), 39–64.
- Green-Pedersen, C. (2001). Welfare-state retrenchment in Denmark and the Netherlands, 1982–1998: The role of party competition and party consensus. *Comparative Political Studies*, 34(9), 963–85.
- Grootegoed, E., Knijn, T., & Da Roit, B. (2010). Relatives as paid caregivers: how family carers experience payments for care. *Ageing and Society*, 30(3), 467–489.
- Helderman, J. K., Schut, F. T., Van der Grinten, T. E. D., & Van de Ven, W. (2005). Market oriented health care reforms and policy learning in the Netherlands. *Journal of Health Politics, Policy and Law*, 30(1/2), 189–209.
- Jacobzone, S., Cambois, E., Chaplain, E., & Robine, J. M. (1999). The health of older persons in OECD countries: is it improving fast enough to compensate for population ageing? Labour Market and Social Policy Occasional Papers 37. Paris: OECD.
- Knijn, T. (2001). Care work: innovations in the Netherlands. In M. Daly (Ed.), *Care Work. The quest for security* (pp. 159–174). Geneva: ILO.
- Knijn, T., & Da Roit, B. (2008). Working and caring for an older parent in the Netherlands, WOUPS Project. Dutch National Report on the qualitative study. Woups project, August 2008.
- Knijn, T., & Verhagen, S. (2007). Contested professionalism. Payments for care and the quality of home care. *Administration and Society*, 34(4), 451–475.
- Kraan, R., Baldock, J., Davies, B., Evers, A., Johansson, L., Knapen, M., Thorslund, M., & Tunissen, C. (1991). *Care for the elderly: Significant Innovations in Three European Countries*. Frankfurt: Campus Verlag.
- Kremer, M. (2006). Consumers in charge: The Dutch personal budget and its impact on the market, professionals and the family. *European Societies*, 8(3), 385–401.
- Kuiper, D. Th., Bremmer, C. (1983). 'Van verzorgingsstaat naar verzorgingsmaatschappij'. Aantekening over de christendemocratische inzet in de jaren '80, in Extra Editie CdAktueel, Oktober 32–48.
- Kuiper, D. Th., Bremmer, C. (1987). *Discussienota over de verantwoordelijke samenleving*. The Hague: CDA.
- Landelijke Vereniging van Indicatieorganen. (2003). *Werkdocument gebruikelijke zorg*. The Hague: LVIO.
- Miltenburg, T., Ramakers, C. (1998). *Beleidsgerichte evaluatie persoonsgebonden budget 1996–1997*. Nijmegen: Instituut voor Toegepaste Sociale Wetenschappen.
- Ministry of Health, Welfare and Sport (VWS). (2007). *Feiten en cijfers persoonsgebonden budget*, Retrieved from http://www.minvws.nl/dossiers/persoonsgebonden_budget_pgb/feiten-en-cijfers-pgb/
- OECD. (1996a). *Ageing in OECD countries*. Paris: OECD.
- OECD. (1996b). *Caring for frail elderly people. Policies in evolution*. Paris: OECD.
- OECD. (2009). *Society at a glance 2009, OECD Social Indicators*. Paris: OECD.
- OECD. (2010). OECD Health Data 2010. Retrieved from http://www.oecd.org/document/30/0,3746,en_2649_37407_12968734_1_1_1_37407,00.html
- Pennings, P. (2010). Exploring variations in the political discourse on public sector reforms, 1981–2005. *Public Management Review*, 12(2), 173–190.

- Plas, L., Noordhuizen, B., & van Vree, F. (2008). *Wet maatschappelijke ondersteuning. Het aflopen van het overgangsrecht: effecten voor cliënten, gemeenten en thuiszorgorganisaties. Eindrapport. Een onderzoek in opdracht van het ministerie van Volksgezondheid, Welzijn en Sport*. Zoetermeer: Research voor Beleid.
- Raad voor Volksgezondheid en Zorg. (2003). *Van patiënt tot klant*. Zoetermeer: RVZ.
- Raad voor Volksgezondheid en Zorg. (2008). *Schaal en zorg*. Den Haag: RVZ.
- Ramakers C., de Graauw, K., Sombekke, E., Vierke, H., Doesborgh, J., & Woldringh, C. (2007). *Evaluatie persoonsgebonden budget nieuwe stijl 2005–2006*. Eindrapport. Nijmegen: ITS.
- Schut, F. T. (1995). Health care reform in the Netherlands: Balancing corporatism, etatism, and market mechanisms. *Journal of Health Politics, Policy and Law*, 20(3), 615–652.
- Schut, F. T., & van den Berg, B. (2010). Sustainability of comprehensive universal long-term care insurance in the Netherlands. *Social Policy and Administration*, 44(4), 411–35.
- Sociaal-Economische Raad (SER). (2000). *Naar een gezond stelsel van ziektekostenverzekeringen. Advies uitgebracht aan de Minister van Volksgezondheid, Welzijn en Sport. Publicatienummer 12*. Den Haag: Sociaal-Economische Raad.
- Sociaal-Economische Raad (SER). (2008). *Advies Langdurige zorg verzekerd: Over de toekomst van de AWBZ*. Den Haag: Sociaal-Economische Raad.
- Sociaal en Cultureel Planbureau. (2002). *De kwaliteit van de quartaire sector. Sociaal en Cultureel Rapport 2002*. The Hague: SCP.
- Stolk Elly A., & Rutten, H. (2005). The 'Health Benefit Basket' in The Netherlands. *European Journal of Health Economics*, 6, S53–S57.
- Trappenburg M. (2005). Fighting sectional interests in health care. *Health Care Analysis*, 13(3), 223–237.
- Van Campen, C. (2009). *Profielen van vragers naar AWBZ-GGZ*. The Hague: Sociaal en Cultureel Planbureau.
- Van den Heuvel, W. (1997). Policy towards the elderly: Twenty-Five years of Dutch experience. *Journal of Aging Studies*, 11(3), 251–258.
- Van den Wijngaart, M., & Ramakers, C. (2004). *Monitor budgethouders pgb nieuwe stijl. Eindrapport*. Nijmegen: ITS.
- Van der Velden, H. (1996). The Dutch health services before compulsory health insurance, 1900–1941. *Social History of Medicine*, 9(1), 49–68.
- Van Ewijk, H., & Kelder, T. (1999). *Who Cares? An overview of the Dutch system of health care and welfare*. Utrecht: Netherlands Institute of Care and Welfare (NIZW).
- Van Gameren, E. (2005). *Regionale verschillen in de wachtlijsten verpleging en verzorging. Een empirisch onderzoek naar verklarende factoren*. The Hague: Sociaal en Cultureel Planbureau.
- Van Oorschot, W. (2006). The Dutch welfare state: Recent trends and challenges in historical perspective. *European Journal of Social Security*, 8(1), 57–76.
- Weissert, W. G., & Cready, C. M. (1989). A prospective budgeting model for home and community-based long-term care. *Inquiry*, 1 116–129.

Chapter 6

Radical Institutional Change and Incremental Transformation: Long-Term Care Insurance in Germany

Hildegard Theobald and Sarah Hampel

6.1 Introduction

With the introduction of the Long-Term Care Insurance Scheme (LTCI) in 1995–1996, Germany established a universally oriented, long-term care scheme on a central level to provide support in situations of care dependency throughout the whole country. The law was established after a long political debate (originally developing in the late 1970s) on the need to provide long-term care assistance where required versus the cost of alternative policy responses. Finally, the increasing fiscal burden on the local levels triggered the reform process.

The LTCI fundamentally changed social rights related to long-term care needs, as well as the mode and principles of funding and care provision. Although the law introducing the scheme drew on predominant social values and existing social policies, the *introduction* of the scheme can be defined as a “radical change” from existing regulations on funding and on social rights. The law represented a compromise between the ideas and interests of different groups, including politicians on different levels, experts in para-state organizations such as insurance funds, social partners, and other social actors outside the governmental system (see Meyer 1996). The radical change of care policies was influenced by the need to create a sound funding basis for long-term care needs through the expansion of welfare state coverage and was facilitated by the compromise acceptable to the significant actors. However, in recent years, various regulations have elaborated on and adapted the LTCI in response to various (un)intended effects and so subsequent *reform* of the scheme, and of care provision in general, can be described as a process of “reproduction by adaptation” (see Table 6.1).

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Table 6.1 Overview of long-term care insurance (LTCI) and reforms in Germany

Effective from	Reform
1st April 1995	Introduction of the first part of LTCI related to home-based care support
1st July 1996	Introduction of the second part of LTCI related to residential care support
1st April 2002	Complementary nursing act
1st January 2002	Act on quality assurance and consumer protection
1st January 2002	Reform of residential home act (introduced in 1975) regulations on rights of residents in residential care facilities, related to contracts, obligations of the providers, quality control, etc.
1st August 2003	Standardization of the <i>elder carer occupational training program</i> at the federal level
1st January 2005	Increase of insurance contributions for childless members of social LTCI older than 23 years with 0.25–1.95 % of gross wages
1st September 2006	Federal states became mainly responsible for residential home act
1st July 2008/1st January 2009	<i>Comprehensive reform related to (see text)</i> Act on quality assurance and consumer protection Complementary nursing act Introduction of single access points (Pflegestützpunkte) Introduction of an individual right of care/case management services free of charge Introduction of two leave schemes for informal carers to facilitate combination of informal care provision and employment General increase of insurance contributions (social LTCI) to 1.95 % of gross wages respectively 2.2 % of gross wages for childless members Adaptation of benefits to cost developments in several steps 2008, 2010, 2012 (see Appendix 3, Table 6.6) Increase of benefits related to day care services
1st October 2009	Reform of residential home act on federal level Right on access on plain information on care quality, care offers and costs of the residential care facility before conclusion of a contract Regulations related to changes/adaptations of care provision and termination of a contract

In this chapter, both types of developments—radical change and incremental transformation—will be analyzed. Processes of radical change will first be analyzed through the examples of the system of funding and the definition of social rights, where clearly defined regulations on a federal level were introduced after intense debates (with only minor changes made since). Second, reform strategies related to the restructuring of care provision will be examined to reveal processes of incremental step-by-step change. The study looks at processes of policy development as shaped by the interplay of actors, ideas, interests, and institutions; and the rationale for and content of the policies as well as their effects. Empirically, the chapter is based on a literature review, statistical and documentary analysis.

6.2 Funding: Combining a Social Insurance Scheme and Basic Support

Before the introduction of the LTCI, only residual public support related to long-term care needs was available. Under the Federal Social Assistance Act (BSHG) 1961, payments for home-based and residential care were covered by the tax-based welfare system just for people in need of long-term care who could not meet the costs. With the Health Reform Law of 1989, the cost for respite care for informal carers could be refunded, and with the Reform in 1991, a limited group of very frail people were entitled to cash or in-kind service by the Statutory Health Insurance Scheme. The health care-related schemes were meant as a first step to a universal public support and were abolished with the introduction of the LTCI.

The increasing high costs for residential care at local level within the framework of the Federal Law of Social Assistance provided the main incentive for the establishment of a new pillar within the German social insurance system in 1995–1996 (Campell and Morgan 2005). The establishment of the LTCI meant a reduction in social assistance costs at the local level—from € 9 billion a year in 1994 to € 3.5 billion a year in 1997 and, within the health insurance system, an estimated € 3.3 billion due to the abolition of the long-term care support and the reduction of hospital days (Federal Statistical Office 2010; German Federal Parliament 1993; see Appendix 1, Table 6.2–6.4). Despite the reduction, the introduction of the LTCI resulted in a considerable expansion of the available funds—providing a total of additional € 15.94 billion within the framework of the “social” Scheme and € 2.10 billion within the framework of the “private” scheme in 1997 (see Appendix 1, Table 6.2–6.4, explanation on the division between social and private LTCI see below).

The final construction of the funding scheme can be viewed as a compromise between the various relevant actors, including political parties and social partners embedded in a distinct institutional framework. At the beginning of the policymaking process, the introduction of a social insurance scheme, compulsory private insurance schemes, and more rarely, a tax-based system were each proposed by different actors. Due to the expected high fiscal burden related to the reunification process, a tax-based system was regarded as unrealistic. Various organizations, including the Liberal Party (which was in office with the Christian Democratic Party at the central level), employers’ organizations, the private insurance industry, and (for a time) the federal state Baden-Württemberg, favored a private insurance solution emphasizing individual responsibility. Others, including the Christian Democratic Party (led by Minister Norbert Blüm), the Social Democratic Party with the social expert Rudolf Dreßler, and most of the trades unions, opted for a social insurance solution. Those advocating for the social insurance model insisted on the necessity of redistribution between societal groups inherent in such a scheme (Behning 1999; Meyer 1996).

As the Council of the Federal States had to approve the new law, a Working Group was set up during the policymaking process, made up of (Social Democratic) members of the Council of the Federal States and representatives of the federal

Ministry of Social Affairs—in fact, a Grand Coalition—to work out a proposal.¹ In the end, owing to the increasing pressure of the Christian Democratic Party, the Liberal Party agreed to a social insurance scheme under the proviso that individual responsibility and market orientation would be strengthened (Behning 1999; Meyer 1996).

The final proposal was worked out by the federal government, supported by experts of the social assistance authorities and the health insurance funds responsible for the existing social schemes (Meyer 1996). The LTCI combined traditional features of German social policy with an emphasis on individual responsibility of the insured party and cost containment measures:

- In Germany, social insurance contributions are traditionally shared in equal parts by employers and employees. In this case, the employers' organizations fought successfully to be compensated for their share of the contribution with the abolishment of a bank holiday, a considerable departure from the German social insurance system (Landenberger 1994). The abolishment of the bank holiday was accepted as a compromise after a year of negotiations between the unions and the Social Democratic Party on one hand and the federal government and the employers' organizations on the other hand. The latter first suggested the introduction of "waiting days" in health insurance, which met strong resistance (Meyer 1996).²
- At the beginning of the policy-making process, a wide range of actors supported a social insurance scheme covering a significant proportion of the population to strengthen redistribution. However, as noted above, two LTCIs were established, one social and one private, which correspond with the division of social and private insurance funds within the health care system (see new debates on funding below).
- In contrast to the social health insurance system, the contribution rate to the insurance was fixed by law (1.7 % of gross earnings up to a certain threshold) and was valid for all social long-term care insurances funds. Within private insurance funds, the contribution rate fixed by law defines the ceiling, i.e., private insurance funds may only define a lower contribution rate. The corresponding incomes of the funds are defined as a ceiling of expenditure and thus incomes of the insurances, and not care needs, determine the public support available. The contribution rate is strongly related to the cost containment goal of the insurance scheme and also reflects the more critical attitude toward welfare state expenditure, which dominated debates at the beginning of the 1990s (for the debates on funding in a greater detail, see Theobald 2011).

¹ During this time period, the Conservative–Liberal government did not control the majority of votes in the Council of the Federal States and had to negotiate the shape of the new policy scheme with the Social Democratic Party (see Appendix 2, Table 6.5).

² In Germany, in case of illness, employees receive an economic compensation directly from the first day of the period of illness (at the beginning 100 % of the earnings). The introduction of waiting days means that at the beginning of this period the first or even more days (waiting days) are no longer covered by an economic compensation. While this period is financed fully by employers, the introduction of waiting days would save costs.

Since the mid-2000s, various concerns, including deficits within the social insurance scheme, expectations about the impact of demographic change, and the need to adapt the lump sum benefits due to service cost increases, together fueled an intense debate on a sustainable funding system for the future. During the debate, contrasting ideas were put forward that would mean a significant departure of the existing principles.

The division of social and private long-term care insurances resulted in two distinct branches, i.e., private insurance funds covering mainly the population on the upper-income scale (11 % of population) and social funds insuring the rest of the population (88 %). Due to the interrelationship of social position, health and long-term care risks, the division led to a contrasting economic situation for the two groups (Borchert and Rothgang 2008; Theobald 2004; Rothgang 2011). While the private insurance schemes experienced considerable surplus, the social schemes were at risk of deficit (see Appendix 1, Tables 6.2–6.4). Since 2004, the debate on the contrasting situations of social and private insurances has led to demand for the introduction of a “Bürgerversicherung (Citizen’s Insurance)” by the Social Democratic, Green, and Left-Wing parties, as well as the unions and the Left-Wing welfare associations.

The debate on the construction of a Bürgerversicherung focuses on three different models (see Theobald 2011):

1. The whole population should be covered by one social insurance scheme to avoid the construction of two branches with different risk structures.
2. Besides wages, other sources of income (stock market trading, etc.) should be considered by the calculation of the insurance contributions.
3. As an alternative to the construction of one social insurance scheme, balance payments should be transferred from private to social LTCI.

In general, the “Bürgerversicherung” would aim to harmonize the different economic situations of the private and social long-term care insurances, enables possibly a reduction of the insurance contributions and may be used to increase support for people with dementia.³ In contrast, the Christian Democratic and Liberal parties, as well as the employers’ organizations, reject the concept of a Bürgerversicherung, favoring instead a capital funding model, or at least the introduction of an additional capital-funded component within the social insurance framework.

The options for reform have been impeded by the Grand Coalition at the federal level since 2005 as well as a division of power between the Conservative–Liberal federal government and the Council of the Federal States since 2010 (see Appendix 2, Table 6.5). In order to improve the economic situation and to enable an increase of the benefits, the Grand Coalition (2005–2009) agreed to accept an increase of the contribution rate to 1.95 % of the gross earnings—a general increase for the first time since the introduction. Before, in 2005, based on a judgment of the Federal Constitutional Court, the contribution was raised by 0.25 % for childless adherents. The general increase of the contribution rate is expected to secure sound funding despite an increase of benefits (2008, 2010, 2012) until 2014–2015 (Bayern 2008; see Appendix 3, Table 6.6).

³ For an overview of this debate, see Lüngen and Büscher 2007.

6.3 Definition of Social Rights: Universalism and Cost Containment

The provision of universal public support in order to avoid means testing and the related risk of impoverishment of the middle classes in a situation of care dependency can be viewed as the second significant goal for the introduction of the LTCI. During the process of policymaking, however, universal social rights were increasingly discussed in terms of how they related to funding risks and cost containment concerns (Behning 1999; Meyer 1996).

In the end, the various actors involved in the policymaking process defined social rights to reflect both universalism and cost containment policies. It was agreed that both goals should be achieved through the way in which various elements of the scheme were defined, namely the level of support (which stipulated a considerable amount of private responsibility); the type of benefits (including cash benefits); and the thresholds of care needs. As outlined below, these definitions were intensely debated during the policymaking process and remain valid today, though the effects related to the definition of the threshold—in particular the limited support related to dementia—led to an amendment of the policy scheme.

6.3.1 Level of Benefits

At the beginning of the debate, most of the political and social actors involved argued that funding for long-term care should be comparable to the comprehensive funding level for health care. Within the debate, however, the high expenditure on the comprehensive social insurance scheme in the Netherlands and the high public expenditure related to the Statutory Health Care Insurance in Germany were recognized as indicators of the financial obstacles of a more comprehensive social insurance scheme (see Behning 1999; Meyer 1996).

During the final negotiations between the Christian Democratic and Liberal federal government and the Social Democratic Party (the leading party of the Council of the Federal States), it was agreed that the LTCI should only provide basic funding, i.e., a defined lump sum benefit not covering all of the care needs strictly defined by the level of care dependency and the type of support. The nonprofit associations that viewed themselves as advocates for beneficiaries and which were responsible for the provision of most care services at the time, finally acceded to the principle of a basic funding scheme. However, they claimed success (even against the municipalities as financiers) in gaining the availability of supplementary social assistance benefits to fully cover the care needs for beneficiaries with lower incomes after means testing (Meyer 1996).

Since the introduction of the LTCI, public debate on the principle of basic funding has only recently been laid to rest. In representative surveys of both the German and wider European populations, respondents expressed an appreciation for public

financial support in a situation of long-term care needs and a sizable minority (45 %) even appeared supportive of a full funding system (Alber and Köhler 2004; Runde et al. 2003). The level of benefits was increased for the first time in 2008 with the reform of the LTCI. Before this, the nonadaptation of the benefits to the increasing service costs led to a loss in purchasing power of 18.8 % relative to the Consumer Price Index and to an increase of beneficiaries relying on social assistance benefits (Schneider and Reyes 2007).

6.3.2 *Types of Benefits*

As noted earlier, the definition of each of the various types of benefits is related to cost containment policies as well as ideas on the interplay of family and formal care provision. Thus, in the policymaking process, the provision of “in-kind services only,” comparable to the health care insurance schemes, was rejected by almost all actors as inconsistent with the existing patterns of care arrangements. The costs related to in-kind benefits only were also judged to be insupportable. In particular, the health insurance funds and the unions opted for a more service-oriented system (Behning 1999; Meyer 1996). Civil society organizations, e.g., pensioners or disability groups, welfare associations, and market liberals advocated for the introduction of cash payments only to increase the autonomy of beneficiaries—albeit on different levels. Most of the actors, including members of the Christian Democratic and Social Democratic parties, favored a mixed system with both cash benefits (as a way of acknowledging the importance of informal care provision) and care services to guarantee high-quality care. Finally, long-term care was defined as being provided by a combination of informal family care, professional home-based and institutional care. A corresponding mixed system of public benefits was thus introduced, consisting of a lower-level cash benefit to acknowledge family care provision but to avoid the “economization of family care” and also higher benefits oriented toward the more costly home-based and residential services. The higher benefit level for residential services aimed to reduce the dependency of the beneficiaries on complementary social assistance benefits (Meyer 1996).

The mix of public benefits is still valid. Based on a pilot project (2005–2008), a new type of benefit, the “personal budget,” has temporarily been added in seven selected regions in Germany. Modeled partly on the Dutch system (see Arntz and Spermann 2004; Arntz et al. 2006; <http://www.pflegebudget.de>), with the personal budget the home-based service-related benefit is directly provided to the beneficiaries as a regulated cash benefit. The beneficiaries can use it to purchase legal assistance and services, even those outside the regular care infrastructure, but it is not possible to transfer it to relatives. This benefit aimed to offer greater flexibility, greater user choice when using legal types of services and paid assistance. With the exemption of some professional care service providers, the type of support was welcomed by most social actors in the area. Around 900 LTCI beneficiaries participated in the pilot project. Subsequent evaluations found an average increase in care hours, which

improved the difficult care situation of beneficiaries without a stable social or family network. The improvement is mainly based on an increase of support by paid care services on lower social security standards (Blinkert and Klie 2006b).

6.3.3 *Definition of the Threshold*

Due to cost containment considerations, access to benefits requires a considerable level of care dependency as defined by the amount of help needed. The need for support with household services only is not covered within the insurance framework, i.e., users must require at least 45 minutes of care for personal hygiene, eating, or mobility to be supported by insurance benefits. Moreover, the support is oriented toward people with functional impairment and neglects psychological or cognitive impairments, above all dementia. Despite a considerable increase of beneficiaries, the proportion of older adults (65+) receiving benefits is quite low overall; only 11.5 % in 2009 (Federal Statistical Office 2011).

Both the functional orientation of the insurance and the neglect of certain difficulties, particularly dementia, created debate following the introduction of the insurance. Although all actors—in particular The Alzheimer Society, welfare associations, academic experts, and politicians—agreed on the need to increase the support for those with dementia disorders, cost consideration has so far only allowed a step-by-step improvement of the situation.

Three steps can be distinguished:

1. In 2002, the Complementary Nursing Act was drawn up to provide more comprehensive support for sufferers and to alleviate the heavy care burden of informal carers on the basis of an additional lump sum. According to the law, beneficiaries suffering from dementia can receive up to € 460 per annum to unburden care providers. The benefits may be used to purchase day care or short-term care services, as well as low-threshold services such as care in small groups on an hourly basis provided by professionals and volunteers (see Sect. 6.4.3 below). While the reform was welcomed by social actors, the level of the benefit has been criticized as being too low and not enough to relieve the care burden of informal carers or to improve the caring situation (Theobald 2004). In 2006, only 17.5 % of the beneficiaries eligible for the benefits applied for the scheme. This low take up rate was partly motivated by the low level of benefits and the bureaucratic procedures (Sauer and Wißmann 2007).
2. The still disadvantaged situation of beneficiaries, particularly those with cognitive impairments, as well as the low use of benefits, led to an amendment of the regulation. With the 2008 reform, the benefit was increased from € 460 per annum to € 1,200 and in exceptional cases up to € 2,400 per annum and the eligibility criteria were changed. With the reform, even applicants who were not eligible for the first level of care dependency but who fulfilled the criteria defined by the Complementary Nursing Act received at least this lump sum (Bayern 2008). The reforms resulted in an increase of benefit use (Rothgang et al. 2010).

3. The extension of the definition of care dependency within the framework of the Complementary Nursing Act in 2002 (reformed in 2008) has been welcomed by most social actors, though it is only viewed as a first step. At the moment, there is an ongoing reform process, which aims at establishing a new definition of care dependency within the LTCI, including cognitive and mental impairments. To date, an expert group has already recommended a new definition of care dependency and corresponding assessment instruments based on standards in nursing science or gerontology (Wingenfeld et al. 2008a, b). While the political and social actors generally agree on the basic ideas and construction of the new instrument, the expected increase of the number of beneficiaries and the corresponding issue of funding together dominate the debate (Rothgang et al. 2008). There is no indication of whether, when, or how reform will take place.

6.4 Care Provision: Interplay of Family, State, Market, and Welfare Associations

A third significant goal of the LTCI was to promote the use of home or domestic care instead of residential care services, based on a certain interplay of formal and informal care provision. According to the law governing the scheme, the role of the family in care provision should be promoted and formal care provision should be organized more efficiently. Against this background, the law on the LTCI provided the starting point for a restructuring of the interplay of different social sectors—state, family, market, and welfare associations—with regard to care provision. The state adopted a regulatory role by defining the mode of the interplay of different societal sectors, as well as types of care work and the qualification levels of carers. Yet, in the course of the introduction—with the exemption of marketization—only basic ideas have been defined. Regulations and laws since then have elaborated on the ideas and have tried to adapt them to the (un)intended effects of long-term care insurance in general.

6.4.1 Emphasis on Informal Family Care Provision

The LTCI draws on predominantly traditional values regarding the significance of family care, which should be maintained by the availability of cash payments and care services (Behning 1999; Meyer 1996). A corresponding mixed system of public benefits was thus implemented, aiming to provide greater freedom of choice for the beneficiaries (see Sect. 6.3.2 above). The emphasis on family care, the support of informal carers, and quality control still correspond with the ideas of the majority of the population (Alber and Köhler 2004; Runde et al. 2003).

Within the framework of the LTCI, a largely family-oriented care strategy has emerged, which is confirmed by the take up rates of homecare services, cash

payments, and residential care services among the beneficiaries. The majority of beneficiaries are cared for at home mainly within the family context supported by cash payments. Despite the dominance of cash payments, the use of home and residential care services has increased since the introduction of the scheme. In contrast to the goal of the LTCl, the proportion of beneficiaries using residential care services was not reduced but increased from 554,000 (27.7 % of beneficiaries) in 1999 to 717,490 (30.7 % of beneficiaries) in 2009 (Federal Statistical Office 2001; 2011). The increasing use of residential care services can be explained by population aging based on an almost stable age-related quota of beneficiaries voting for residential care benefits (Rothgang et al. 2009).

The largely family-oriented strategy is related to considerable differences in care arrangement patterns dependent on gender, socioeconomic class, living situation, social or family network, and adherence to certain migrant groups. The use of cash payments or professional services can be considered as one indicator for the unequal patterns of care arrangements. Generally, care services are more often used by beneficiaries who live alone with precarious social and family support, or else by older adults from the higher socioeconomic strata; users are also more likely to be German nationals than certain migrant populations (Baykara-Krumme and Hoff 2006; Blinkert and Klie 1999; Heusinger and Klünder 2005; Klie and Blinkert 2002; Okken et al. 2008). The distinct care arrangements are not related to a balanced care situation, where one type of support is replaced by another. On the contrary, it 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 % of care recipients reported a lack of care provision (Blinkert and Klie 2006a, b; Blinkert and Klie 2008; Schneekloth 2006).

These different patterns emerge in an interaction of the design of the benefits, the social and economic situation, as well as cultural values of the beneficiaries, respectively, their families. The lump sum service benefits not covering the costs of service provision and the nonadaptation of the prices to the income of the beneficiaries render it particularly difficult for beneficiaries with lower incomes to use care services. This incentive is even strengthened by the idea that long-term care should be provided without any costs by family members within this social group. Beneficiaries with a stable family or social network turn to their informal networks (Blinkert and Klie 1999; Heusinger and Klünder 2005). Moreover, recent studies reveal the impact of the social and family network on care provision, i.e., the amount of care provision proved to be much more dependent on the available social or family network than on the level of care needs (Blinkert and Klie 2008).

The family-oriented care strategy introduced measures to unburden family carers, particularly those caring for someone with dementia such as increasing the available caring time through the use of personal budgets. The strategy also introduced access to case/care management services (see Sect. 6.4.2; Blinkert and Klie 2006a, b; Bayern 2008). In contrast, there are no indications for an increase of benefit levels beyond efforts to counteract the loss of purchasing power (see above), particularly their adaptation to an individual's income or social situation to provide access to more comprehensive service provision.

Moreover, changing labor market policies impact on informal care provision. With the introduction of the insurance, “pension credit points” were introduced, offering care recipients at least 14 hours a week of informal care (and up to 30 hours of employment per week for each carer). The scheme aimed to provide incentives, particularly for women with low qualifications, to take over care responsibilities (Schneider and Reyes 2007). New policy approaches, which promoted the facilitation of care work within the context of paid employment. With the reform in 2008, two leave schemes were established to improve the combination of informal care work and employment. One scheme grants 10 days unpaid leave to allow individuals to organize or adapt a care arrangement. A second scheme enables carers to interrupt their employment on an unpaid basis or to take up part-time work for up to 6 months. In addition, day or night care services can be granted if the services enable participation in the labor market (Bayern 2008).

6.4.2 Formal Care Provision: Market, Cost Efficiency, and Quality Assurance

Prior to the introduction of the LTCI, nonprofit providers delivered care in close cooperation with the municipalities, often supported by different types of state subsidies (see Burau et al. 2007). Following the introduction of the scheme, the long-lasting privileged position of the nonprofit providers was abandoned and now both for-profit and nonprofit providers have the opportunity to deliver care on equal terms. This change was based on the philosophies of both market-based principles and user choice. The law prescribes the right of insurance providers to negotiate a contract on care offers and prices with every care provider. However, it also obliges insurance companies to accept every provider that fulfills the defined preconditions—qualification levels of the care workers and cost-efficient, high-quality care provision—without regard to the market situation, i.e., the care providers already established and expected care provision. The regulations aimed to allow insurance companies to oversee efficient care delivery by care providers, and also to promote competition between care providers, thus ensuring both cost-efficient prices and greater user choice between care providers (Landenberger 1994; Meyer 1996; Schmidt 2002). Welfare and homecare associations were skeptical about the basic assumption that an increase of market competition would improve care quality without a cost increase.⁴

⁴ Five big welfare associations—Workers Welfare Federal Association (Arbeiterwohlfahrt), German Caritas (Deutscher Caritasverband—related to the Catholic Church), Diakonie of the Protestant Church in Germany (Diakonisches Werk der Evangelischen Kirche in Deutschland), German Red Cross (Deutsches Rotes Kreuz) and The Paritätische (Paritätischer Wohlfahrtsverband—association of social movements)—were traditionally developing and providing care support in close cooperation with the state mainly on local levels. The close cooperation changed significantly with the introduction of LTCI and the opening-up of a care market. As significant social actors they were involved above all in social-political debates on the construction of Long-term Care Insurance (Sachße 2011; Meyer 1996).

In order to avoid price competition between for-profit and nonprofit organizations, the welfare associations (see Footnote 3) successfully requested quality standards as a further goal of care provision (Meyer 1996; in greater detail on policy process Theobald 2012). However, as outlined below, the assumptions of welfare associations that they could succeed vis-à-vis for-profit providers on a care market based on care quality proved to be illusory.

While market principles were already clearly defined with the introduction of the insurance, the quality of service provision has been regulated to a greater extent since then. In 2002, the law on Quality Assurance and Consumer Protection came into effect, which obliged providers to conduct ongoing quality assurance measures and to comply with expert standards established on the national level. Furthermore, the Medical Services of the Statutory Health Insurance Funds conduct external quality control measures. The reform of the law in 2008 enabled spot check quality controls at least once a year from 2010 and also required inspection results to be published in a transparent and accessible manner. Although the provider organizations welcomed quality assurance measures, they criticized the increasing documentation and bureaucratization of care provision.

The basic rationale for the expansion of the care infrastructure included the need to open up the care market to different providers on equal terms and offer users greater choice between service providers. Opportunities to instigate “social planning” to achieve an adequate care infrastructure were seen as a less important criterion (Landenberger 1994). In contrast to the introduction of a care market, the neglect of social planning by state authorities fed an intense debate by the actors involved (see Meyer 1996). Both the Christian Democratic Party and the Social Democratic Party favored a more decisive role for social planning, while the Liberal Party prevailed with the market orientation as a precondition to accept a social insurance scheme in general. In the last round of negotiations between the federal government and the Council of the Federal States, user demand, free choice, competition as principles for the expansion of care services were confirmed as fundamental requirements for the new scheme. However, the obligation of the Federal States to secure an adequate care infrastructure (related to the right to subsidize investments of private nonprofit and for-profit care providers on equal terms) provided some space for social planning (see Bureau et al. 2007). The opportunity to subsidize the care infrastructure has mainly been used in relation to residential or semi-residential care facilities (Theobald 2004).

Since the introduction of the LTCl, the proportion of private for-profit home and residential care providers has steadily increased. In 2009, 61.5 % of homecare service providers were private for-profit organizations. With 35 users on average for for-profit providers in comparison with 64 users on average for nonprofit providers, for-profit providers serve fewer users than the nonprofit organizations. Regional differences are manifest in that private for-profit providers dominate in the big cities as well as in the new Federal States. However, only 39.9 % of residential care providers are private for-profit organizations and 54.8 % nonprofit organizations (Federal Statistical Office 2011).

While the principle of marketization is rarely questioned in Germany, many have voiced concerns about the capacity of frail older adults to act as consumers. Others have also voiced concerns about the work situation of care workers (discussed in greater detail in Sect. 6.4.3). Market orientation with the range of service providers is named as one reason for the difficulties for the users to establish an integrated care arrangement. The 2008 LTCI reform required the development of care bases—the so-called “Pflegestützpunkte,” i.e., single-access points on the local levels, which should provide information on LTCI or available services, etc. up to case management services, in cooperation with different actors. This was followed in 2009 by the introduction of an individual right to case/care management services exists, free of charge for all (potential) beneficiaries of the LTCI (Bayern 2008).

6.4.3 Carers: Care Activities, Qualification Levels, and Working Situation

The restructuring of the funding and provision of long-term care for older people, as well as the definition of social rights, has led to a process of deskilling and reskilling of care work, an expansion of the labor market area and a deterioration of working and employment conditions (see Burau et al. 2007). The introduction of the LTCI promoted the professionalization of care activities. In contrast to the health care insurance, within the framework of the LTCI, nurses have the right to assess independently on the level of care dependency. In fact, today most assessments are conducted by nurses. In addition, the head of a care service provider, mainly nurses or elder carers, have the right to independently develop care provision and negotiate fees and conditions for care provision funded through the LTCI.

The LTCI defined the qualification levels and forms of cooperation between different types of carers. Accordingly, long-term care has to be provided under the guidance of a nurse or elder (head) carer in charge and other carers such as nurse assistants, volunteers, and family carers who deliver basic daily care. With the increasing involvement of nurse assistants in formal care provision, and the higher status given to informal family care, professional organizations feared the deskilling of the sector (Welti 1999a, b). In contrast, the five nonprofit welfare associations supported the recognition of informal family care and the involvement of voluntary workers as a fundamental element of the care provision, while simultaneously advocating the need for professional care services (Meyer 1996). Where no professional services are involved, a mandatory visit by a professional nurse or elder carer was introduced as a mechanism to secure care quality.

Since the introduction of the LTCI, further laws and regulations have aimed to further restructure care provision—in particular, the cooperation between comparatively well-qualified care workers and care/nurse assistants, informal carers, and voluntary workers. The new laws or regulations aimed to secure high-quality professional care and the availability of a care infrastructure at “reasonable prices”:

- In 2003, federal occupational training programs for elder carers were standardized. Debates ensued, concerning the content and level of the training as well as the transfer of regulatory competence to the central level. In general, improvement and standardization of occupational training schemes were welcomed by relevant social and political actors, motivated by the demands related to care provision and to secure care quality, the necessity and the chances to increase the status of the activity and thus to attract more care workers (Oelke and Menke 2002).
- In 2002, within the framework of the Complementary Nursing Act, a new type of service was created—low-threshold services such as, e.g., social activities for beneficiaries suffering dementia illness, unburdening services for informal carers, to be provided by voluntary workers under the guidance of a professional carer. The inclusion of that type of service was welcomed by social and political actors alike. Research, however, revealed that such low-threshold services also led to precarious employment conditions in paid care work (Sauer and Wißmann 2007).
- As noted above, a personal budget scheme was offered, which allowed the beneficiaries to use the higher benefit related to homecare services to purchase legal services outside the established care infrastructure. Evaluations showed that the amount of care provision available has increased but simultaneously more precarious employment conditions have emerged (Blinkert and Klie 2006b).

Yet, despite these efforts, the restructuring of care provision has been influenced more by processes of marketization of care provision than by further regulations and by activities of the beneficiaries, particularly their families. Political actors partly reacted to (un)intended effects in order to restructure the development from their own perspective.

The introduction of the LTCI led to the expansion of a formal care labor market and a deterioration of working conditions. The workforce increased from approximately 320,000 care workers in 1995 to 890,283 in 2009.⁵ With a share of 86 % in 2007, care provision is still a female-dominated sector (Federal Statistical Office 2011; Schölkopf 1998). Indeed, the need for flexible working hours, the increase in for-profit providers, and the emphasis on cost containment within the framework of the LTCI have arguably each contributed to a deterioration of employment conditions within the sector LTCI (Oschmianski 2010).

The development of nonstandard employment was selected as one strategy to increase flexibility and lower costs. It is reflected in a rise in different forms of part-time work from 54.2 % in 1995 to 73.2 % in 2009 in homecare and from 39.1 to 66.7 % in residential care. In 2007, 13.8 % of the care workers in both sectors even conducted part-time work with lower social security standards and a further 15.0 % worked less than 19 hours a week (Federal Statistical Office 2009, 2011; Schölkopf 1998). Concerning the qualification levels of the carers, the development is more contradictory. The demand for care services was met with a rise in employment rates for both qualified carers and carers without occupational training (Oschmianski

⁵ Due to the integrated provision of home-nursing and long-term care the home-based care workers are involved in both types of activities and funded partly by the Long-term Care—and the Health Care Insurance.

2010). In 2009, approximately 39.0 % of employees had concluded 3-year occupational training courses as nurses or elder carers: 7.5 % had received training as care assistants, but also around 38.2 % had no (or inadequate) formal occupational training, which meant a decline in fully trained personnel and an increase in care assistants and carers without or with inadequate formal training since 2007. The demand for qualified labor is based on both the mix of services in home care, with 97 % of all providers providing social services, personal care, and home nursing and qualification requirements in residential care with 50 % quota of care workers with an occupational training in nursing care homes (Federal Statistical Office 2009, 2011).

Due to the difficult employment conditions, but also to enable more culturally sensitive homecare provision, the proportion of migrant carers has increased, with an estimated share of 18 % in elder care provision overall. It is comparatively high compared to their share of 7 % in the labor market as a whole. Typically, the migrant care workers, mainly from eastern European countries, Russia, and the Ukraine, live in Germany as citizens or as residents with permanent work permits. In principle, they can draw on the same employment benefits as workers with a German background. There has been very little research on the situation of migrant workers in Germany (Steffen 2009).

The entrance of private for-profit care providers into the market triggered both the lowering of wages and an increase of wage differentials between trained nurses and elder carers and carers without adequate occupational training (Theobald 2004; Dahme and Wohlfahrt 2007). The introduction of a minimum wage scheme in August 2010 (to run until December 2014) aimed to guarantee a certain wage level for care workers employed by a formal care provider who provide personal care, support with eating, or mobility. Care workers employed within private households are not included. 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. The minimum wage scheme was introduced following agreement between the trades unions, employers' organizations, and the Ministry of Labor at the federal level. Employers' groups agreed to the scheme to protect care providers from the new EU member states from with lower cost bases when the borders opened up in May 2011.

The most significant hierarchization between groups of carers can be seen in the emergence of a mainly gray labor market for the provision of household tasks and care work. Since the end of the 1990s, a new segment of the gray care market has emerged: the provision of 24-hour care within the family context by migrant workers mainly from eastern European countries, i.e., the Czech Republic, Poland, and Romania. According to estimates, about 120,000 migrant carers deliver 24-hour home care services in about 60,000 households in Germany (Lutz 2009; Steffen 2009). Migrant carers are mainly hired to take care of severely care-dependent older adults on higher income levels. Families with migrant carers cite lower private costs for care compared to 24-hour formal homecare provision or residential care as incentives to hire a migrant care worker. Furthermore, the wish to remaining living in one's own home despite a high level of care dependency and the need to relieve the burden on family carers encourage individuals to choose this form of care (Lutz 2009; Neuhaus et al. 2009).

In Germany, the bottom-up solution established mainly by middle-class families caused an intensive societal debate and inspired new policies to regulate the situation.

A recruitment scheme was implemented to hire domestic workers to families with dependent members from eastern European countries on a temporary basis until 2005 and thereafter permanently. Homecare providers voted against the introduction of the scheme, citing concerns of care quality and the need to improve formal care provision. Regulations of the recruitment scheme correspond to standard working conditions for domestic workers in Germany. Only since 2010, the provision of basic nursing care such as, e.g., personal care, is allowed. According to the authority responsible for placements, only 3,032 domestic workers were officially employed on this basis of the scheme in 2007. Compared with a gray market care with about 120,000 migrant carers, the law is largely ineffective. Moreover, the agencies use—until now unsuccessfully—regulations related to the EU’s single market project to legitimize the activities (Theobald 2010).

6.5 Conclusion

With the introduction of the LTCI, Germany established a social support system related to long-term care needs. The scheme aimed to combine universalism with cost containment efforts. Indeed, within the scheme, a new type of universalism was created, characterized by comparatively high thresholds, a medium level of support (which declined until the reform of 2008 due to increasing costs of care provision), and cash benefits to maintain family care provision on a lower level. The scheme fundamentally restructured both funding and social care rights and also defined the principles for the reorganization of care provision. The mechanism for change can be described as both “radical change” (in terms of the restructuring of care rights and funding) and “incremental transformation” (related to the reorganization of care provision; see Chap. 1 by cf. Streeck and Thelen 2005).

The mode of funding—social and mandatory private insurance—and the design of social rights were clearly defined in the course of the establishment of the scheme and remain valid today. The extension of social rights to those with dementia can be viewed as the only exception. The main goal of the reform was the creation of a sound funding basis and a corresponding reduction of fiscal constraints on the local levels. Both—mode of funding and the design of social rights—are based on a compromise between mainly political actors on different levels and some social actors. While the Social Democratic and Christian Democratic parties and most social actors were in favor of a social insurance scheme and redistribution, the Liberal Party and the employer organizations preferred a private insurance scheme. The latter accepted the social insurance scheme under the premise that employers’ organizations have to be compensated for their contributions. Moreover, more budget-oriented actors prevailed by introducing a defined lump sum related to care needs and a ceiling related to expenditure. Both significant departures from the traditional German welfare state model were accepted by more support-oriented actors—such as, e.g., the unions—because the reform expanded social rights and significantly improved the care situation.

The LTCI also provided the starting point for the reorganization of the provision of care, which was gradually adapted to new policies and unintended effects of the original scheme. Basically, it aimed to strengthen domestic family care, which corresponds to the normative orientation in society. The reorganization of formal care provision—based on market principles—weakened the status of nonprofit service providers as the traditional main providers. The efforts of the nonprofit associations to prevail on the market on the basis of care quality were not successful. Indeed, state control was increased via quality assurance measures. The LTCI also brought about an expansion of formal care work on different qualification levels, impulses for a professionalization of care work but also for a deterioration of employment conditions. Finally, the orientation of home-based care services toward bodily care triggered the development of a semiformal, gray care market related to more time-consuming care activities or household assistance.

The LTCI, which is related to the improvement of the care situation, is widely supported in Germany. Basic principles of the scheme, including free choice and the emphasis on family care, correspond with traditional societal values. However, despite an increasing public support, various aspects of the scheme, including the design of social rights; the mix of private and public funding; and the organization of care provision have resulted in care gaps for certain groups and emerging inequalities among beneficiaries dependent on gender, socioeconomic status, living situation, migrant status, and type of care need. Moreover, the goal to reduce the use of residential care services has not been achieved.

Appendix 1: Financial Development of the Social and Private Long-Term Care Insurance As Well As the Long-Term Care Assistance within the Federal Law on Social Assistance

Table 6.2 Social long-term care insurance (in billion euros). (Adapted from: <http://www.bmg.bund.de/pflege/pflegeversicherung/zahlen-und-fakten-zur-pflegeversicherung.html>)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
Income	8.41	12.04	15.94	16.00	16.32	16.54	16.81	16.98	16.86	16.87	17.49	18.49	18.02	19.77	21.31
Expenditure	4.97	10.86	15.14	15.88	16.35	16.67	16.87	17.36	17.56	17.69	17.86	18.03	18.34	19.14	20.33

Table 6.3 Private long-term care insurance (in billion euros). (Adapted from Private Health Care Insurances [PKV] 2003, 2010)

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
Income	1.66	2.10	2.10	2.10	1.97	2.01	1.96	1.99	1.85	1.87	1.87	1.87	1.88	1.97	2.07
Expenditure	0.29	0.44	0.44	0.44	0.46	0.47	0.49	0.50	0.52	0.53	0.55	0.56	0.58	0.62	0.67

Table 6.4 Long-term care assistance (Hilfe zur Pflege) within the federal law on social assistance: expenditure and number of beneficiaries. (Adapted from Federal Statistical Office [Statistisches Bundesamt] 2010)

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
Expenditure (in million euro)	9.062	8.934	7.100	3.500	3.001	2.901	2.876	2.905	2.943	3.005	3.142	3.152	3.120	3.217	3.262
Beneficiaries (in thousands)	563	574	426	328	289	310	324	332	313	323	328	344	366	372	397

Appendix 2: Federal-Level Governments and Majorities of Votes Within the Council of Federal States

Federal Governments:

1982–1998: Conservative—Liberal government (Christian Democratic Party/Christian Social Party (Bavaria), Liberal Party).

1998–2005: Red—Green government (Social Democratic Party/Green Party).

2005–2009: Grand Coalition (Christian Democratic Party/Christian Social Party (Bavaria), Social Democratic Party).

2009–2013: Conservative—Liberal government (Christian Democratic Party/Christian Social Party (Bavaria), Liberal Party).

Council of the Federal States

Three Groups Within the Council:

1. Left-Wing-oriented federal states (Social Democratic, Green, and/or Left-Wing parties in office).
2. Balanced states (coalitions between Conservative–Liberal and Left-Wing-oriented parties in office). Related to controversial decisions, the balanced states typically abstain from voting.
3. Conservative–Liberal Federal States (Christian Democratic Party, Christian Social Party (Bavaria), and/or Liberal Party in office).

Table 6.5 Number of votes and majorities

	Left-wing oriented federal states	Balanced federal states	Conservative liberal federal states	Total
Since May 2011	30	14	25	69
2010/II–2011	21	14	34	69
2010/I	15	17	37	69
2009	11	22	36	69
2008	11	19	39	69
2007	8	22	39	69
2006	7	19	43	69
2005/II	7	19	43	69
2005/I	17	15	37	69
2004	17	11	41	69
2003	23	11	35	69
2002	27	11	31	69
2001	26	15	28	69
2000	26	15	28	69
1999	38	15	16	69
1998	35	18	16	69
1997	32	21	16	69
1996	32	27	10	69
1995	31	27	10	68
1994	23	24	21	68

Appendix 3

Table 6.6 Increase of benefits. (Adapted from SGB XI, Bayern 2008)

	Care dependency level		
	I (Considerable)	II (Substantial)	III (Most substantial)
<i>Cash payments: per month (€)</i>			
July 2008	215.00	420.00	675.00
January 2010	225.00	430.00	685.00
January 2012	235.00	440.00	700.00
<i>Home-based care services: per month (€)</i>			
July 2008	420.00	980.00	1470.00
January 2010	440.00	1040.00	1510.00
January 2012 (extraordinary high need of care 2008–2012)	450.00	1100.00	1550.00 (1918.00)
<i>Residential care services: per month (€)</i>			
July 2008	1023.00	1279.00	1470.00 (1750.00)
January 2010	No increase	No increase	1510.00 (1825.00)
January 2012 (extraordinary high need of care)	No increase	No increase	1550.00 (1918.00)

References

- Alber, J., & Köhler, U. (2004). *Health and care in an enlarged Europe*. Luxembourg: European Foundation for the Improvement of Working Conditions.
- Arntz, M., & Spermann, A. (2004). Die internationale Diskussion. Nationale und internationale Konzepte in der Praxis. In T. Klie & A. Spermann (Eds.), *Persönliche budgets—Aufbruch oder irrweg?* (pp. 15–39). Hannover: Vincentz-Netzwerk.
- Arntz, M., Michaelis, J., & Spermann, A. (2006). Reforming long-term care in Germany. Preliminary findings from a social experiment with matching transfers. *Schweizerische Zeitschrift für Volkswirtschaft und Statistik*, 142(S), 37–42.
- Baykara-Krumme, H., & Hoff, A. (2006). Die Lebenssituation älterer Ausländerinnen und Ausländer in Deutschland. In C. Tesch-Römer, H. Engstler, & S. Wurm (Eds.), *Altwerden in Deutschland. Sozialer Wandel und individuelle Entwicklung in der zweiten Lebenshälfte*. Berlin: Verlag für Sozialwissenschaften.
- Behning, U. (1999). *Zum Wandel der Geschlechterrepräsentationen in der Sozialpolitik*. Opladen: Leske und Budrich.
- Blinkert, B., & Klie, T. (2008). Die Versorgungssituation pflegebedürftiger Menschen vor dem Hintergrund von Bedarf und Chancen. In U. Bauer & A. Büscher (Eds.), *Soziale Ungleichheit und Pflege* (pp. 238–255). Wiesbaden: VS Verlag.
- Blinkert, B., & Klie, T. (1999). *Pflege im sozialen Wandel*. Hannover: Vincentz.
- Blinkert, B., & Klie, T. (2006a). Die Zeiten der Pflege. *Zeitschrift für Gerontologie und Geriatrie*, 39, 202–210.
- Blinkert, B., & Klie, T. (2006b). Der Einfluss von Bedarf und Chancen auf Pflegezeiten in häuslichen Pflegearrangements. *Zeitschrift für Gerontologie und Geriatrie*, 39, 423–428.
- Borchert, L., & Rothgang, H. (2008). Soziale Einflüsse auf das Risiko der Pflegebedürftigkeit älterer Männer. In U. Bauer & A. Büscher (Eds.), *Soziale Ungleichheit und Pflege* (pp. 215–237). Wiesbaden: VS Verlag.

- Bureau, V., Theobald, H., & Blank, R. H. (2007). *Governing home care: A cross-national comparison*. Cheltenham: Elgar.
- Campell, A. L., & Morgan, K. J. (2005). Federalism and the politics of old-age care in Germany and the United States. *Comparative Political Studies*, 38(8), 1–28.
- Dahme, H. J., & Wohlfahrt, N. (2007). Vom Korporatismus zur strategischen Allianz von Sozialstaat und Sozialwirtschaft: Neue „Sozialpartnerschaft“ auf Kosten der Beschäftigten. In H. J. Dahme, A. Trube, & N. Wohlfahrt (Eds.), *Arbeit in sozialen Diensten: flexibel und schlecht bezahlt?* (pp. 22–34). Baltmansweiler: Schneider-Verlag Hohengehren.
- Federal Statistical Office (Statistisches Bundesamt). (2001). *Pflegestatistik*. Wiesbaden: Federal Statistical Office.
- Federal Statistical Office (Statistisches Bundesamt). (2009). *Pflegestatistik*. Wiesbaden: Federal Statistical Office.
- Federal Statistical Office (Statistisches Bundesamt). (2010). *Statistik der Sozialhilfe*. Wiesbaden: Federal Statistical Office.
- Federal Statistical Office (Statistisches Bundesamt) (2011). *Pflegestatistik*. Wiesbaden: Federal Statistical Office
- German Federal Parliament (Deutscher Bundestag). (1993). *Entwurf eines Gesetzes zur sozialen Absicherung des Risikos der Pflegebedürftigkeit (Pflege—Versicherungsgesetz—PflEGV), Drucksache 12/5262*. Bonn: Deutscher Bundestag—12 Wahlperiode.
- Heusinger, J., & Klünder, M. (2005). „Ich lass mir nicht die Butter vom Brot nehmen!“ *Aushandlungsprozesse in häuslichen Pflegearrangements*. Frankfurt/Main: Mabuse-Verlag.
- Klie, T., & Blinkert, B. (2002). Pflegekulturelle Orientierungen. In C. Tesch-Römer (Ed.), *Gerontologie und Sozialpolitik* (pp. 197–217). Stuttgart: Kohlhammer.
- Landenberger, M. (1994). Pflegeversicherung als Vorbote eines anderen Sozialstaats. *Zeitschrift für Sozialreform*, 40(3), 314–342.
- Lutz, H. (2009). Migrantinnen in der Pflege in deutschen Privathaushalten. In C. Larsen, A. Joost, & S. Heid (Eds.), *Illegale Beschäftigung in Europa. Die Situation in Privathaushalten älterer Personen* (pp. 41–52). München: Rainer Hampp.
- Bayern, M. D. K. (2008). *Prisma Gesundheit. Die soziale Pflegeversicherung*. Landsberg: Ecomed Medizin.
- Meyer, J. A. (1996). *Der Weg zur Pflegeversicherung*. Frankfurt/Main: Mabuse.
- Neuhaus, A., Isfort, M., & Weidner, F. (2009). *Situation und Bedarfe von Familien mit mittel- und osteuropäischen Haushaltshilfen*. Köln: Deutsches Institut für angewandte Pflegeforschung e. v.
- Oelke, U., & Menke, M. (2002). Qualifizierung des Pflegepersonals. In G. Igl, D. Schiemann, B. Gerste, & J. Klose (Eds.), *Qualität in der Pflege* (pp. 79–96). Stuttgart: Schattauer.
- Okken, P. K., Spallek, J., & Razum, O. (2008). Pflege türkischer Migranten. In U. Bauer & A. Büscher (Eds.), *Soziale Ungleichheit und Pflege* (pp. 396–422). Wiesbaden: VS Verlag.
- Oschmianski, H. (2010). Wandel der Erwerbsformen in einem Frauenarbeitsmarkt. Das Beispiel Altenpflege. *Zeitschrift für Sozialreform*, 56(1), 29–55.
- Private Health Care Insurances (PKV). (2003). *Zur Versorgung der Versicherten im Rahmen der Pflegeversicherung*. Unveröffentlichte Statistik. Köln: Verband privater Krankenversicherungen. (Figures 1995–1998)
- Private Health Care Insurances (PKV). (2010). *Zahlenbericht der privaten Krankenversicherung 2009/2010*. Köln: Verband privater Krankenversicherung. (Figures 1999–2009)
- Rothgang, H., Holst, M., Kulik, D., & Unger, R. (2008). *Finanzielle Auswirkungen der Umsetzung des neuen Pflegebedürftigkeitsbegriffs und des dazugehörigen Assessments für die Sozialhilfeträger und die Pflegekassen*. Bremen: Abschlussbericht.
- Rothgang, H. (2011). Solidarität in der Pflegeversicherung: Das Verhältnis von Sozialer Pflegeversicherung und Privater Pflegepflichtversicherung. *Sozialer Fortschritt*, 60(4–5), 81–87.
- Rothgang, H., Kulik, D., Müller, R. & Unger, R. (2009). *GEK-Pflegereport 2009. Schwerpunktthema: Regionale Unterschiede in der pflegerischen Versorgung*. Schwäbisch Gmünd: GEK-Gmünder ErsatzKasse.
- Rothgang, H., Iwansky, S., Müller, R., Sauer, S., & Unger, R. (2010). *Barmer GEK Pflegereport 2010. Schwerpunktthema: Demenz und Pflege*. Schwäbisch Gmünd: Barmer GEK.

- Runde, P., Giese R., & Stierle, C. (2003). *Einstellungen und Verhalten zur häuslichen Pflege und zur Pflegeversicherung unter den Bedingungen des gesellschaftlichen Wandels. Bericht, Universität Hamburg: Arbeitsstelle Rehabilitations- und Präventionsforschung*. Hamburg: Universität Hamburg.
- Sachße, C. (2011). Zur Geschichte sozialer Dienste in Deutschland. In A. Evers, R. G. Heinze, & T. Olk (Eds.), *Handbuch Soziale Dienste* (pp. 94–144). Wiesbaden: Verlag für Sozialwissenschaften.
- Sauer, P., & Wißmann, P. (2007). *Niedrigschwellige Hilfen für Familien mit Demenz*. Frankfurt: Mabuse-Verlag.
- Schmidt, R. (2002). Die neue Pflegelandschaft: Erste Konturen und Steuerungsprobleme. In C. Tesch-Römer (Ed.), *Gerontologie und Sozialpolitik* (pp. 137–162). Stuttgart: Kohlhammer.
- Schneekloth, U. (2006). Entwicklungstrends beim Pflege- und Hilfebedarf in Privathaushalten—Ergebnisse der Infratest-Repräsentativerhebung. In U. Schneekloth & H.-W. Wahl (Eds.), *Selbständigkeit und Hilfebedarf bei älteren Menschen in Privathaushalten* (pp. 57–102). Stuttgart: Kohlhammer.
- Schneider, U., & Reyes, C. (2007). Mixed blessings: Long-term care benefits in Germany. In C. Ungerson & S. Yeandle (Eds.), *Cash for care in developed welfare states* (pp. 137–165). Houndmill: Macmillan.
- Schölkopf, M. (1998). Die Altenpflege und die Daten. Zur quantitativen Entwicklung der Versorgung pflegebedürftiger Menschen. *Sozialer Fortschritt*, 47(1), 1–9.
- Steffen, M. (2009). *Branchenbericht: Die Arbeitssituation von Migrantinnen in der Pflege*. Berlin: Verdi.
- Streeck, W. & Thelen, K. (Eds.). (2005). *Beyond continuity: Institutional change in advanced political economies* (pp. 1–39). Oxford: Oxford University Press.
- Theobald, H. (2004). *Care services for the elderly in Germany, Infrastructure, access and utilisation from the perspective of different user groups* (Discussion Paper, SP I 2004–302). Berlin: Social Science Research (WZB).
- Theobald, H. (2010). Prekäre Pflege. Osteuropäische Migrantinnen in der häuslichen Altenfürsorge. *Osteuropa*, 60(5), 117–129.
- Theobald, H. (2011). *Long-term care insurance in Germany. Assessments, benefits, care arrangements and funding. Arbeitsrapport 2011:13*. Stockholm: Institut für Framtidsstudier.
- Theobald, H. (2012). Combining welfare mix and new public management: The case of long-term care insurance in Germany. *International Journal of Social Welfare*, 21, S61–S74 (early view online version before inclusion in an issue, Feb. 2012).
- Welti, F. (1999a). Vorbehaltliche Aufgabenbereiche für Pflegeberufe, Part 1. *Pflege- und Krankenhausrecht*, 2(2/99), 29–33.
- Welti, F. (1999b). Vorbehaltliche Aufgabenbereiche für Pflegeberufe, Part 3. *Pflege- und Krankenhausrecht*, 2(4/99), 85–90.
- Wingenfeld, K., Büscher, A., & Gansweid, B. (2008a). *Das neue Begutachtungsassessment zur Feststellung von Pflegebedürftigkeit*. Anlagenband: Bielefeld/Münster.
- Wingenfeld, K., Büscher, A., & Gansweid, B. (2008b). *Das neue Begutachtungsassessment zur Feststellung von Pflegebedürftigkeit*. Anlagenband: Bielefeld/Münster.

Chapter 7

Steps Toward a Long-Term Care Policy in France: Specificities, Process, and Actors

Blanche Le Bihan and Claude Martin

7.1 Introduction

The definition of a specific long-term care (LTC) policy or—to use the French terminology—a policy toward “dependent elderly people,” only really emerged in France at the end of the 1980s. It has been a long process, which is still open to different *scenarios* in the forthcoming years (Martin 2003). Because it developed slowly over time, the French system is rather complex, combining different elements (old and new ones), fragmented between health insurance, domiciliary and residential social care, fiscal, and employment incentives. However, since the end of the 1990s, public policy on LTC has mainly been organized around a specific allowance. After a period of local experimentation (1995–1996), it consists of a “cash for care” scheme, initially targeted at the more dependent and economically disadvantaged; subsequently opened up to include all frail older people in 2002. The 2002 reform, which created the “*Allocation personnalisée à l’autonomie*” (APA—“personal allowance for autonomy”), represents the main turning point in the policy framing process to date. The number of recipients rose dramatically, from 150,000 in December 2001 to 1,185 million in September 2010 (Fragonard and Juéry 2011).

As in many other countries (Colombo et Mercier 2011), French LTC policy is facing demographic challenges and financial constraints, which are exacerbated by the context of the financial crisis. The common exposure to funding pressures could even be one of the main arguments in defense of the hypothesis of a European convergence (Pavolini and Ranci 2008), as all the systems in Europe are gradually becoming mixed, taking ideas from each other. Indeed, they combine informal care, assistance, social and private insurance, commoditized and public services—in other

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words, they are based on a welfare-mix or a complex combination of State, family, and market. The cash for care orientation constitutes another important common trend in the evolution of different European countries (Da Roit et al. 2007; Da Roit and Le Bihan 2010), as it supports at once recourse to both informal and formal care, cost containment and “choice” for users (Ungerson and Yeandle 2007). Conceived as a complement to family care, and presented as a financial support to externalize part of the caring activities and buy services, cash for care schemes imply significant investment on the part of family carers as case managers.

Nevertheless, beyond these common characteristics, the French LTC system has a number of unique elements, which are in need of clarification. This chapter presents the French policy framing process, which began in the 1980s and has led to the so-called “French compromise” (Le Bihan and Martin 2007), combining elements of different types of care systems. To understand the role of some of the main actors, we begin by developing the process of defining this policy over time, in order to identify the main phases of, and drivers for, reform.

We then focus on the cost of this policy—which is currently the main issue—and its various dimensions, both public and private. In the discussion, we trace the development of the current debate, which lays the ground for a long-awaited and presumably imminent reform. Since the last presidential election in May 2007, a new direction has been announced, heading toward an insurance model—or, as the expression goes in the French debate: “a fifth risk.” Although this reform was supposed to be adopted before the 2012 presidential election, it has been postponed once again, and the scenario of the reform remains vague. Many professional and social partners are worried about both the time scale and concrete aspects of this project, which appears to be a new compromise between the three poles of protection: family, state, and market. But this very peculiar moment of intense debate (and publication of multiple reports) is useful in that it maps the various positions of the actors. The ongoing discussion provides additional aspects, which may be useful in understanding the conditions of the reform in the French context as a combination of both political impulse and continuous reports by diverse experts, senior civil servants, and professional coalitions.

7.2 The Development of a Public Policy Based on Cash for Care: Challenges, Process, and Actors

In France, the development of LTC policy has been a very slow and hesitant process. First, it is important to mention that the expression “long-term care” is not in common usage as a description of this policy sector. The time-honored expression, in use since the 1970s and 1980s, is “policies toward dependent older people” and, more recently—in a bid to avoid the discriminatory and negative connotation of the term “dependency”—“policy aimed at maintaining autonomy.”

One group of actors played a central role in promoting this notion of “dependency”: geriatricians. The biomedical basis of this notion is a crucial factor in

understanding one of the French specificities. For geriatricians, “dependency” means that incapacities have to be assessed, in order to be able, in a second phase, to evaluate needs and related costs. This conceptualization of dependency has been disseminated from the professional to the political domain, in particular for financial reasons (Frinault 2005, 2009).

7.2.1 *Initial Challenges*

One of the main political challenges in the 1980s was facing up to the growing cost of the care for people with disabilities, and dividing this target group into two main categories (each requiring its own distinct policy) depending on their age: access to employment as a way of enabling autonomy for adults with disabilities (under-65) and medical, healthcare, and/or social care for the over-65s (Ennuyer 2003). So “dependency” came onto the political agenda at the start of the 1980s, first as a necessity to the reform of an allowance—the “Compensatory allowance for a third party” (*Allocation compensatrice pour tierce personne*, ACTP)—a policy for people with disabilities created in 1975, funded and managed by local authorities and mainly used by older people with incapacities. This cash allowance was distributed to people with disabilities (at least 80 % incapacitated) to help them to pay for third-party support, but it lacked any system of verification. Over the next 10 years (mid-1980s to mid-1990s), the main proposal was the creation of a specific “in-kind” benefit,¹ attributed to older people with physical and mental incapacities who needed to be helped in their daily living activities. But until 1994, there was no specific LTC policy as such, only a rich political debate and numerous expert reports (Kessler 1994; Martin 2003).

The slow process of defining this cash for care orientation raised important issues and fuelled debate over a decade. The first of these issues concerned the possibility of raising a new social insurance tax (Frinault 2003). This social insurance model was defended in one of the first official reports, back in 1979 (Arreckx 1979),—but since then, very few experts have supported the scenario of a fifth social security risk² for dependency (at least, until 2007). The second issue was whether the scheme should be universal, or should concern only those unable to pay for services (poor dependent older people), within the logic of social assistance.³ The third issue was how the policy should be funded and managed, and to what extent the State, local authorities, and health service funds should contribute. A fourth element of discussion concerned

¹ “In-kind” means that the allowance (the cash) has to be used for the payment of services, mainly formal, in return of invoices.

² The French social security system is based on four risks: illness, retirement, family, and accident at work.

³ This principle has important consequences in terms of family obligations. There is indeed in France a legal obligation—called “*obligation alimentaire*”—to intergenerational solidarity (upward and downward), which imposes to support one’s relatives. The application of such a principle can mean that public coverage is secondary to family support.

the conceptualization of dependency in old age. Whilst Arreckx's report defended the biomedical model, another report published in 1980 by the Planning Commissariat, entitled "Lion's Report," offered a more social perspective (Commissariat general au Plan 1980).⁴

Yet, the main obstacle to the development of a coherent national LTC policy was a financial one. In fact, in the context of budgetary constraints, with a policy of curbing public expenditure, it was difficult to promote a policy the cost of which had not been properly estimated. At that time, even the number of dependent old people and potential recipients was unknown. The choice of a social insurance scheme was therefore considered to be inappropriate and too risky for social security sustainability. Once again, the biomedical perspective dominated, with a joint venture between the geriatricians' lobby and the Ministry of Social Affairs. This professional lobby succeeded in imposing a tool to estimate dependency, with the adoption of a single scale of evaluation: the AGGIR (*Autonomie G eronte Groupes Iso-Ressources*). "In 1991, two official reports, Boulard and Schopflin, underlined this issue to link public policy to a common system of evaluation of dependency, to estimate the number of dependent people, to classify them into categories, to estimate the costs and to fix the prices of institutions for elderly" (Frinault 2005, p. 28).

7.2.2 A Slow Burning Start to the Definition Process

The slowness of the decision-making process might be explained by the government's difficulty in the face of these uncertainties. Since the mid-1990s, four steps can be identified in the creation of a specific public LTC scheme and the gradual broadening of the number of recipients (Martin 2001). The first step began in 1994–1995 when 12 local authorities (*Conseils g n raux*)⁵ were invited by the government⁶ to participate in pilot scheme. The objective was to enable local actors to develop their own system, following a few general guidelines, and experiment with the possibility of creating a "specific dependency allowance." At that time, social security funds—namely the health insurance fund (*Caisses d'assurance maladie*) and the pension insurance fund (*Caisses d'assurance vieillesse*)—were directly involved in managing the allowance at the local level.

In 1997, the government⁷ and the *Senate* (upper house of the French parliament) decided to scale down the initial ambition of the experimentation and to adopt and

⁴ This Lion's report inspired the first socialist Government after the election of Franois Mitterrand in May 1981. Concretely, it was the main orientation of the *Secr tariat d'Etat aux personnes  g es* set up by this Government. But this orientation disappeared after the "neoliberal turn" of the socialists in 1983.

⁵ There are 101 *conseils g n raux* in France: one for each department.

⁶ Right-wing government "Balladur" (March 1993–May 1995): Prime minister: Edouard Balladur; minister of Social Affairs: Simone Weil.

⁷ Right-wing government "Jupp  II" (November 1995–November 1997). Prime minister: Alain Jupp ; minister of Work and Social Affairs: Jacques Barrot.

implement a temporary national assistance scheme throughout the French territory—the “Specific dependency allowance” (*Prestation spécifique dépendance*, PSD), with the following characteristics and objectives: the appointment of local authorities to pilot the scheme; the reduction of public costs; the maintenance of family obligations; and a focus on more disadvantaged and dependent older people. The benefit—both means-tested and needs-tested, and granted to dependent older people at home and in institutions, was very limited. It excluded any individuals with or below average dependency, which represented almost 40 % of all recipients. It also excluded individuals on middle (and high) incomes. The prospect of recovering assets from their estate also excluded a significant proportion of potential recipients, as most families wanted to preserve their inheritance. The cost containment objective was therefore met, and families remained the main carers.

In May 1997, there was an important political upheaval following the dissolution of parliament. A new socialist government⁸ was appointed (third cohabitation)⁹. Many criticisms have been made of the PSD scheme, focusing in particular on the fact that, in 2001, only 15 % of frail older people received the benefit (150,000 recipients)¹⁰, which made it necessary to reform the system. The aim of the 2002 socialist reform was clear: to face the challenge of care needs and to increase the number of recipients. Thus, the policy shifted from being assistance-based to a more universal scheme. The new allowance, called “personal allowance for autonomy” (APA), is allocated to older people with high and middle dependency levels, proportionate to income level and without any possible recovery from inheritance.

A fourth step occurred in 2004, after the heat wave of summer 2003, during which 15,000 older people died. This demonstrated the poor responsiveness of the health-care system, the need for better coordination between health and social services, and for the combination of formal and informal sources of support. It also revealed the importance of local responses to such crises and the need for local authorities to prepare for such events. Although immediately prior to the heat wave, the right-wing government¹¹ had considered the possibility of reducing the public cost of the APA scheme, there was a drastic change of direction, and an alternative to cuts was proposed.¹²

⁸ Left-wing government “Jospin” (June 1997–May 2002). Prime minister: Lionel Jospin; minister of Employment and Solidarity: Martine Aubry.

⁹ Political “cohabitation” means in that case that a right-wing President, Jacques Chirac, had to cohabit with a left-wing Prime minister, Lionel Jospin.

¹⁰ The first national inquiry (*Handicap, incapacité, dépendance*) of the National institute of statistics (*INSEE*) estimated for the first time in 1999 that the number of dependent elderly people was almost a million people.

¹¹ Right-wing government “Raffarin II” (June 2002–March 2004). Prime minister: Jean-Pierre Raffarin; minister of Health, Family and Handicapped People: Jean-François Mattei.

¹² The media even considered that Jean-François Mattei paid the political price of this tragedy by losing the charge of the ministry of Health, Family and Handicapped People.

In this new context, the 1995 German reform, which introduced social insurance for LTC (Geraedts et al. 2000; Igl 2003), was presented by the government¹³ as a model. So the government adopted a new *Plan for Frail Elderly People*.¹⁴ Three main elements were introduced: a program to deal with any new heat wave—air conditioning in retirement homes and hospitals, recruitment of professionals—improvement of the epidemiological warning system, and—in 2005—a specific fund for older and disabled people (the “*Caisse nationale de solidarité pour l’autonomie*”). Similar to the German insurance scheme, this new fund is financed by an employers’ contribution¹⁵ in exchange for the abolition of one public holiday,¹⁶ an additional contribution (0.3 % on financial and property holdings), and 0.1 % of the CSG (*Contribution Sociale Généralisée*) tax, and the transfer of credits devoted to older and disabled people in the social security fund. This fund, amounting to 14 billion € in 2006, was presented as a step toward the social insurance principle.

7.2.3 *Beyond Dependency: The Employment Challenge*

Another challenge characterizes the French situation: the employment issue. In developing a cash for care scheme, the main objective of French policy makers was also to find a way to support new jobs in the services sector. Indeed, from the very start, the improvement of care services for frail older people also sought to support a potential source of employment, be it relational (family, neighbors, friends) or home help services, which in France are called “*services à la personne*” (personal services). These concern the sphere of childcare, as well as housework, care for frail older people, or any help that a family might receive with everyday life. In 1997, the creation of the PSD was considered an opportunity to reinforce the local nonprofit service providers who managed personal assistants for older people. Though the effects of this allowance were initially far from positive—the allowance destabilized existing qualified jobs and created unskilled labor—recent statistics (Chol 2008) have shown an improvement since the 1990s.

The 2002 reform, and the creation of the APA, has had a positive impact on professional carers (Le Bihan 2012). First, with the APA scheme, the way in which the three types of services are shared out has evolved, as follows, between: *prestataire* (the care worker is a professional recruited in a nonprofit private or public organization, which is also the employer), *mandataire* (the older person is the employer but the care worker is recruited by a nonprofit private or public organization), and *gré à gré* (an individual agreement with the care worker of your choice). The number of

¹³ Right-wing government “Raffarin III” (March 2004–May 2006). Prime minister: Jean-Pierre Raffarin; minister of Health and Social Protection: Philippe Douste-Blazy.

¹⁴ A first Plan was implemented for the period 2004–2007 and a second one for the period 2008–2012.

¹⁵ Called “*Contribution solidarité autonomie*.”

¹⁶ Called “*journée de solidarité*.”

employees in *prestataires* services (the most highly qualified service) has increased: from 167,000 in 2003 to 211,000 in 2005.¹⁷ This means that the organization is now the employer. This shift corresponds to the policy objective of enhancing the level of quality and professionalization of care. Second, services toward frail older people are now covered by a “quality agreement,” and professionalization of personal assistants is organized.¹⁸ In 2005, the number of services covered by a “quality agreement”¹⁹ was assessed at 11,000²⁰ (in comparison with 7,000 in 2002). Therefore—and this is the third consequence of the creation of the APA—scheme has significantly increased the number of qualified workers, even though there are still too few, and their working conditions remain unstable. The number of employees working for individuals at home increased from 960,000 in 2003 to 1.1 million in 2005.

The link between care and employment issues is also relevant with regard to the development of measures in favor of employment. In the 1990s, a tax deduction was introduced, which aimed at encouraging families to employ people to work in their homes. This measure concerned childcare as well as housework and the care of older people. French families have the option of deducting half of the costs incurred by the employment of such a worker from income tax due. This measure had a significant impact, enabling upper and middle-class families to make use of such facilities. Moreover, a voucher was created: the “*chèque emploi service*” (“service employment voucher”), which simplified the payment of administrative charges for families. More recently, in 2005, the “Borloo social cohesion plan” (*Plan de cohésion sociale*) has organized the development of employment in this sector of personal services. The objective was to extend access to such services, to professionalize the sector and to simplify administrative procedures.²¹

In summary, this framing process reveals different elements about LTC policies in France. First, and obviously, it is highly dependent on the political agenda (succession of governments, political alternations, etc.). Before any real decisions could be reached, a lengthy first phase was devoted to an intense public debate around the *necessity* of building an innovative policy to face an *inevitable* challenge. But this

¹⁷ Concerning specifically the sector of elderly care, the *prestataires services* represented 46 % of the services used, 18% the *mandataires*, and 36 % the *gré à gré* (FNORS 2008, p. 54).

¹⁸ Until March 2002, the CAFAD (*certificat d'aptitude aux fonctions d'aide à domicile*) was the only diploma available to personal assistants and only a few of them had it (only 18 % of personal assistants had a qualification in social and health sector and 9 % the CAFAD). The training has since been improved with the DEAVS (*Diplôme d'Etat d'auxiliaire de vie*).

¹⁹ These statistics concern a larger sector than “personal assistants” who cares for frail elderly. The service to individuals includes care toward frail elderly, childcare, domestic tasks, and all support needed by individuals (such as gardening, computer help, odd jobs. . .). Care toward frail elderly represents 60 % of the global activity of services covered by “quality agreement” and domestic tasks 33 %.

²⁰ A total of 12,000 if one includes private firms.

²¹ In February 2006, a specific plan for the development of such services (“*plan de développement des services à la personne*”) announced the creation of 1 to 2 million jobs by 2010 and created a specific Agency to organize this sector (*Agence des services à la personne*).

phase was also unquestionably a “nondecision” phase, in the sense that the main contributions were official think tank and expert reports aimed at preparing for the decision and legal proposals. There followed a series of “false starts”—ambitious and promising measures (local experimentation; APA) and backing down (PSD). This process also highlights the antagonistic way in which political actors and professional coalitions interact in France and how secondary objectives such as the issue of employment in the care sphere played a role in the policy framing.

7.3 A Broader View of a Fragmented Policy Combining Informal Care, Health Care, Social Care, and Private Insurance

As shown in the previous section, the scope of the French LTC system is not easy to assess, because it does not constitute a homogeneous policy field—on the contrary, it cuts across public and private systems and, within the public sector, across different policies such as social care, health care, family, employment, or aging. The issue of the scope of this policy is currently at stake. In order to identify the many financial sources and specify the overall cost of such a fragmented policy, it is important to make the distinction between the public policy core, based on the *Allocation personnalisée d'autonomie* (APA), private insurance contributions, and more peripheral measures.

7.3.1 The Public LTC Policy

As mentioned previously, the core of French LTC policy is based on a specific allowance, “*Allocation personnalisée à l'autonomie*,” distributed and managed at *territorial* level. The French APA scheme has three main features. First, it is a benefit delivered to old people at home and in institutions²² according to their level of dependency. The APA is allocated up to the fourth level of the official assessment scale (AGGIR), which distinguishes six levels of dependency, from the highest (GIR1) to the lowest (GIR6). Because the French scheme is a national one, implemented at a local level, and in order to guarantee access to the same services across the country, each level of dependency entitles recipients up to a maximum preordained allowance. In April 2010, the monthly amounts were as follows: a maximum of 1,235 € for a GIR1, 1,059 € for GIR2, 794 € for GIR3, and 529 € for GIR4.

²² In the case of institutions, the benefit can either be allocated to individuals or globally to the institution itself, which uses it according to the dependency needs of the residents. The choice between the two options is made by the institution. In France, institutions for the elderly distinguish among three expenditure components: dependency costs (paid by the resident and the APA), accommodation costs (paid by the resident), and healthcare costs (paid by the health insurance).

Table 7.1 Average amount of APA depending on dependency level. (Adapted from DREES, Ministry of Social Affairs, Debout and Lo 2009)

	Local authority contribution	Recipient contribution (and percentage of recipients concerned by copayment)	Average amount
<i>Average amount of APA (home-based) (€)</i>			
GIR1	830	179 (70)	1,009
GIR2	634	151 (74)	785
GIR3	481	104 (74)	585
GIR4	288	59 (76)	348
<i>Total</i>	<i>406</i>	<i>88(75)</i>	<i>494</i>
<i>Amount of APA (institution-based)</i>			
GIR1 and 2	383	159	543
GIR3 and 4	192	146	338
All	307	154	461

Second—and this is a key feature of the French scheme—the benefit is paid to finance a specific care package determined by a team of professionals according to the needs of the recipient. The use of the benefit is controlled and it can only finance the care identified as necessary by the professionals. The paid carers can either be professional workers or relatives (spouses are excluded). The logic is therefore that of “free choice”—the family takes part in the choice of the care arrangements and can combine professional and family care—but the type of care needed is determined by professionals. This control of the benefit is an important feature of the scheme²³ and indicates that the system is controlled by a stronger regulatory framework than in other European countries where cash for care has also been adopted (Da Roit et al. 2007; Glendinning 2006; Ungerson and Yeandle 2007).

Finally, France has adopted a twofold system to finance care packages. On the one hand, an “assistance principle” is applied: below a fixed income threshold (695 € per month), recipients do not contribute at all to the funding of the care package. On the other hand, a “user fee” or copayment system has been introduced: above the threshold, the recipient contributes to payment for the care package according to his or her level of income. Thus, all recipients can receive the APA allowance, but their contribution or copayment varies in line with their means (see Table 7.1). Above an income of 2,750 € per month, the APA recipient pays 90 % of the care package cost. The fact that every person in need can receive public support to pay for the care package (even if only 10 % of its cost) explains the term “universal,” which is sometimes used to describe this scheme. Nevertheless, it is clearly more a “general” scheme than a universal one.

APA replaced PSD in January 2002. It was immediately a real success, with a very rapid increase in the number of claimants. Between January 2002 and June 2003, 1,390,000 people claimed APA, and 723,000 people received it.²⁴ In September

²³ The administrative control is organized by the local authorities and can vary according to the “*départements*.”

²⁴ This success also had an impact on the political debate, both local and national, after the political change of April 2002 and the comeback of a conservative Government. The new government and

Table 7.2 Number of APA recipients (in thousands) by dependency level in September 2010. (Adapted from DREES September 2010)

	At home		In institution		Total	
	Number (thousands) and percentage of all recipients	Public cost (million €) and percentage of total cost	Number (thousands) and percentage of all recipients	Public cost (million €) and percentage of total cost	Number (thousands) and percentage of all recipients	Public cost (million €) and percentage of total cost
GIR 1	(19) 1.6	(187) 3.5	(68) 5.7	(1,383) 26.1	(87) 7.3	(2,548) 48.1
GIR 2	(130) 10.9	(978) 18.5	(211) 17.8		(341) 28.8	
GIR 3	(157) 13.3	(882) 16.6	(71) 6	(438) 8.3	(228) 19.2	(2,750) 51.9
GIR 4	(421) 35.5	(1,430) 27.0	(108) 9.1		(529) 44.6	
All	(727) 61.4	(3,477) 65.6	(458) 38.6	(1,821) 34.4	(1,185) 100	(5,297) 100

2010, 1,185,000 people were receiving APA. Statistics show that the more dependent people are mainly cared for in institutions and conversely, recipients with medium and medium-high dependency levels remain at home (see Table 7.2). About 58 % of recipients at home are classified as GIR4. In Table 7.2, we also show the overall cost of this allowance: about 5.3 million € (65.6 % at home and 34.4 % in institutions).

7.3.2 *A Fragmented Supply of Health and Social Services*

The various LTC-related public measures concern two types of care: home-based and residential. To support families in their caring tasks, older people can turn to professional services from both the health and social sectors. Nurses and nursing auxiliaries (*aide-soignantes*), who are either independent or working out of nonprofit organizations (SSIAD, *services de soins infirmiers à domicile*—home care nursing services), are the main healthcare professionals. They visit the older care recipient at home and deliver personal and medical care (medicine, personal hygiene, etc.). However, there is an overall shortage of such services, which are funded by the health system and are therefore free to the user. In 2007, there were 2,000 SSIADs offering 88,000 places, adding up to just 1.8 places for every 100 over-75s (*Fédération nationale des observatoires régionaux de la santé* FNORS 2008). The policy toward older people has also served to develop professional social care services. Organized in public structures or nonprofit organizations, these services offer staff to provide personal care and domestic services to older people. But the provision of home care services is organized at a local level, with limited availability of resources and

right-wing local authorities criticized the increasing cost and the previous socialist government's failure to plan the funding of their care system for frail elderly people. In April 2003, the decision was taken to reduce the threshold below which the recipient does not contribute at all to the funding of the care package, from 943 to 623 € per month. This reform has reinforced the copayment system by increasing the user's contribution and has contained the costs.

geographical inequality. Payment for such services thus relies on family support and on the APA.

When home-based care is no longer possible, old people can resort to residential care. At the beginning of 2006, there were 669,000 places in residential care and 10,000 residential homes for old people (FNORS 2008) organized as follows: 435,000 places in nursing homes, 153,000 in collective housing (*logement foyer*), 72,400 in LTC hospital services (*unités de soins de longue durée*), and 7,800 in temporary housing (FNORS 2008). Since 2002, institutions for dependent older people have been reorganized and a unique category, grouping the various institutions devoted to old people in need of care, has been created: the *EHPAD (Etablissement d'hébergement pour personnes âgées dépendantes*—residential institutions for dependent older people). The funding of these LTC institutions is based on three elements: accommodation—the cost of which varies according to the institution and is paid by the older resident and their family or, in situations of low income, by social assistance; the cost linked to dependency, which is paid by the APA and the resident, and the cost of health care, which is covered by social health insurance.

7.4 Overall Cost of Public LTC Policy

Many recent reports have offered estimates of the overall cost of the French LTC system (Fragonard and Juéry 2011; Rosso-Debord 2010; Vasselle 2008, 2011). But the question of its scope is still controversial. According to the report presented by right-wing MP Valérie Rosso-Debord, the overall public cost of this policy in 2009 was about 21.6 billion €, which was a little more than 1 % of the GDP—more or less the same as in the United Kingdom or Germany, but only half as much as in the United States or in Scandinavian countries. Estimates for the next 20–25 years calculate that the overall cost of LTC policies in France could reach 2–2.5 % of GDP.

Within this global budget, the APA represented 5.1 billion € in 2009: 1.5 billion € of which is covered by the *Caisse nationale de solidarité pour l'autonomie* (CNSA), whilst the 3.6 billion is paid for by taxation at *département* level. Yet, the public cost of “dependency” is also supported by other measures, which don't specifically concern older people. It is important to take into account the major contribution of the health-care system, which pays hospitals and medical costs for older people, health costs in residential homes and for nursing at home, which represent almost 12 billion €, or 55 % of the overall public cost of the LTC policy. Paradoxically, then, the main cost does not correspond to the core of the policy, but rather to the expenses related to the healthcare system as a result of the “treatment” needs of older people. Another measure, which contributes to LTC policy funding (1.75 million €), is the tax reduction policy, which was implemented in the late 1990s, in a bid to reduce the cost of home-based care services and thus develop employment in this sector of activity. Last, the family and pension branches of the social security system are also concerned, respectively, paying 600 and 400 million € toward the support of older dependent people.

Table 7.3 Dependency accounts (in billion € 2010). (Adapted from Direction du Budget, DREES, Fragonard calculations 2011)

Nature of cost	Name of expenditure	Nature of expenditure (public/private)	Amount
Dependency (strict sense; GIR 1–4)	APA	Public	5,297
	Income tax deduction for home help	Public	996
	Tax credit	Public	417
	Social activities paid for by CNSA	Public	76
	Copayment at home	Private	812
	Copayment in institutions	Private	917
	<i>Total dependency policy (strict sense)</i>		
Housing cost (GIR 1–4)	Housing allowance, social assistance on housing, tax deductions	Public	1,872
	Private cost	Private	7,988
	<i>Total</i>		9,860
Healthcare or medical needs (GIR 1–4)	Medicosocial work	Public	6,807
	Health cost in institution	Public	912
	Ambulatory care	Public	3,000
	LTC hospital	Public	990
	Hospital	Public	2,000
	Copayment	Private	725
	<i>Total healthcare cost</i>		14,434
<i>Total GIR 1–4</i>			32,809
Public cost for GIR 5–6	Pension fund contribution, departmental and municipal social policy, etc.	Public	1,536
<i>Total: all GIR (1–6)</i>			34,345

New estimates are just about to be published, in the course of a broad consultation about the future of this policy measure, discussed later in greater detail. If we take into account both public and private costs (meaning expenditure paid by the older care recipient and their family), an estimate of the overall cost of dependency is shown below (Table 7.3). This table shows that the overall cost for 2010 is divided between a 22.4 billion € public cost and a 10.4 billion € private cost—and even more, if we add in the cost of low dependency (GIR 5 and 6).

7.5 The Private LTC System

With about 3 million policyholders, for a total amount of 2.1 billion € in 2007, France is proportionately the top private insurance market in this field, ahead of the United States (with approximately 7 million policy holders for a population that is five times

bigger). However, in comparison with the 13 million over-60s in France, it remains a small proportion of the potential market (de Castries 2009; Dufour-Kippelen 2008; Kessler 2008).

This market began developing in the mid-1980s and offers a range of products, both individual and collective (“*mutuelle*”), which guarantee a monthly payment in the event of dependency. In the United States, private insurance policies offer reimbursement of the care and services costs generated by dependency, which is not an easy system to control, because of uncertainty as to the level of reimbursement (Taleyson 2007). In contrast, the French system is based on a fixed sum payment, which is far more flexible, leaving policyholders free to organize care and services as they see fit.

The development of this private sector is firstly linked to the actual costs of dependency and the difficulty of covering these costs. To give an idea of the gap between public support and actual costs, here are some overall estimates: dependency generates a mean monthly cost of 2,000 € (up to 3,000 € for a high dependency level). The public allowance (APA) contributes about 500 € (up to 800 € for a very high level of dependency), given that the mean pension is about 1,200 € per month. The main difficulty concerns the middle classes, as the more disadvantaged people rely solely on public support, whilst the well-off have their own economic resources to fall back on. For those who have it, private insurance policies contribute about 300 € more, on average. In practice, therefore, a high level of dependency means that older people have to use their savings, reducing their assets and often selling their homes to pay for the services. Very often, they even go into debt in order to meet these costs—this phenomenon could get worse and worse in the near future as a result of demographic pressure. As Courbage and Roudaut (2008) put it: “Low rates of public LTC coverage suggest that the financial consequences of dependency could be catastrophic, even resulting in ruin, for a number of older people and their families” (p. 645). Thus, many experts (mainly those working in the field of private insurance) argue that a public–private partnership is necessary in order to meet these increasing costs in the immediate future.

7.6 Discussion: Scenarios and Method for an Upcoming Reform

After the 2007 presidential election, an important reform was announced with fanfare because it was meant to be imminent, but has in fact been systematically postponed over the 5 ensuing years. Since the political agenda had to give priority to other crucial issues, such as, for example, the pension reform, the Government began a broad consultation exercise, asking for different official reports—from the French national assembly and the Senate, in particular. In comparative analysis, France often earns the epithet: “The Republic of Reports,” because reporting constitutes a sort of a methodology aimed at preparing both the decision and public opinion. This issue is a perfect demonstration of the unique characteristics of the French system.

Between 2005 and 2010, at least six important official reports were published concerning French policy for the care of older people²⁵ and its future. As if this were not enough, in the spring of 2011, Fillon's government appointed four different working groups of elected representatives, social partners, representatives of civil society, and experts to prepare the next reform²⁶ (meaning four new substantial reports), but also asked for another report from the *Centre d'analyse stratégique*(CAS) on "international perspectives to clarify the national debate on dependency" (*Centre d'analyse stratégique*, CAS 2011). Five further reports followed over the next 6 months. The intense public debate also gave rise to other initiatives, of which we might mention the publication by *Terra Nova*—the socialist think tank—of a report on this policy (Broussy 2011) and another by the *Fondation Copernic*, another left-wing network of experts and activists (Marty 2011). A synthesis of the mass of information collected in these thousands of pages is not possible in this analysis. We can only underline the main controversies and suggest some hypotheses concerning the reforming process and methodology.

The main challenge for the next reform unquestionably concerns the funding of the system, taking into account the demographic and public health estimates. Thus, the Ministry of Work and Social Affairs considers that the cost of the APA in 2040 is set to double, reaching 10–11.5 billion € per year. Moreover, 5,000–7,500 more places per year will be needed in nursing homes. These growing needs are challenging the system, and decision-makers have been in search of a solution. From this perspective, the private/public coverage balance appears to be a main solution, in a context in which privatization has received political preference.

Since coming to power, President Sarkozy has announced a reform based on the creation of a "Fifth Risk"—namely, dependency—which was supposed to be implemented at the end of 2008, was then delayed to 2009. However, we are still awaiting the details of this long-awaited reform as of April 2012. One first needs to understand more clearly what this announcement means—as well as what lies behind this "Fifth Risk" expression. It refers directly to the French social protection system, and corresponds to the social insurance glossary. On the government's website, it is defined as follows: "The fifth risk is a new field of the social security system. It will complement those which cover health, family, pensions and work injuries. The fifth risk can also be named 'dependency risk' or 'risk of losing autonomy'."²⁷

The experience of the German LTC social insurance, coupled with the increasing deficit that must be faced, suggest that the creation of a stabilized "Fifth Risk" has not been invented yet (Taleyson 2007). Considering the health system's difficulties and the weight of existing taxes in France, a compulsory public system based on an

²⁵ Cour des Comptes (2005); CAS (2006); Gisserot and Grass (2007); Vasselle (2008); CAS (2010); Rosso-Debord 2010.

²⁶ The first one on "society and aging" (President: A. Morel, 54 members); second on demographic and financial trends for dependency (President: J-M. Charpin, 40 members); third on "services for elderly people" (President: E. Ratte; 57 members), and fourth on "funding strategy of the dependency policy" (President: B. Fragonard; 52 members).

²⁷ http://premier-ministre.gouv.fr/information/questions_reponses_484/est_cinquiemerisque.

additional social contribution appears difficult to develop (Albouy 2009). Thus, it is perfectly clear that the new Fund (*caisse nationale de solidarité pour l'autonomie*) is quite different from the Social security funds (“*caisses de sécurité sociale*”), which exist in the fields of health, pension, and family: the social partners are not represented on the board (*conseil d'administration*) of the CNSA, and so there is no compulsory contribution from salary.²⁸ It is, however, impossible to consider the French LTC system to be a social insurance system.

The question of the insurability of the risk of dependency is in itself a major challenge. The unpredictability of the costs involved is an obstacle to the development of a social insurance policy. The definition of “dependency” is a second problem. Dependency is a complex risk, due to several different factors: physical, mental, and social. Defined as the inability to perform some of the most basic daily activities (getting up, washing, dressing, etc.) without the assistance of a third party, it is accentuated by social factors, such as the presence or absence of family support. The precise definition of the risk of dependency is presented by Durand and Taleyson (2003) as a main condition in enabling the insurability of such risk and in limiting the uncertainty of the funding.²⁹

Facing these difficulties, the various official reports mentioned above define another conception of this risk. This is the case in the report published by the Senate in July 2008: “Long term care and the creation of the fifth risk” (*La prise en charge de la dépendance et la création du cinquième risque*; Vasselle 2008). The “fifth risk” proposed is in fact a multipillar system, combining public coverage, personal savings, and private insurance. The first pillar is based on the existing public system, with the APA and the Fund (CNSA), and defends collective solidarity. It is also aimed at guaranteeing all older dependent citizens universal access to a needs assessment and a minimum care package to be allocated at *département* level.

The second pillar formalizes the contribution made by the recipient and his/her family: in order to contain the costs, the principle of a “recovery from inheritance” is reintroduced: above a total household capital threshold yet to be defined (between 150,000 and 200,000 €), part of the amount of APA delivered will be recovered from inheritance. An alternative is suggested: recipients can choose to receive only 50 % of the APA allowance, without “recovery from inheritance.” As noted earlier,

²⁸ The executive board is composed of representatives of the funding institutions—the State and local authorities—and representatives of the health branch of the social security system. A specific consultative board has also been set up (“*conseil d'orientation et de surveillance*”), which associates representatives of the private insurances, on one side and of nonprofit organizations providing services, on the other.

²⁹ The two authors identify two types of approach. The first one refers to “care,” which is defined as “long-term” and is characteristic of the American (Long-Term Care) or German (*Pflegeversicherung*) systems. The second, the French approach, does not use the term “care” (*soins*) but “dependency” or “loss of autonomy.” These notions do not refer to the needs, but to the physical, mental, and social state of the old person, an approach which makes the assessment of the situation easier.

inheritance and its bequeathment to children is very important in French culture, and so it is highly likely that families will organize themselves to preserve it.³⁰

Private insurance is presented as the third pillar of the LTC system. With up to 15 % growth annually (Kessler 2008), private insurance is widespread in France. Based on a “lump sum” logic, the French private system offers a precise definition of the risk of dependency. Instead of covering personal care needs, which are very difficult to anticipate, the insurers cover a specific state—high and irreversible dependency—referring to the Activities of Daily Living (ADLs; Taleyson 2007). But the sector remains marginal in proportion to the number of people concerned. The objective of the reform project is to support the expansion of the private insurance market. Different solutions have been proposed: the introduction of tax incentives to attract the middle classes, a link with life insurance,³¹ or a reverse mortgage³² (Courbage 2009). Another official report, produced in July 2010 by a UMP MP (*Union pour la majorité présidentielle*, the main right-wing political party; Rosso-Debord 2010) goes even further in suggesting compulsory private insurance, taken out by individuals from their 50s onward, which could replace the current public allowance. This report also suggests excluding the middle level of dependency from the coverage (GIR4).

These very controversial propositions, based on the development of private insurance, immediately attracted a powerful response. The socialist party and the main left-wing social partners, as well as various left-wing think tanks, consider these projects to be socially regressive, and propose as an alternative the creation of a real new field of social protection, based on collective solidarity (taxes and social security contributions). They also recommend a new system of representation on the board of the CNSA, so as to make room for social partners. Critics also underline the fact that the cost of such a system would weigh heavily on the middle classes, with a low threshold to activate the “recovery from inheritance” (150,000 or 200,000 € of household capital). For the opposition, this reform project is considered to be a Trojan horse in the social security system: a step toward a dual and liberal model.

Furthermore, the reactions among social and professional partners of the sector (such as the *Union nationale des centres communaux d'action sociale*, *Association des paralysés de France*, *Fédération nationale des accidents du travail et des handicaps*, *Union nationale de l'aide*, etc.) are negative. Most of these organizations

³⁰ Recovery on inheritance was one of the criteria to obtain the first allowance created in 1997 (PSD) and at that time, many old people were reluctant to ask for the allowance. The reintroduction of such criteria will probably have similar consequences. Therefore, other solutions have to be proposed.

³¹ A total of 12.5 million people have such a life insurance contract, which represents 40 % of the households for a global amount of 1,100 € billion in 2007.

³² Reverse mortgage is a bank loan guaranteed on real estate and used to enable old people to finance long-term care, without having to sell their property. Some experts (Chen 2001) go even further and propose to develop reverse mortgage in order to finance life or dependency insurance. But there are many obstacles to the development of such a system: it is open only to house owners and even for them it is not an attractive solution, because it could mean the end of succession (Assier-Andrieu and Gotman 2009).

consider that the reform is going to weaken both French care policies for older people and representation of users and citizens in the system. They would also prefer to develop a real social insurance, with new collective contributions. To demonstrate their opposition, they even wrote a manifesto entitled: “In favor of a real fifth risk” defending the creation of a universal social allowance, which was published online.³³

The latest reports, published in June 2011 after very broad consultation of the main players, appear to be a sort of compromise. For example, the report on the funding scenarios (Group 4, Fragonard and Juéry 2011) decided to present three main scenarios without officially supporting any of them, even though there was a clear consensus among a large majority of actors in the group to exclude one of them, namely the compulsory private insurance option. The three scenarios are as follows: consolidation of the current system (in order to reduce private costs for users); the introduction of a new branch of the social security system (universality option); and a new system based on compulsory private insurance.

What can we learn from this last step in terms of the reform process? An initial component of the policy framing is the political agenda: elections and political campaigns. The intensity and radicalism of a reform is directly connected to the period of the reform in the political agenda. A second component is the strategy: it is in a government’s interest to push some radical propositions in official reports, even if they are not acceptable and will not be adopted in a first step. But these radical propositions are just showing the way and providing an impulse toward negotiation. For example, after showing its muscle in announcing a radical turn toward private insurance, the party in power seems to recognize that its room for maneuver is very small in the context of a presidential campaign, which is only just beginning, as long as its champion, President Sarkozy, has public approval ratings of less than 30 %.

A third dimension is the recourse to official reports. The rate of their production makes it seem as though repetition of the data, challenges, and solutions has a first objective: to impose certain inevitable solutions. Hearing the same statements, hypotheses, and propositions month after month, year after year, public opinion is progressively socialized to expect a given scenario.

We are still waiting for this new major reform, now postponed until next Presidential election (Spring 2012). The financial crisis is certainly playing a key role in this attitude of waiting: “Room for maneuver disappeared in the financial turmoil” (Vanackère 2009, p. 4). The Fillon government is clearly also aware of the political risk involved in moving toward private insurance policies too fast and many of the professional partners concerned (*Fédération française des sociétés d’assurance, Fédération nationale des mutuelles de France, caisse nationale de prévoyance*, etc.) are criticizing the project. We would wager that this plethora of proposals will lead to nothing much: big build-up; fizzle finish.

³³ <http://collectif-pour-un-vrai-5eme-risque.over-blog.com>.

References

- Albouy, F. X. (2009). Y a-t-il une économie de la dépendance? *Risques*, 78, 88–93.
- Arreckx, M. (1979). *L'amélioration de la qualité de vie des personnes âgées dépendantes*. Paris: La documentation française.
- Assier-Andrieu, L., & Gotman A. (2009). *Réversion du principe du logement humain. Chronique du prêt hypothécaire inversé* (Rapport de recherche pour le Ministère du logement et le Ministère de l'écologie, de l'énergie, du développement durable et de l'aménagement du territoire, pp. 1–360). Paris: Cerlis, Université de Paris Descartes.
- Centre d'analyse stratégique [CAS]. (2010). *Vivre ensemble plus longtemps*. Paris: Centre d'analyse stratégique.
- Centre d'analyse stratégique [CAS]. (2011). *Les défis de l'accompagnement du grand âge. Perspectives internationales pour éclairer le débat national sur la dépendance*. Paris: Centre d'analyse stratégique.
- Chen, Y. P. (2001). Funding long term care in the United States: The role of private insurance. *The Geneva Papers on Risk Insurance—Issue and Practice*, 26(4), 656–666.
- Chol, A. (2008). Les services à la personne en 2006: one croissance en continue; *DARES, Premières Synthèses n*, 48.2, 8.
- Colombo, F., & Mercier, J. (2011). Financer les services liés à la dépendance dans les pays de l'OCDE. In V. dand Gimbert & G. Malochet (coordonnés par), *Les défis de l'accompagnement au grand âge* (pp. 41–71). Paris: La documentation française.
- Cour des Comptes. (2005). *Les personnes âgées dépendantes* (Rapport au Président de la République), p. 447.
- Courbage, C., & Roudaut, N. (2008). Empirical Evidence on long-term care insurance purchase in France. *The Geneva Papers*, 33, 645–658.
- Courbage, C. (2009). La couverture du risque dependence. *Risques*, 78, 107–113.
- Da Roit, B., Le Bihan, B., & Osterle, A. (2007). Long term care reforms in Italy, Austria and France. Variations in cash for care schemes. *Social Policy and Administration*, 41(6), 653–671.
- Da Roit, B., & Le Bihan, B. (2010). Similar and yet so different: Cash-for care in six European countries' long-term care policies. *The Milbank Quarterly*, 88(3), 286–309.
- De Castries, H. (2009). Ageing and long-term care: Key challenges in long-term care coverage for public and private systems. *The Geneva Papers*, 34, 24–34.
- Debout, C., & Lo, S.H. (2009). L'allocation personnalisée d'autonomie et la prestation de compensation du handicap au 30 Juin 2009. *Etudes et Résultats, DREES*, 710.
- Dufour-Kippelen, S. (2008). *Les contrats d'assurance dépendance sur le marché français en 2006*. Etudes et recherché, DREES, 84.
- Durand, R., & Taleyson, L. (2003). Les raisons du succès de l'assurance dépendance en France. *Risques*, 55, 115–120. (Septembre 2003)
- Ennuyer, B. (2003). *Les malentendus de la dépendance*. Paris: Dunod.
- Fédération nationale des observatoires régionaux de la santé [FNORS]. (2008). *Vieillesse des populations et état de santé dans les régions de France* (Rapport de la FNORS, Septembre 2008, p. 85).
- Fragonard, B., & Juéry J.-F. (2011). *Stratégie pour la couverture de la dépendance des personnes âgées*. Rapport remis au ministre des Solidarités et de la Cohésion Sociale, Juin 2011.
- Frinault, T. (2003). L'hypothèse du 5ème risque. In C. Martin (Ed.), *La dépendance des personnes âgées. Quelles politiques en Europe?* (pp. 69–92). Rennes: Presses universitaires de Rennes/Édition de l'ENSP.
- Frinault, T. (2005). La dépendance ou la consécration française d'une approche ségrégative du handicap. *Politix*, 4(72), 11–31.
- Frinault, T. (2009). *La dépendance: un nouveau défi pour l'action publique*. Rennes: Presses universitaires de Rennes.
- Geraedts, M., Heller, G. V., & Harrington, C. A. (2000). Germany's long term care insurance: Putting a social insurance model into practice. *The Milbank Quarterly*, 78(3), 375–401.

- Gisserot, H., & Grass E. (2007). *Perspectives financières de la dépendance des personnes âgées à l'horizon 2025: prévisions et marges de choix* (Rapport remis à Mr P. Bas, Ministre délégué à la sécurité sociale, aux personnes âgées, aux personnes handicapées et à la famille, Mars). Paris: La Documentation française.
- Glendinning, C. (2006). Paying family caregivers: Evaluating different models. In C. Glendinning & P. Kemp (Eds.), *Cash and care. Policy challenges in the welfare state* (pp. 127–140). Bristol: Policy.
- Igl, G. (2003). La prise en charge de la dépendance des personnes âgées: quelques observations à partir du cas allemande. In C. Martin (Ed.), *La dépendance des personnes âgées. Quelles politiques en Europe?* (pp. 217–215). Rennes: Presses universitaires de Rennes/Édition de l'ENSP.
- Kessler, D. (2008). The long-term care insurance market. *The Geneva Papers*, 33, 33–40.
- Kessler, F. (1994). *La dépendance des personnes âgées, un défi pour le droit de la protection sociale*. Strasbourg: Presses universitaires de Strasbourg.
- Le Bihan, B., & Martin, C. (2007). Cash for care in the French welfare state: A skilful compromise? In C. Ungerson & S. Yeandle (Eds.), *Cash for care systems in developed welfare states* (pp. 32–59). London: Macmillan.
- Le Bihan, B. (2012). The redefinition of the familialist care model in France: The complex formalization of care through cash payment. *Health and Social care in the community*, 20(3), 238–246.
- Martin, C. (2001). Les politiques de prise en charge des personnes âgées dépendantes. *Travail, genre et Sociétés*, 6(2), 83–103.
- Martin, C. (Ed.). (2003). *La dépendance des personnes âgées. Quelles politiques en Europe?* Rennes: Presses universitaires de Rennes/Édition de l'ENSP.
- Marty C. (Ed.) (2011). *Dépendance, perte d'autonomie: Affaire privée ou sécurité sociale?* Paris: éditions Syllepse.
- Pavolini, E., & Ranci, C. (2008). Restructuring the welfare state: Reforms in long-term care in western European countries. *Journal of European Social Policy*, 18(3), 246–259.
- Rosso-Debord, V. (2010). *Rapport de la commission des affaires sociales sur la prise en charge des personnes âgées dépendantes* (Report No. N2647). Paris: Assemblée Nationale.
- Taleyson, L. (2007). L'enjeu de la définition de la dépendance: Une comparaison internationale. *Risques*, 72, 28–35.
- Ungerson, C., & Yeandle, S. (2007). *Cash for care systems in developed welfare states*. London: Macmillan.
- Vanackère, C. (2009). Dépendance, les clés pour comprendre le retard. *Espace Social Européen*, 893, 4–5.
- Vasselle, A. (2008). *Rapport d'information sur la prise en charge de la dépendance et la création du cinquième risque* (Rapport au Sénat, juillet 2008). Paris: Sénat.
- Vasselle, A. (2011). *Rapport d'information fait au nom de la Mission commune d'information du Sénat sur la prise en charge de la dépendance et la création du cinquième risque* (Rapport au Sénat, Janvier 2011). Paris: Sénat.

Chapter 8

Long-Term Care Reform in Austria: Emergence and Development of a New Welfare State Pillar

August Österle

8.1 The Broader Context of Reform

The Austrian welfare state is commonly identified as a conservative, corporatist, and familialistic welfare state with social insurance against major social risks. Regulatory roles are divided between the central and the provincial level. The delivery of social services is mostly by public and private nonprofit providers (Österle and Heitzmann 2009). Until the early 1990s, social policies in Austria were characterized by expansion. From the 1980s, however, cost containment concerns became more prominent and led to a relative stability in the level of social expenditure from the mid-1990s. Public social expenditure as a percentage of GDP increased from 26.1 % in 1990 to 28.9 % in 1995, and stood at 28.3 % in 2008 (compared to 26.2 % in the EU27 average).

Developments in long-term care were different. Until the early 1990s, long-term care was not identified as a distinctive “social risk.” The bulk of care was provided within families and households, mostly by women. Public support was based on provincial social assistance legislation. Strong family orientation was rooted in widely shared perceptions that it is the family’s responsibility to provide care to family members, both children and frail older people. This perception was also supported by legislation, requiring family members, e.g., to contribute to the funding of care when residential care was needed. Historically, the major source of public cofunding for long-term care was poverty relief programs. These were replaced by provincial social assistance schemes in the 1970s. Different from earlier poverty relief programs attempting to provide a subsistence level, regional social assistance laws also began incorporating social services supporting older, chronically ill, and disabled people (Melinz 2009; Tálos and Wörister 1994). Until the 1980s, provision of long-term care services was dominated by residential care. Providers were either public authorities or private nonprofit organizations. Community care services have historically been

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available in some locations, but remained unavailable in large parts of the country. Only since the 1980s, there has been a stronger political rhetoric to expand community care services. Overall, until the early 1990s, long-term care was not addressed as a distinctive field of social protection. The provision of public support for long-term care was split between federal benefits (including a pension supplement from 1958 and medical home nursing introduced in 1992), regional benefits and services for people with disabilities, social assistance-funded services, and a child care benefit supplement for children with disabilities, and tax regulations (Pfeil 1996).

Initiatives and debates that started in the 1980s finally led to a major long-term care reform in 1993 (see Sect. 8.2). At the core of the reform was a novel and nationwide “cash for care” program. In addition, the reform has contributed to establishing a common understanding of the policy field and confirmed the regional responsibility for service development in residential care and in community care. In Austria, long-term care is now defined as care for people of all age groups in need of constant support due to chronic illness or disability. Care is now organized around three main pillars: family care, cash for care, and social services (Österle 2001). Since the 1993 reform, developments in long-term care have been characterized by gradual changes, by measures of expansion, in particular with regard to social service development and support for informal carers, but also in terms of retrenchment (see Sect. 8.3). A further intensely debated reform was implemented in 2007 as a response to a growing gray economy of migrant care (see Sect. 8.4).

This chapter analyzes the reform developments in the Austrian long-term care sector. In studying the developments from the establishment of long-term care as a separate social policy field in 1993 up until today, this chapter focuses on two major aspects: (1) it analyzes the aims, tools, and effects of major reforms and of gradual changes in that period; and (2) it studies the driving forces behind the changes, including the role of actors and the specific reform mechanisms. The analysis follows the framework introduced in the introductory chapter.

8.2 The 1993 Cash for Care Reform

Year 1993 marked a major turning point for the Austrian long-term care system. The reform implemented in that year included both central and provincial regulations and a so-called State–Provinces Treaty. The latter was a result of the federalist structure of this country, wherein both central and provincial levels have responsibilities in relation to the provision and funding of long-term care. State–Provinces Treaties are aimed at making arrangements between governmental levels where complex matters of competence have to be resolved. The 1993 Treaty on Long-Term Care was aimed at a system of uniform principles for social protection towards the risk of long-term care. The first major element of the agreement was a ‘cash for care’ system detailed in a Federal Long-Term Care Allowance Act, and, following the same principles, objectives, and provisions, in nine Provincial Long-Term Care Allowance Acts (see below). In addition, the agreement confirmed provincial responsibility for

social service developments. Provinces had to develop an adequate infrastructure of residential, semiresidential, and community care services. To achieve this, provinces were required to establish plans on the future need and development of services at the regional and local levels. The agreement included information on how to structure these plans, while criteria for services and quality remained rather vague. Finally, the central level took responsibility for developing a system of social insurance coverage for family carers. For the respective services and benefits, the treaty established that costs had to be covered by the competent governmental level. The treaty was signed in May 1993 and became effective on 1 January 1994.

Together with the treaty, the care allowance system became effective on 1 July 1993. The system was introduced with a Federal Long-Term Care Allowance Act and nine Provincial Long-Term Care Allowance Acts, following the same provisions (Pfeil 1994). Responsibility for funding the care of recipients in receipt of other current or potential federal benefits, such as pensioners, lies with the federal state, while provinces are responsible for funding the care of recipients with no federal benefits, such as recipients of social assistance and for provincial or local civil servants. From 2012, however, the central level will become the only competent governmental level for the administration of the care allowance scheme. According to the legislation, individuals of all age groups with care needs above 60 h per month (above 50 h per month prior to 2011) are eligible for the care allowance (*Pflegegeld*). The benefit is defined as a contribution to care-related expenses and is paid in seven different levels to those in need of care (see Table 8.1). Different from budget-oriented cash for care systems, there is no predefined use of the benefit in the Austrian system. The care allowance is paid to about 5.1 % of the Austrian population or 432,739 recipients (as of 31 December 2009). At the end of 2009, 54 % of recipients were in benefit levels 1 and 2 and 15 % of beneficiaries were in benefit levels 5–7 (see Table 8.1). The 82 % of beneficiaries were aged 61 and above and almost 50 % were aged 81 and above. Recipients of the care allowance account for about 19 % of the total population of those aged 61+ and for about half of the total population of those aged 81+.

According to Article 1 of the Federal Long-Term Care Allowance Act, the intended purpose of the new scheme is to provide a lump sum contribution for care-related costs, ensuring recipients of necessary care and help and to improve the opportunities for a self-determined life. Following the debates leading to the enactment, the care allowance system aims to enable chronically ill people to stay in their private homes; promote autonomy and free choice of care arrangements; support informal care provided in the family; and create incentives for consumer-driven community care development (Badelt et al. 1997; Gruber and Pallinger 1994; Pfeil 1994).

The State–Provinces Treaty, apart from the care allowance scheme, also addresses social service development. The Treaty confirms regional responsibility for service development and obliges regions to develop an adequate infrastructure for residential, semiresidential, and community care development. To achieve this, regions had to establish development plans covering the 15-year period between 1996 and 2010 (*Österreichisches Bundesinstitut für Gesundheitswesen [ÖBIG] 1999*). However, there are only few general standards defined. There are no common benchmarks in terms of service density and no sanctions attached to the agreement. The organization

Table 8.1 Long-term care allowance: benefit levels and benefits 1993, 2002, 2011. (Source: BMA-SK 2011)

Benefit level	Definition of care needs (January 2011)	Benefit recipients (31 Dec 2009)	Benefit level		
			1 July 1993 (€) ^a	1 Jan 2002 (€)	1 Jan 2011 (€)
1	>60 h ^b	90,889	181.70	145.40	154.20
2	>85 h ^b	142,250	254.40	268.00	284.30
3	>120 h	72,975	392.40	413.50	442.90
4	>160 h	62,279	588.60	620.30	664.30
5	>180 h, Exceptional care needed	38,622	799.40	842.40	902.30
6	>180 h, Care measures difficult to time or permanently required care day and night	16,484	1,090.10	1,148.70	1,260.00
7	>180 h, Complete immobility	9,240	1,453.50	1,531.50	1,655.80

^aAustrian Schillings (ATS) converted to €: € 1 = 13.7603 ATS

^bMinimum eligibility requirements have been changed from 50 h/month to 60 h/month (level 1) and from 75 h/month to 85 h/month (level 2) from 1 January 2011.

and governance of the two pillars—cash and services—is only loosely connected. While the care allowance scheme follows nationwide principles, regulations for social services differ across the nine provinces. Care allowances are established as a social right, while this is not the case for social services. While a specific cash benefit level is often used as a criterion defining access to publicly cofunded services, the content of service use is determined separately. Assessment procedures for the cash and the service pillar are not integrated. As a consequence, developments in the cash for care system and in the service sector are not systematically coordinated, leaving considerable room for unintended effects and reactions.

This leads to the question about the factors that have driven the development of a cash-oriented and tax-funded long-term care policy in Austria. Behning (1999) defines three phases leading to the 1993 reform. The period prior to 1985 is defined as a “period of problem definition.” Activities started with emerging critique on the status quo in the 1970s and in particular with activities around the UN “International Year of Disabled Persons” in 1981. Key actors at that time were representatives of people with disabilities (organized in the Austrian Working Group for Rehabilitation) and an Austrian National Committee bringing together representatives of disability organizations, social service providers, and central, regional, and local levels. Documents from that period published by the aforementioned stakeholders already proposed a cash for care system. The second phase is defined as the “agenda setting period” lasting from the mid-1980s until 1990. In the second half of the 1980s, disability organizations and Members of Parliament intensify their efforts in lobbying for a long-term care reform. A 1988 Working Group, not specifically addressing people with disabilities, but individuals in need of long-term care, indicated an attempt to

broaden the focus beyond the interests of disability groups, even if the latter remained the main drivers of the reform debates. It was disability organizations and provinces in particular that pushed for long-term care reform in this phase. From the late 1980s, some provinces become increasingly active in the debate, the two Western provinces of Vorarlberg and Tyrol favoring a cash-oriented system and Vienna favoring a service-oriented system. At that time, the provision of social services was comparatively well-developed, both in Vorarlberg and in Vienna. Vorarlberg, a more rural region with smaller cities and dominated by conservative governments, in many respects, has a tradition as innovator in local social policies. At the same time, family orientation is strong in this province. In Vorarlberg and in Tyrol, the cash benefit approach was favored as a measure to support families in care provision and to facilitate care in the private environment of the user. Vienna is the most urban agglomeration in the country and is dominated by social democratic governments. This provincial government strongly preferred federal support for social service development. The Working Group, however, closed its activities in the early 1990s without consensus in terms of both cash versus service orientation and funding. Nonetheless, activists further drove debates towards a nationwide reform. Developments were also facilitated by the introduction of a regional ‘cash for care’ program in the province of Vorarlberg in 1990, which later became an important template for the nationwide scheme.

The third phase of “policy formulation” (1990–1993) started after the federal election in October 1990. The new government defined the objective as the development of a comprehensive nationwide system of social protection towards the risk of long-term care. Policy formulation was delegated to several working groups and was repeatedly pushed by manifestations of disability organizations, including a hunger strike. In 1991 and 1992, draft acts were sent out for expert opinions. Cash versus service orientation was a major issue of debate. While the Minister of Social Affairs (social democrat) was supportive of the ‘cash for care’ system, the capital city Vienna (which at the same time was a province), governed by the Social Democratic Party, promoted a service model. The ‘cash for care’ approach was also supported by the Conservative Party, in particular by some of the provinces, and by the Green Party. Disability groups, as throughout the reform process, were strongly advocating for the cash option. In this phase, funding became a second major issue in the discussions. Some provinces (in particular Vienna and Salzburg, governed by social democratic and conservative governments, respectively) and some representatives of the governing coalition parties (the Social Democratic and the Conservative Party) stressed the budgetary implications and recommended a step-by-step introduction. Social partners also became more involved in the debates in this phase. The trade unions (voluntary membership) and the Chamber of Labour (mandatory membership), who were representing the views of employees, were in favor of a service-oriented system, and so emphasized the need to strengthen employment in the social services. Before the enactment of the legislation, the social partners—in particular the Chamber of Commerce and the Chamber of Labour—articulated strong objections because of the financial implications for labor-related costs. Together with disability groups, however, the Minister pushed for full implementation in 1993. The Act finally became enacted in early 1993 and effective from 1 July 1993.

With the 1993 reform, Austria confirmed and clarified the traditional model of shared responsibilities between national, regional, and local levels in long-term care. Despite the roots in earlier provisions and despite continuity in the general organization of social service provision, 1993 signified a major turning point in terms of addressing the challenge of funding and organizing long-term care and in terms of considerable welfare state expansion from that point. Compared to an earlier federal benefit—*Hilflosenzuschuss*, which was paid at a flat rate benefit of about € 220 to pensioners—the introduction of the care allowance scheme led to an increase of central public expenditure by 64 % in 1994. While federal long-term care expenditure on the care allowance amounted to € 1.34 billion in 1994, it would have been just € 0.82 billion according to the pre-1993 legislation (*Bundesministerium für Arbeit, Soziales und Konsumentenschutz* [BMAASK] 2011). In terms of the care regime or the broader welfare regime, the reform involved both continuity and change. Unlike Germany, Austria did not follow the tradition of social insurance. Establishing a fifth social insurance pillar was not an intensely debated option in Austria. Increasing labor costs, articulated by the Chamber of Commerce and the Chamber of Labour, was a major argument against social insurance. However, there was an intense debate on cash versus service orientation; the latter favored by the region of Vienna and by social service providers. The final decision for a ‘cash for care’ system was rooted in a variety of factors. As noted above, disability organizations, following independent living ideas, emphasized autonomy and self-determination throughout the reform debates and also strongly favored the cash approach. Political actors across the political spectrum were also in favor of a ‘cash for care’ scheme even if for very different reasons, including support for family care, support for autonomy, for user-driven market developments, or cost containment. In terms of benefit design, the new care allowance system replaced a previous highly fragmented and partly means-tested system of cash benefits. Apart from these policy-specific factors, the use of cash benefits is also rooted in the broader welfare regime setting. Similar to long-term care policies, cash orientation also characterizes family policies in this country (Leitner 2011). In terms of the welfare mix (dominated by public and nonprofit providers), the 1993 reform did not establish any particular incentives for changes. However, it was assumed that the cash benefit would induce consumer-driven developments in service provision. Finally, the new care regime retained a strong family orientation, even if actors pushing for the reform had very different perspectives on the role of the family in terms of the delivery of care (Behning 1999). Taken together, the reform was partly an abrupt transformation and partly it started a process of “reproduction by adaptation” (Streeck and Thelen 2005).

8.3 Stability with Gradual Changes After 1993

The period after the 1993 reform was characterized by gradual changes, both in the regulatory framework and as a result of actor behavior. The changes, which led to both extensions and retrenchment, occurred in three areas, in the ‘cash for care’

system, in the social service sector, and in policies related to the role of informal carers. With regard to the care allowance, very little change occurred. There have been some adaptations in the criteria applied in the assessment, a cut in the benefit level 1 (in 1996), changes in the definition of benefit level 5 (in 1999), an extension in the definition of care needs recognizing the particular needs of people with dementia and of severely disabled children (in 2009), and a tightening of eligibility criteria for benefit levels 1 and 2 (in 2011). As agreed in the State–Provinces Treaty, benefit levels were price-adjusted in 1994 and 1995. After that, however, for many years benefit levels were not adjusted to inflation (see Table 8.2). As a consequence, the “no changes” policy has significantly decreased the purchasing power of the benefit by almost 20 %. A cost containment policy was not made explicit, but cost containment considerations have driven decisions not to adjust benefit levels. In particular, disability groups and social service providers opposed nonadjustment, but this was not widely supported in the policymaking arena or by the media.

As mentioned before, in the State–Provinces Treaty, provinces agreed to develop an adequate infrastructure of residential, semiresidential, and community care services. Even though the Treaty did not establish common benchmarks for levels of provision, the service sector has seen a substantial growth since 1993, with regard to staff numbers, service provision, and public expenditure. Surveys on long-term care workers indicate a significant increase in the total number of employees. Between 1999 and 2003, the number of employees in the long-term care sector increased by about 20 %, by 13 % in residential care, and by 32 % in home care (ÖBIG 2005). This trend was prolonged in the following period. Between 2003 and 2006, employment increased by 12 % in the long-term care sector overall, and by 36 % in the home care sector (ÖBIG 2008). At the same time, the average level of qualification among staff improved. With regard to service provision, in the residential care sector, the total number of beds remained relatively stable, but the number of nursing beds steadily increased while the number of beds with little or no nursing component decreased. By the end of 2008, residential care facilities provided a total of 72,358 places, with about 81 % designated as nursing care beds (*Bundesministerium für Soziales und Konsumentenschutz* [BMSK] 2008). Total public expenditure for nursing homes increased by 72 % between 2000 and 2008 (BMASK 2009). The home care sector has also seen a general increase in levels of provision. In 2008, 13.7 million h of community care services were provided in Austria, including home nursing, personal help, consultation, and other services. Compared to the year 2000, this is an increase of about 30 %. Total public expenditure for community care services increased by 46 % in the same period (BMASK 2009).

While there is no systematic analysis of the forces that led to the growth of the service sector, several factors have to be taken into account. Firstly, the care allowance has increased the purchasing power of potential users. At the same time, this effect was limited because copayments to be made by users have been increased since the introduction of the care allowance (Da Roit et al. 2007; Kreimer 2006; Österle and Hammer 2007). The calculation of copayments differs between provinces, but is usually designed as a combination of a flat rate contribution related to the care allowance, and a means-tested contribution related to the income of the user.

Table 8.2 Changes in the Austrian long-term care system 1993–2011

Effective from	Changes in the long-term care system	Central (c) Provincial (p)
1 July 1993	Introduction long-term care allowance (<i>Pflegegeld</i>): Federal Long-term Care Allowance Act (<i>Bundespflegegeldgesetz</i>), Provincial Long-term Care Allowance Acts (<i>Landespflegegeldgesetze</i>)	c, p
1 January 1994	State–Provinces Treaty: defining federal and provincial responsibilities in long-term care	c, p
1 January 1994	Increase care allowance by 2.5 %	c, p
1 January 1995	Increase care allowance by 2.8 %	c, p
1 January 1996	Regional development plans for residential, semi-residential, and community care services implemented (covering 1996–2010)	p
1 January 1998	Family carers: subsidized pension insurance (hypothetical employer contribution paid by the state)	c
1 January 1999	Redefinition eligibility criteria for care allowance level 4	c, p
1 July 2001	Elimination of the previous age limit (3 years) in the care allowance scheme	c, p
1 July 2001	Family carers: noncontributory social health insurance from care allowance level 4	c
1 July 2002	Family hospice leave scheme	c
1 January 2004	Financial support scheme for temporary respite care	c
1 July 2004	Residential Home Act (<i>Heimvertragsgesetz</i>)	c
1 January 2005	Increase care allowance by 2 %	c, p
1 July 2005	Residential Home Residence Act (<i>Heimaufenthaltsgesetz</i>)	c
26 July 2005	State–Provinces Treaty on a modular educational system for social care professions	c, p
1 July 2007	Regularization 24 h care: Home Care Act (<i>Hausbetreuungsgesetz</i>), amendments to several other Acts, introduction of financial support scheme for 24-hour care	c, p
10 April 2008	Amendment to the Health and Nursing Act	c
1 November 2008	Financial support for 24 h care: extension of benefit, abolition of asset test	c, p
1 August 2009	Family carers: free social pension insurance and noncontributory social health insurance from care allowance level 3	c
1 January 2009	Increase care allowance by 3–4 %	c, p
1 January 2009	Extension in the definition of care needs recognizing the particular needs of people with dementia and of severely disabled children	c, p
Till 1 January 2009	Recourse to family members in funding residential care abolished in all provinces	p
1 January 2011	Tightening eligibility criteria for benefit levels 1 and 2	c, p

For the provincial level, only changes implemented in the entire country are listed.

In addition, copayment schemes might differ in whether and how they refer to household composition. For example, in Vienna, copayment calculation considers the level of the care allowance, the income of the user, and the number of service hours needed. The maximum copayment is € 24.95 per hour for home nursing or € 19.00 for home help in 2011 in this province. For specific services, low-income users can be exempted from copayments. Another limitation in the purchasing power of the care allowances arises from the aforementioned lack of regular price adjustment of the benefit. Secondly, the evolution of social services was determined by the regional development plans, which led to activities on regional and local levels in expanding home care services (ÖBIG 2008). The rhetoric of “outpatient before inpatient” was increasingly translated into policies by offering residential care to those with more extensive care needs and by developing social services to enable users to remain at home. Thirdly, while family orientation and the sole use of family care are still widespread in Austria, community services increasingly became perceived as a supplementary option to cover specific care needs (Österle et al. 2011).

Throughout the past two decades, there have been repeated calls for some harmonization in the social service sector beyond provincial borders. While respective attempts have regularly received considerable opposition, harmonization became effective in three particular areas. The provisions of the Residential Home Act (2004) and the Residential Home Residence Act (2005) were aimed at transparent relationships between residents and homes and included regulations on contracts, personal rights, and confidentiality (Ganner 2005). In 2005, a State–Provinces Treaty established the framework for a modular nationwide educational system for social care professions, which was implemented at the regional level until 2008 (BMASK 2011).

The third area of change after 1993 was in relation to the provision of support measures for informal carers, or, more specifically for family carers. The State–Provinces Treaty required the central level to establish a system of social insurance coverage for family carers. The respective steps took more than a decade to implement. From January 1998, family members caring for a care allowance recipient with benefit level 5 and above had access to social pension insurance coverage at a reduced contribution rate. Later, this option was extended to family members of care allowance recipients in receipt of benefit level 3 and above. However, the take up remained low. Only from August 2009 have contributions for social pension insurance of family carers been fully covered by the state, if the care receiver is in receipt of benefit level 3 or above. Noncontributory coverage for social health insurance has been available for family members caring for someone with benefit level 4 and above since 2001. From August 2009, eligibility is extended to family members caring for a care allowance recipient with benefit level 3 and above. Apart from family members, this option is also open to nonkin if they have been living in the same household with the person in need of care for at least 10 months. Several other measures also address the needs of family carers; however, many of these, only as pilot programs or as programs limited to single regions or single provider organizations. A nationwide financial support program is offered for respite care for family members caring for someone in receipt of benefit level 3 and above, and—from 2009—when caring for people with dementia or for children in receipt of benefit level 1 and above. This support is means-tested

and is limited to a maximum of 4 weeks per year. Another major federal program supporting informal care is the Family Hospice Leave Scheme (introduced in July 2002) allowing 3 months leave (extendible to 6 months) when caring for a terminally ill family member. For seriously ill children, it can be extended to 9 months (since 2006).

The period from 1993 until today is then characterized by mostly moderate and gradual regulatory changes but quite substantial extensions in the level of social service provision. In the social service sector, regional development plans had an important indicative role for these changes. Changes were not the result of a major new legislation but of changes in the institutional and administrative practice between social service providers and provincial and local levels. Changes on the ground have also been important in terms of case management or quality management procedures. In this period, social service providers, in particular a Working Group representing the major provider organizations became key actors in pushing for further reforms. Disability groups remain another key actor, in particular in advocating the particular ‘cash for care’ approach, while representatives of senior organizations—at least until very recently—have not been proactive in calling for long-term care reforms.

Taken together, the period after 1993 can be characterized as one of regulatory stability. Changes in that period do not signify a move away from the model implemented with the 1993 reform. There has been a considerable extension in community care provision, but without any major changes in the regulatory framework. There have been repeated calls for some harmonization in social service delivery across the country. The aforementioned central laws on residential care and the State–Provinces Treaty on the educational system indicate some trend in that direction, but it is unclear whether this is the beginning of a “layering” process (Streeck and Thelen 2005), which will lead to convergence in the governance of social service provision. While debates on the future of long-term care arise now and then, it was only in the summer 2006 that long-term care again became a major public policy issue.

8.4 The Regularization of Migrant Care 2007

From the 1990s, an increasing number of migrant “24-hour care workers” have been providing paid care work in private households in Austria. What started as informal arrangements in border regions based on informal social networks across borders soon developed into a system where commercial agencies acted as placement organizations. The typical arrangement was with two carers working on a fortnightly shift in one household. The characteristics of the Austrian care allowance scheme, limitations in the availability and the affordability of home care services, and the availability of cheap labor just across the border in an increasingly open border regime have been identified as major drivers of the emergence of a gray economy of care (Österle and Hammer 2007; Schmid 2009).

It is estimated that at least 30,000 or so, 24 h care workers have been active in Austria in 2006 (Schmid 2009). The respective work arrangements have predominantly

been outside labor and social security regulations. After a media-driven debate (see below), the first regulatory step was an intermediate amnesty. Accordingly, there was no prosecution for illegal 24 h care work arrangements until June 2007, later extended until June 2008. The regularization of 24 h care became effective from July 2007. At the center of the reform was the Home Care Act (*Hausbetreuungsgesetz*) defining a new occupational group, the personal care workers. Such individuals can work as self-employed or as employees, though the latter are to some extent rare because of work time and social security regulations, which make this option considerably more expensive. The implementation into the broader care and labor market regime was achieved through amendments to several laws. The reform determines qualification requirements, which are linked to a financial support scheme, and the tasks that personal care workers are allowed to perform. As a qualification requirement, the reform accepts a training course equivalent to that of home helpers (amounting to 200 h), but also proof of previous care work experience in a private household for at least 6 months. To users of the arrangement, the regularization involves considerable additional costs. To ensure affordability, the second major objective of the reform, a financial support scheme, was added to the Federal and the nine Provincial Long-Term Care Allowance Acts. The respective benefit is means-tested and amounts to a maximum of € 1,100 per month (€ 800 until October 2008) for employed personal care workers and to a maximum of € 550 per month (€ 225 until October 2008) for a self-employment arrangement (BMASK 2009). In spring 2011, about 27,000 individuals have been registered and are active as self-employed personal care workers.

Apart from regularizing employment arrangements in private households, the reform has also some important indirect implications for the long-term care sector more generally, and will probably impact on the development of the sector to an even greater extent in the future. After the regularization, social service providers have also started to act as placement organizations. With the involvement of social service providers, a coordination of the different types of services and even the inclusion of personal care in case management procedures might gradually become more common (Österle and Bauer 2010). The personal care scheme allows a connection of a previously gray economy of care with the traditional social service system. However, the construction of the new personal care arrangement could also encourage a tendency toward deprofessionalization. Compared to social care workers with similar tasks, formal qualification requirements for personal 24 h care workers are smaller. Given both the costs involved and the work time the different arrangements allow, 24 h care can become a significantly cheaper and more attractive option for users than traditional home care services, in particular where users need extended hours of home care services and where they have to make larger copayments (Österle and Bauer 2010). However, while the regularization establishes labor and social security rights, personal 24 h care work often remains a precarious work arrangement. This is because of the dominance of the self-employment arrangements and because of the particular patterns of the work arrangement such as the hidden character of work in private households or the insecurity in the duration of the work relationship (Haidinger 2010; Kretschmann 2010).

The initial impulse for the regularization of 24 h care was an intense, media-driven debate in the summer of 2006. Prior to a federal election on 1 October 2006, the illegal status of migrant care arrangements suddenly became a major public issue in that summer. The starting point was a couple of cases in Lower Austria, where individuals were charged for the illegal employment of carers in private households. These cases were reported in the media. A few similar cases had been recognized in the media before, but this time the issue turned into a broad and intense public debate. Not least because media-disclosed cases included families of leading politicians who had been using migrant care work. The context of a preelection phase during the usual media summer slump allowed long-term care or rather, the issue of migrant care, to become a major issue of public debate. In view of the election, there was considerable consensus in the messages of the political parties, which were also widely supported in the media: (a) that the arrangements were illegal, (b) that care recipients should not be kept responsible (following the assumption that they often did not have any affordable alternative to receive the necessary care), and (c) that politicians should urgently find a response. The short-term response was a temporary amnesty, followed by the reform outlined above.

The main actors in the preelection period were the media and representatives of political parties. While early responses by the governing parties attempted to play down the significance of migrant care (“there is no stage of emergency in long-term care”), it soon became obvious that the public debate would not fade away. Soon, there was consensus on the aforementioned messages. However, there were significant differences in the ideas about how to regularize migrant care (Bachinger 2009). Most parties supported approaches to legalize 24 h care, except for the right-wing parties (after a split, one of these parties was coalition partner, the other opposition party), who were calling for approaches to employ Austrian workers rather than migrants. Representatives of the governing Conservative Party emphasized the need for legalization, but also a need to consider the costs that regularization would involve. Opposition parties and the unions strongly criticized low-cost regularization approaches for legalizing highly precarious work contracts. Overall, the two dominant issues in the debates were regularization and affordability. A call for extensions in community care and an emphasis on quality of care, mainly articulated by social service providers and by representatives of the nurse and social care professions, received little support beyond rhetoric. Altogether, the debates and the policy responses discussed in 2006 and 2007 were almost exclusively around 24 h care. Any attempt to take the opportunity for a more far-reaching reform of the long-term care system was not taken up.

The 2007 regularization reform consisted of two major elements. The Home Care Act defined a new occupational group, the so-called personal care workers in private households, who can work either as self-employed personal care workers or as employees. The self-employment mode became the preferred option, both because of the lower costs involved and because of the flexibility in work time arrangements. The second major effort of the 2007 reform was a financial support scheme to ensure affordability of the personal care arrangement as compared to the previous irregular 24 h care arrangement. The Home Care Act was passed as

proposed by the government, despite much criticism. The debate on the financial support scheme, however, continued for the entire year of 2007 (Bachinger 2009). In particular, it was disputed how to share funding responsibilities between central and provincial levels and how to define means-testing criteria. Originally, means testing considered income and assets of the user. After one province started to abolish the asset test, others followed soon, which led to the abolition across the country in November 2008. These debates led to an interesting side effect in the residential care sector. In the course of the discussions, recourse toward family members in funding residential care—still in place in the majority of provinces at that time—was abolished.

From a care regime perspective, 24 h care was an unintended development. There was no reference to the potential development of a gray economy of care in the early 1990s. However, the concept of 24 h care and the particular arrangement did fit with a predominant care responsibility culture (Weicht 2010). Most actors have always emphasized care at home as a preferred care arrangement, even if with very different understandings of the role of the family and other potential caregivers. The care allowance established social rights and extended public support, but at the same time followed the familialistic tradition. When families were unable to provide necessary care for long hours, 24 h care often offered the only option for home care. Before the regularization, however, 24 h care was a separate pillar, parallel to the traditional social service sector. Following law suits, service providers even followed a policy not to provide services when there was a 24 h care worker in the private household. The regularization was an effort not only to develop a framework for legal employment of care workers in private households, but also to establish qualification requirements and task descriptions to contribute to an integration of services.

Separate from the 1993 reform and the phase of continuity that followed over the next 15 years, the regulation of 24 h care can be described as “institutional change through process sequencing” (Jensen 2009). The reform very strictly focused on one aspect of the long-term care issue, namely the regularization of a previously gray economy of care. It did not change the general care regime characteristics, but has added an important new element. Given an estimated 30,000 irregular 24 h care workers in 2006, the 27,000 regularized personal care workers in Spring 2011 can be seen as a success, in terms of take up of the regularization. In an overall perspective, however, migrant care is less frequent than in countries like Italy or Spain. Considering the typical arrangement with two personal care workers on biweekly or monthly shifts in the private home of the user, the arrangement is used by about 3.1 % of those receiving a care allowance, or 6.7 % of those in receipt of benefit level 3 and above. While the personal care work arrangement is used by about 13,500 private households, there are 130,000 users of traditional home care services. How the two sectors evolve and whether the two types of services will become more integrated will have important implications for the future development of the care sector in Austria.

8.5 Developments, Dilemmas, and Perspectives

The 1993 reform marks an important turning point for the ways in which long-term care is addressed in the Austrian welfare system. Before that reform, responsibilities for the provision of long-term care were largely attributed to families. Welfare state responses were highly fragmented (in terms of target groups, eligibility criteria, and regional governance) and were mostly social assistance oriented. With the 1993 reform, a distinctive welfare sector was established that is regularly covered in public debates and in the media. Long-term care became defined as a sector that provides support for people in need of care and help due to chronic illness, disability, or frailty, independent of their age or the cause of the limitations.

The perception of family responsibility and the actual role of families in caregiving is still strong in this country, as shown, for example, in Eurobarometer surveys on preferences and expectations regarding long-term caregiving (European Commission 2007). At the same time, there is also increasing expectation that the welfare state should support those in need. The 1993 reform and subsequent developments have substantially extended public responsibility in this sector. The care allowance is designed as a universal benefit, but as a benefit that contributes to, rather than fully covers care-related costs. In the residential care sector, the major change has been a move towards settings that primarily focus on those with more severe care needs. The community care sector has seen a substantial increase in the level and the diversity of services. Services became available across the country, which has reduced previous enormous territorial inequalities in the availability of respective provisions. Despite these expansions, there has also been some significant retrenchment. A major example for cost containment is that care allowances for many years have not been price-adjusted. The tightening of eligibility criteria for benefit levels 1 and 2 in 2011 is another example. On the other hand, in 2009, eligibility for disabled children and for people with dementia was facilitated. This indicates that there is some trend to limit access for those with more moderate care needs and to extend it for those with more intense care needs. In the service sector, retrenchment is less visible because of a general expansion of services. However, limitations in publicly cofunded provisions or the specific rules for calculating copayments put a limit to the respective provisions. It was not least these limitations in social service consumption that helped the development of 24 h migrant care to become an additional option between family care and publicly cofunded community care provisions from the 1990s. The illegal work status only became a major political issue in 2006 leading to a regularization of migrant care work in private households in 2007 and a financial support scheme with the aim to ensure affordability for users. While the approach opened up a new regular option for arranging the necessary care, it was also recognized as a cost-effective way to provide long hours of care.

Overall, there is broad support for the major elements of the current long-term care system in Austria. There are, however, also important tradeoffs and dilemmas. The cash orientation is a strong pillar in the Austrian system. It is supported and defended with reference to concepts of autonomy and choice as well as recognition

and support for family care, but also for reasons of financial sustainability. Giving more substance to these aims reveals potential conflicts. For example, despite the existence of the cash benefit, choice is still limited as the benefit remains too small for many to actually exercise a broad range of choice options. The emergence of 24 h care was at least in part a response to this limitation. Another area for potential dilemmas is the link between cash provision and service consumption. In the German long-term care insurance system, ‘cash for care’ and services are integrated in the same system. Users have to make an explicit choice between ‘cash for care’ or services, or a combination of the two. In Austria, ‘cash for care’ and services are two separate pillars of the long-term care system. Applications for ‘cash for care’ and for service provision are two different procedures. Also, in contrast with Germany, there is no quality system in place to carry out regular inspection visits of the homes of care allowance recipients in Austria, even though recent programs attempt to at least partly cover recipients with such visits. These missing links between the cash and service system limit room for systematic quality assurance and for consultation and advice to care users and family carers. It is not least cost containment considerations that hinder broader implementation of such tools. Another area of conflict is the issue of professionalization. Evidence for the 1990s and the early 2000s shows that staff numbers have grown, in particular among those with larger levels of qualification (ÖBIG 2005, 2008). This is at least partly because of more intense care needs of users (in particular in the residential care sector), but it also indicates a further professionalization of the sector. On the other hand, the recent regularization of 24 h care offering relatively cheaper options for care work provision with smaller qualification requirements might create incentives for deprofessionalization, even more so when budgetary pressures increase (Österle and Bauer 2010).

While many of these issues regularly appear in the public debate, the current discourse is dominated by two major themes, the multilevel character of long-term care governance and the future funding of long-term care. Long-term care is characterized by the division of responsibilities between health and social care and between central, provincial, and local levels. While the care allowance scheme has been based on a Federal and nine Provincial Long-Term Care Allowance Acts, provisions have been harmonized across the country. According to a proposal already agreed between central and provincial levels, the central level will become the only competent governmental level for the administration of the care allowance scheme from 2012. In addition to the care allowance scheme, social insurance coverage for family carers is a federal responsibility. The provision and funding of residential and community care services, instead, is a provincial and local responsibility. In the health care sector, social health insurance funds—responsible for medically defined nursing care—are also important actors. As a consequence, attempts to further develop the system, to improve integration between health and social care, to better link cash provision and service provision, or to partly standardize procedures in the service sector across the country require cooperation and consensus between central and provincial levels.

Compared with other federal states, Austria is a relatively weak example (Obinger 2005). This is particularly true with regard to central fiscal jurisdiction. The

allocation of tax revenues to provinces and communities follows a fiscal equalization scheme. While federalism has often been identified as a barrier in welfare state expansion (Obinger et al. 2005), the federal structure in Austria, in a historical perspective, has also worked as a driver of innovation. The 1993 long-term care reform with some provinces as major drivers of the reform is an example of this. Currently, however, multilevel relations seem rather conflict-loaded in this country. This is true for long-term care, but also for other areas where competencies are split or where specific central and provincial responsibilities overlap, as in health, education, or child care. Despite considerable ideological differences between political parties, conflict lines on specific questions between the central level and the nine provinces often interfere with differences between political parties. This can work as a major hurdle for the development and implementation of reforms where central and provincial competences exist in the same sector. Many commentators have therefore called for a fundamental revision of central and provincial roles in this country.

In the recent past, the regularization of 24 h care, the introduction of the Residential Home Act, and the Residential Home Care Act are examples for federal legislation, while the harmonization of the educational system builds on a State-Provinces Treaty. In other areas, convergence took place. Examples are some convergence in social service development during the past two decades, which is due to provincial development plans and the political will to extend service infrastructure, or the abolition of recourse to family members in funding residential care in all provinces till 2008. Another typical feature of reform proposals with substantial financial implications is that representatives of central, provincial, or local levels call for a renegotiation of the fiscal equalization scheme. This was the case when the financial support scheme for 24 h care was introduced. Also, in current debates about the future system of funding long-term care, there are repeated calls to link this with a renegotiation of the fiscal equalization scheme.

Financial sustainability was always part of long-term care debates, but mostly just as one aspect among others. In the more recent and current debates, financial sustainability and the development of a new funding scheme have come to the forefront of long-term care debates. From the 1990s, several studies have looked at the implications of aging societies and the growing pressure on traditional family care models for future care needs and future long-term care expenditure (Badelt et al. 1996; European Commission 2009; Mühlberger et al. 2008; Streissler 2004). Arguments for a new funding scheme refer to the budgetary implications arising from sociodemographic changes, from the need to further expand publicly cofunded provisions and from already pressing budgetary situations on provincial and local levels, but also with reference to the existing general tax-funded system that might be more vulnerable to short-term cuts than a social insurance system. While the reform direction is still rather vague, various actors have become involved. A Working Group of the largest social service providers has worked out a proposal for a new funding scheme. Representatives of the Ministry, political parties, senior organizations, and disability groups have also articulated the need to establish a new funding scheme. The concept put forward for a structural reform is currently termed a “long-term care fund.” Indeed, a move towards social long-term care insurance is regarded

rather critically by most actors. Following the idea of an already existing fund in family policies, the long-term care fund idea implies that financial means should be pooled in a long-term care fund, which then serves as the major source for funding long-term care provisions. To what extent the fund should cover all or just part of current public long-term care funding is a major issue to be resolved. The multilevel character of long-term care could create a major hurdle for an agreement. While, e.g., the central level signals a willingness to financially support social service development, provinces oppose any attempt to link this financial contribution with a harmonization in the governance of social service provision, such as standardization in eligibility criteria, quality criteria, or copayment arrangements across the country. While representatives of the central level would be in favor of some harmonization, it is in particular social service organizations, which advocate for harmonization of eligibility and quality criteria. Disability groups do not oppose harmonization, but they fear that strengthening investment in the service sector will lead to a shift from a cash orientation to a service orientation in the Austrian long-term care system. As provinces and communities increasingly complain about the rapid growth of long-term care expenditure, this common challenge of budgetary pressure could finally work as leverage for a long-term care reform driven by the funding issue, but going beyond funding and involving broader structural reforms.

Summing up, long-term care is a latecomer in welfare state development in Austria as in many other European countries (Österle and Rothgang 2010). With the 1993 reform, however, long-term care became established as a distinctive welfare sector. The reform marks a major turning point in the history of Austrian long-term care policies, even if the reform also takes on board many traditional patterns of the long-term care system. Subsequent developments are characterized by continuity and adaptation but also by significant changes in specific parameters, in particular with the regularization of migrant care work. In terms of welfare coverage, the changes imply important extensions and a reduction of inequalities (as compared to the period before 1993), while cost containment considerations have continuously worked as a limiting factor. Whether current debates on a novel funding regime will lead to another major transformation of the Austrian long-term care system will not least be decided by how diverse interests and conflicts in the multilevel system are resolved.

References

- Bachinger, A. (2009). *Der irreguläre Pflegearbeitsmarkt. Zum Transformationsprozess von unbezahlt in bezahlte Arbeit durch die 24-Stunden-Pflege*. (Doctoral Dissertation). Universität Wien, Wien.
- Badelt, C., Holzmann, A., Matul, C., & Österle, A. (1996). *Kosten der Pflegesicherung. Strukturen und Entwicklungstrends der Altenbetreuung*. Wien: Böhlau Verlag.
- Badelt, C., Holzmann-Jenkins, A., Matul, C., & Österle, A. (1997). *Analyse der Auswirkungen des Pflegevorsorgesystems*. Wien: Böhlau Verlag.
- Behning, U. (1999). *Zum Wandel der Geschlechterrepräsentation in der Sozialpolitik. Ein policy-analytischer Vergleich der Politikprozesse zum österreichischen Bundespflegegeldgesetz und zum bundesdeutschen Pflege-Versicherungsgesetz*. Opladen: leske+budrich.

- Bundesministerium für Arbeit, Soziales und Konsumentenschutz (BMASK). (2009). *Österreichischer Pflegevorsorgebericht 2008*. Wien: Bundesministerium für Arbeit, Soziales und Konsumentenschutz.
- Bundesministerium für Arbeit, Soziales und Konsumentenschutz (BMASK). (2011). *Österreichischer Pflegevorsorgebericht 2009*. Wien: Bundesministerium für Arbeit, Soziales und Konsumentenschutz.
- Bundesministerium für Soziales und Konsumentenschutz (BMSK). (2008). *Altenheime und Pflegeheime in Österreich. Ost, Mitte, West*. Wien: Bundesministerium für Soziales und Konsumentenschutz.
- Da Roit, B., Le Bihan, B., & Österle, A. (2007). Long-term care policies in Italy, Austria and France: Variations in cash-for-care schemes. *Social Policy and Administration*, 41(6), 653–671.
- European Commission. (2007). *Health and long-term care in the European Union. Special Eurobarometer 283/Wave 67.3*. Brussels: European Commission.
- European Commission. (2009). *The 2009 ageing report: Economic and budgetary projections for the EU-27 Member States (2008–2060). Joint report prepared by European Commission (DG ECFIN) and the Economic Policy Committee (AWG)*. Brussels: European Commission.
- Ganner, M. (2005). *Selbstbestimmung im Alter: Privatautonomie für alte und pflegebedürftige Menschen in Österreich und Deutschland*. Berlin: Springer.
- Gruber, G., & Pallinger, M. (1994). *BPGG Bundespflegegeldgesetz. Kommentar*. Wien: Springer.
- Haidinger, B. (2010). “Was sind schon 1.000 Euro für 24 Stunden ohne Freizeit und Freiheit?” Undokumentierte Arbeitsverhältnisse von Migrantinnen in der häuslichen Pflege. In E. Appelt, M. Heidegger, M. Preglau, & M. A. Wolf (Eds.), *Who Cares? Betreuung und Pflege in Österreich. Eine geschlechterkritische Betrachtung* (pp. 77–85). Innsbruck: Studienverlag.
- Jensen, C. (2009). Policy punctuations in mature welfare states. *Journal of Public Policy*, 29(3), 287–303.
- Kreimer, M. (2006). Developments in the Austrian care arrangement: Women between free choice and informal care. In C. Glendinning & P. Kemp (Eds.), *Cash and care. Policy challenges in the welfare state* (pp. 141–153). Bristol: Policy Press.
- Kretschmann, A. (2010). Die Legalisierung hat uns überhaupt keine Vorteile gebracht. Die Vorteile gibt es nur für die Österreicher. In E. Appelt, M. Heidegger, M. Preglau, & M. A. Wolf (Eds.), *Who Cares? Betreuung und Pflege in Österreich. Eine geschlechterkritische Betrachtung* (pp. 187–195). Innsbruck: Studienverlag.
- Leitner, S. (2011). Germany outpaces Austria in childcare policy: The historical contingencies of ‘conservative’ childcare policy. *Journal of European Social Policy*, 20(5), 456–467.
- Melinz, G. (2009). Vom “Almosen” zum “Richtsatz”: Etappen österreichischer Armenfürsorge-/Sozialhilfe(politik): 1863 bis zur Gegenwart. In N. Dimmel, K. Heitzmann, & M. Schenk (Eds.), *Handbuch Armut in Österreich* (pp. 646–663). Innsbruck: Studienverlag.
- Mühlberger, U., Knittler, K., & Guger, A. (2008). *Mittel- und langfristige Finanzierung der Pflegevorsorge*. Wien: Österreichisches Institut für Wirtschaftsforschung.
- Obinger, H. (2005). Austria: Strong parties in a weak federal system. In H. Obinger, S. Leibfried, & F. G. Castles (Eds.), *Federalism and the welfare state. New world and European experiences* (pp. 181–221). Cambridge: Cambridge University Press.
- Obinger, H., Castles, F.G., & Leibfried, S. (2005). Introduction: Federalism and the welfare state. In H. Obinger, S. Leibfried, & F. G. Castles (Eds.), *Federalism and the welfare state. New world and European experiences* (pp. 1–48). Cambridge: Cambridge University Press.
- Österle, A. (2001). *Equity choices and long-term care policies in Europe. Allocating resources and burdens in Austria, Italy, the Netherlands and the United Kingdom*. Aldershot: Ashgate.
- Österle, A., & Bauer, G. (2010). *Migrant personal carers in private households: Motivations and perspectives*. Paper presented at the 8th Annual ESPAnet Conference. Budapest.
- Österle, A., & Hammer, E. (2007). The formalisation of informal care work: The case of Austria. In C. Ungerson & S. Yeandle (Eds.), *Cash for care in developed welfare states* (pp. 13–31). London: Palgrave.

- Österle, A., & Heitzmann, K. (2009). Welfare state development in Austria: Strong traditions meet new challenges. In K. Schubert, S. Hegelich, & U. Bazant (Eds.), *The handbook of European welfare systems* (pp. 31–48). London: Routledge.
- Österle, A., & Rothgang, H. (2010). Long-term care. In F. G. Castles, S. Leibfried, J. Lewis, H. Obinger, & C. Pierson (Eds.), *The Oxford handbook of the welfare state* (pp. 378–390). Oxford: Oxford University Press.
- Österle, A., Meichenitsch, K., & Mittendrein, L. (2011). Long-term care in Austria: Between family orientation, cash for care and service provision. In A. Österle (Ed.), *Long-term care in central and south eastern Europe* (pp. 41–66). Frankfurt: Peter Lang.
- Österreichisches Bundesinstitut für Gesundheitswesen (ÖBIG). (1999). *Dienste und Einrichtungen für pflegebedürftige Menschen in Österreich. Übersicht über die Bedarfs- und Entwicklungspläne der Länder*. Wien: Bundesministerium für Arbeit, Gesundheit und Soziales.
- Österreichisches Bundesinstitut für Gesundheitswesen (ÖBIG). (2005). *Beschäftigte im Alten- und Behindertenbereich. Entwicklung 1999–2003*. Wien: Bundesministerium für Soziale Sicherheit, Generationen und Konsumentenschutz.
- Österreichisches Bundesinstitut für Gesundheitswesen (ÖBIG). (2008). *Beschäftigte im Alten- und Behindertenbereich 2006*. Wien: Bundesministerium für Soziales und Konsumentenschutz.
- Pfeil, W. J. (1994). *Die Neuregelung der Pflegevorsorge in Österreich*. Wien: ÖGB Verlag.
- Pfeil, W. J. (1996). *Bundespflegegeldgesetz und landesgesetzliche Pflegegeldregelungen*. Wien: ÖGB Verlag.
- Schmid, T. (2009). Hausbetreuung. Die Legalisierungspolicy in Österreich. In C. Larsen, A. Joost, & S. Heid (Eds.), *Illegale Beschäftigung in Europa. Die Situation in Privathaushalten älterer Menschen* (pp. 53–78). München: Rainer Hampp Verlag.
- Streeck, W., & Thelen, K. (2005). Introduction: Institutional change in advanced political economies. In W. Streeck & K. Thelen (Eds.), *Beyond continuity. Institutional change in advanced political economies* (pp. 1–39). Oxford: Oxford University Press.
- Streissler, A. (2004). Geriatrische Langzeitpflege. Eine Analyse aus österreichischer Sicht. *Wirtschaft und Gesellschaft*, 30(2), 247–271.
- Tálos, E., & Wörister, K. (1994). *Soziale Sicherung im Sozialstaat Österreich. Entwicklungen, Herausforderungen, Strukturen*. Baden-Baden: Nomos Verlag.
- Weicht, B. (2010). Embodying the ideal carer: The Austrian discourse on migrant carers. *International Journal of Ageing and Later Life*, 5(2), 17–52.

Chapter 9

Long Term Care Reform in England: A Long and Unfinished Story

Caroline Glendinning

9.1 Introduction

This chapter is not about a single reform, or series of reforms. It documents some major changes that have taken place in the organization and delivery of long term care in England over the past two decades—in particular the introduction and elaboration of quasi-markets, and what might be considered to reflect New Public Management ideas aimed at improving efficiency both within long term care and at the interfaces between long term care and acute health care. However, it also documents the *failure* over the same period to achieve reform in the critically important area of funding. It is widely agreed that the current budgets for long term care services are woefully inadequate and unsustainable in the longer-term; and that the ways in which these resources are allocated are neither fair nor transparent. It is difficult to interpret these contrasting developments as characterizing any one of the modes of transformative change proposed by Streeck and Thelen (2005). Indeed, it is striking that one series of policy preoccupations—quasi-markets and choice—has been pursued so consistently and assertively over two decades by Conservative, Labour and Conservative–Liberal Democrat coalition governments alike, when all have found more fundamental funding reforms much harder to achieve.

A range of political and policy interests—not all with equally high public profiles—are involved in debates about long term care reform in England. Given their statutory responsibilities (see the following section), local authorities and social care professional leaders are important players, as are the associations of private (for profit and charitable) residential and domiciliary care providers. Organizations representing older people, people with learning disabilities and articulate campaigning groups of younger physically disabled people are key actors; indeed the latter groups have exerted major influences over the shape of reforms, by arguing that cash-based arrangements offer greatest opportunities for choice, control and citizenship. England also has a long-established and highly effective organization promoting the

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interests of family carers. Because they do not contribute directly to the funding of long term care, neither employers nor trade unions have historically been involved in debates about reform, although since 2010 public sector trade unions have begun to campaign against the coalition government's public spending cuts by highlighting the damaging impacts on quality of care.

9.2 Structure and Scope of LTC in England

England is unusual among developed welfare states, not only in the fragmentation of responsibilities within the care sector, but also in the residual nature of state funding for long term care and in the variable local arrangements governing access and levels of provision. Arrangements for funding and delivering long term care are highly fragmented. There is no single policy, funding or service stream that is widely understood as 'long term care'. Resources contributing to long term care are embedded within the separate budgets of the National Health Service (NHS), local authorities and the Department for Work and Pensions (DWP). Each of these also determines its own macro-level policies and micro-level resource allocation processes.

- Residential care, help with personal care and domestic tasks at home, day care and other daytime activities are the responsibilities of local authority adult social care departments. They are funded through a mixture of national taxation, distributed by central government to local authorities but without ring-fencing for specific services; local property taxation; and user charges. People with assets above £ 23,250 (including the value of a family home) are generally unable to access any local authority-funded residential or domiciliary care and even poor people pay charges. Overall, income-related user charges make up around 17 % of the entire spending on social care. Local authorities also have statutory duties to assess the needs of family carers and provide help for carers, most commonly in the form of respite care (or funding to be spent on respite care). Local authorities are additionally responsible for some housing-based support services, particularly for people with learning disabilities or mental health problems. In relation to older people, there is currently interest in developing 'extra care' and supported housing (specially designed or adapted housing with high level support services on the premises) as a less costly alternative to residential care.
- The National Health Service (NHS) contributes around £ 3.0 billion to long term care through the funding and direct provision of nursing care and therapy services for people in their own homes or residential care. NHS services are funded from general taxation and are free of charge at the point of delivery. In addition, a small number of people—about 14 % of all nursing home residents in 2005—have healthcare needs that are so intensive or unstable that all their care is funded by the NHS (NHS continuing care), a funding regime equivalent to hospital in-patient status (Laing and Buisson 2005).

- Relevant social security benefits include the Attendance Allowance (AA), which is received by 1.4 million older people needing regular or substantial help with personal care or supervision; and Disability Living Allowance (DLA), which is claimed by 2.8 children and working age disabled people and includes an additional element covering extra transport costs for those with moderate to severe mobility difficulties. Both benefits are intended to meet the extra costs associated with disability. Benefit rates vary from £ 20 to £ 131 a week, depending on age, the level and frequency of help needed and whether the claimant has additional mobility difficulties. It is extremely difficult to calculate how many eligible people actually receive these benefits because of difficulties in estimating the size of the eligible population. Estimates range from 40 to 60 % (AA); 30 to 50 % (DLA care component) and 50 to 70 % (DLA mobility component; Kasparova et al. 2007).
- Family carers of AA and DLA recipients who have little or no income from other sources can also claim Carers Allowance, which is intended to replace earnings lost because care responsibilities prevent paid employment. These benefits are the responsibility of the Department of Work and Pensions and are administered nationally. However, because AA is usually included in means-tested calculations of user contributions for local authority social care, at least some of these benefits are effectively public expenditure transfers from one government department to another.

Total UK spending on long term care, as a percentage of GDP, is broadly comparable with other advanced welfare states such as Australia, Canada and Germany (OECD 2005). However, public expenditure accounts for only about 65 % of this total. The remainder is made up of user charges (around 17 %) and private purchase of services (Comas-Herrera et al. 2004). In addition, in 2007, the 6 million informal carers (about one in ten of the total UK population, according to the 2001 Census) contributed care equivalent to £ 87 billion (Carers UK 2007).

An estimated £ 13 billion (Wanless 2006) is allocated to people aged 65+ in England through these different arrangements. However, responsibilities for funding, assessment and service delivery are profoundly fragmented between different central government departments and between national and local organizations. Thus macro-level policies and resource allocations for both social care and NHS services are the responsibility of (different sections of) the Department of Health. Social care budgets are determined by individual local authorities; individual local authorities also decide whether they can support people with only critical level, or less acute, support needs in the light of their local budgets. There is more uniformity across England in the allocation of NHS services, but these ultimately rely on local professional assessments of need and discretion and some local variations still exist. The DWP administers AA, DLA and Carers Allowance on a national level across the UK as a whole.

In summary, access to public funding for long term care involves assessments that use different combinations of several different criteria, including: income and assets/wealth tests; health needs and needs for medical treatment; capacity for self-care and risks of harm; and other individual circumstances, especially the availability

of informal carers. These allocation arrangements lack strategic coherence; are not transparent or easily understood; may not be well-targeted on those with the highest level needs (Wanless 2006); and often involve costly duplicate assessments. In addition, policies and funding for NHS and local authority social care services are the responsibility of the individual countries of England, Scotland, Wales and Northern Ireland; only in relation to the DWP social security benefits are eligibility criteria and entitlements the same across all four countries of the UK (see Glendinning 2007 for further details). The following account relates only to England.

Partly because of this systemic fragmentation and partly because there are no national thresholds of eligibility for health or social care services, it is very difficult to estimate the coverage of English publicly-funded long term care services relative to need. In 2009, a Parliamentary Committee was told by senior civil servants in the Department of Health that about 6,000 older people had high support needs but received no social care services or informal care and around 1.5 million people (60 % of all disabled older people) had some shortfall in their care needs, if it is assumed they had no informal care to make up the deficit (House of Commons Health Committee 2010, p. 41). Reflecting policies to shift care from hospital and residential settings to community-based services, there has been a 1 % shift in expenditure from residential to community services over each of the five years from 2002–2003 to 2005–2007. During that time, the total number of older residents living in care homes with funding from local authorities fell by 13 %. Home care services are increasingly targeted at those with the highest levels of need; there was a 22 % reduction in the number of households receiving home care services of five or less hours per week during the same period. Meanwhile, the number of people using non-residential intermediate care services (see Sect. 9.5.2) following early hospital discharge rose from 98,000 to 225,000.

These structural arrangements have their origins in the institutions of the English post-war welfare state. In the late 1940s, responsibilities for ‘treatment’ and ‘cure’ were assigned to the newly established NHS, with local authorities responsible for longer-term personal and practical services for older people. Accordingly, while the NHS provided for the ‘ill’ and ‘sick’, the 1948 National Assistance Act made local authorities responsible for supporting people in need of ‘care and attention’ (Means and Smith 1998). In addition, policies and funding for both health and social care are entirely separate from cash benefits for maintaining income and living standards, including benefits to help meet the extra costs of disability and care. The funding and accountability mechanisms underpinning these divisions of responsibility have remained fundamentally unchanged ever since. However, the boundaries between NHS and local authority responsibilities have shifted markedly over time (Glendinning and Means 2004; Lewis 2001). Since the late 1940s, the NHS has withdrawn from virtually all responsibilities regarding non-medical care for people with long term support needs. Thus, during the 1970s, a series of central government circulars defined older people with ever higher levels of frailty and ill-health as ‘appropriate’ for local authority residential care, so that those considered to need ‘care and attention’ came to include people with severe cognitive impairments, those who were bed-bound and those in the final stages of terminal illness (Means and Smith 1998).

Similarly, since the mid-1990s, a series of legal test cases and government directives has restricted long term NHS services to only those with intensive or unpredictable health needs, as noted above (Glasby and Littlechild 2004; Glendinning and Lloyd 1998).

The following account will focus primarily on developments (and the lack of developments) within social care. These developments are characterized by the simultaneous co-existence of, and tensions between, institutional inertia and incremental innovation (particularly the extensive marketization that has been introduced into English long term care over the past two decades). Thus, long term care services have been transformed by two distinct waves of quasi-market development, and by the search for greater efficiency in service organization and delivery. At the same time, there have been repeated—and continuing (2011) failures to reform a system that is widely regarded as inadequate, inequitable and unsustainable; indeed, it is arguable that the twin pressures of marketization and efficiency have actually increased the difficulties of introducing more radical, transformative change. The following sections describe these contradictory developments and their consequences: the introduction and elaboration of quasi-markets within adult social care; the drive for improved efficiency; and the unresolved problems of funding and fairness.

9.3 The Development of Markets in LTC

The marketization of English social care has occurred in two main phases:

- The community care structural reforms of the 1990s.
- The development of consumerist initiatives from 2000 onwards.

9.3.1 *The 1993 Community Care Reforms—Introducing Markets into Social Care*

Until the 1980s, local authorities were both the funders and the providers of social care services, including home help (domiciliary care) services, residential homes and day centres. However, a series of reforms to means-tested social assistance benefits in 1980 made it easier for low income older people and those with disabilities to obtain social assistance funding for the fees for private residential and nursing home care. There is debate about how far the implications of these changes were anticipated or unexpected; however, their impact was dramatic. Both local authorities and NHS hospitals rapidly saw the opportunity to shift responsibilities for funding residential and nursing care to the social assistance budget and a private market in residential and nursing homes quickly developed in response to this new funding opportunity. Older people with low incomes and assets increasingly entered to institutional care solely on the basis of their low financial means, with no assessments of their actual needs for care, or consideration of whether alternative domiciliary based services might

provide appropriate levels of support. At the same time, NHS policies aimed to close the remaining long-stay hospital provision for people with learning disabilities and long term mental health problems and move them to community-based accommodation. The NHS was also experiencing considerable pressures on its long term geriatric hospital facilities. Again, social security funding for new community-based residential care was an attractive option.

Quite simply, these developments illustrated ‘cost-shunting’—the transfer of funding for long term care from constrained local authority and NHS budgets to the open-ended, needs-led social assistance budget. ‘The social security budget had inadvertently come to the rescue of families, local authorities and the NHS, all of them under tight budgetary limits and increasing demand. What the government had done was to create an effective voucher system’ (Lewis and Glennerster 1996, p. 4).

The result was an exponential increase in public spending on residential care; the rapid growth of a private market in residential and nursing home care, funded through the social assistance budget; and major disincentives to local authorities to develop domiciliary and community-based services to support people in their own homes. Between 1986 and 1991, social security spending on residential care rose from £ 10 m to over £ 2,000 m. For the first time in English social care, a substantial private care market had developed.

These trends were, however, contrary to the stated government policy of encouraging ‘community-based’ care—that is, care for older and disabled people in their own homes or at least non-institutional settings. The Audit Commission is an influential independent watchdog, responsible for ensuring that local authorities and the NHS secure good value for money through their use of public funding. In 1986, the Commission published a report (Audit Commission 1986), criticizing the ‘perverse effects of social security policies’ created by the social assistance rules and the consequent rapid increase in residential and nursing home provision, in contradiction to official policy. The Commission also criticized the fragmentation of responsibility between NHS and local authorities for community-based care and the lack of a single organization with clear lead responsibility.

Eventually, the then Conservative government appointed a Committee of Enquiry to review the resourcing of community care services and advise on changes. The report of this Enquiry (Department of Health and Social Security 1988) recommended that responsibility for funding and assessing social care needs should rest clearly with local authority social services departments. However, rather than recommending an expansion of the volume and range of directly-provided local authority social care services, the Enquiry argued that choice and efficiency should be stimulated through a ‘mixed economy’ approach, in which the public, private and voluntary sectors should compete on an equal footing to provide services: ‘The primary function of the public services is to design and arrange the provision of care and support in line with people’s needs’; a ‘mixed economy’ would encourage choice, flexibility and innovation, in a climate of competition (Department of Health and Social Security 1988, para 3.4). Information about the range of local needs that should shape local market development was to be generated through annual community care plans, created jointly with health and other local partners at the macro/strategic

level (Lewis and Glennerster 1996; Means et al. 2002). At the level of individual care recipients (older people or those with disabilities), the assessment of eligibility and micro-purchasing of services was to be the responsibility of local social care ‘care managers’. This was an important new ‘gatekeeping’ function, intended to cap the burgeoning social assistance expenditure on residential care by restricting eligibility to those with higher levels of need and encouraging the search for less costly and more appropriate alternative arrangements.

The proposed ‘mixed economy’ in social care reflected the dominant ideology of the Conservative Government, which was in a powerful position, having just won its third consecutive election. ‘Mixed economies’ were being imposed on other local government and National Health Services. The creation of a ‘mixed economy’ in social care was also a response to the then Prime Minister Thatcher’s antipathy towards public sector services in general and local authorities in particular, and her concern to support the newly emergent private residential care sector that had developed with social assistance resources.

Simply to cut off the flow of social security money to new applicants would lead to the bankruptcy of many small private homes. Not only had they become an influential pressure group, but they were exactly the kind of small family businesses which Mrs Thatcher approved (Lewis and Glennerster 1996, p. 6).

Eventually, Mrs Thatcher was persuaded to agree to the transfer of the social assistance budget to local authorities on condition that it was used to purchase private sector provision. In summary, the reforms were a response to a funding crisis—the haemorrhaging social assistance budget being spent on long-term residential care—with additional elements designed to minimize political outcry, appeal to groups representing service users and carers, and avoid awarding additional resources to local authorities (Lewis and Glennerster 1996).

Nevertheless, it was in 1993, another five years, before these recommendations were implemented. At that point, the social assistance funding that had been supporting people in residential care was capped and transferred to local authorities, who were encouraged increasingly to purchase services from independent, charitable and for-profit providers. In-house services were to compete with these alternative service providers. Social workers became care managers, responsible for assessing needs and for purchasing ‘packages’ of support to suit individual needs from those providers with whom the local authority had or was able to negotiate contracts (Means et al. 2003). In effect, market and consumer choices were exercised by care managers, on behalf of service users.

In summary, this stage of marketization reforms involved:

- Introducing ‘gatekeeping’ assessments of individual needs and separating these from the planning and procurement of services to meet those needs.
- Separating purchaser/commissioner and provider functions within the local authority.
- The gradual transfer of provision from local authorities’ own in-house services to the charitable and for-profit sectors.
- Business development, licensing and regulatory activities to support the development of new services and providers.

These reforms were successful. In 1992, the year before the reforms, the private sector was supplying only 2 % of all home care contact hours; by 2001 this had increased to 60 %. By 2001, 85 % of all residential care places for adults were provided by private organizations, although this was no longer an expanding market as increasing demand for domiciliary services, falling occupancy rates and other economic pressures squeezed the sector (Means et al. 2003). Some residential care providers diversified into new service areas such as respite care. Others closed, with associated insecurities for their residents. Subsequently the sector has been described as displaying ‘traditional tendencies to monopoly and standardization’ (Drakeford 2006, p. 936), as corporate and global healthcare organizations have acquired significant market shares and considerable policy influence at national and local levels (Schofield 2007). Thus the number of homes, and the number of places in them have both dropped, in line with policies of supporting people in their own homes for as long as possible, although the average size of homes has increased (CSCI 2009).

9.3.2 Consumerism, Disability Rights and Personal Budgets—Making Users the Purchasers

Since the 1980s, organizations of working-age physically disabled people had campaigned to receive their support in the form of a cash payment instead of services in kind. They argued that this would enable them to employ personal assistants and other carers to provide help with the tasks of their choosing, at the times and in the ways that best suited them. Exercising choice and control over their support arrangements through cash payments instead of services in kind constituted essential steps in achieving human rights and full, active citizenship (Morris 2006).

Legislation allowing local authority adult services departments to make cash direct payments instead of services in kind was implemented in 1997,¹ first to working age disabled people and from 2000 to people aged 65+, parents of disabled children, carers and disabled 16- and 17-year olds. This marked a clear break with the traditional post-war welfare state structure, in which cash payments were restricted to the social security and income maintenance functions of the Department for Social Security (later DWP), while local authorities provided (and, increasingly commissioned and purchased) services in kind (Glasby and Littlechild 2006). Commentators were quick to point to the uncomfortable alignment between disability and civil rights discourses and the neo-liberal discourses of the then Conservative Government that emphasized the rolling back of state responsibilities and a greater role for individual consumer choice:

¹ The 1996 Community Care (Direct Payments) Act was passed before constitutional devolution in the UK; it therefore covered, and was implemented in, the four countries that make up the UK.

When we talk about the introduction and expansion of direct payments, we are really talking about two different processes—on the one hand a victory for disabled campaigners . . . on the other, an attempt by a Conservative government to introduce the values of the market into social care (Pearson 2006, p. 28).

However, relatively few people chose the direct payments alternative to receiving services. Take-up remained stubbornly low and characterized by major variations between the countries of the UK; between local authorities within those countries; and between different groups of service users within those authorities (Davey et al. 2007). Take-up rates were highest in England and lowest in Northern Ireland. People with physical and/or sensory impairments consistently had higher rates of take-up. Older people, people with learning disabilities and, particularly, people with mental health problems were much less likely to opt for direct payments (Davey et al. 2007). Direct payments appeared more popular among those with the most severe disabilities and among younger age groups.

Local authorities themselves identified a range of factors considered to promote take-up of direct payments (Davey et al. 2007). These included effective support services to help people recruit personal assistants and manage direct payments; leadership, training and support for the care managers who introduced older and working age disabled people to the option of direct payments instead of directly provided services; and demand from service users themselves. Conversely, anxieties among older and disabled people about managing direct payments and shortages of people willing to work as personal assistants were considered to hinder take-up. Local political and policy factors appeared to play a significant role (Fernández et al. 2007), as did professional resistance by front-line care managers anxious about the threats to traditional social care practice (Ellis 2007).

By 2009, only 6.5 % of all people using adult care services were using direct payments, ranging from 9.5 % of adults aged 18–64 to 3.6 % of those aged 65 and over (Care Quality Commission [CQC] 2010). Consequently, in 2001, legislation was introduced *requiring* local authorities to offer direct payments as an alternative to direct service provision; and direct payment take-up rates were introduced into the indicators on which local authority performance was judged. In 2003, the then Labour Government introduced a £ 9 million Direct Payment Development Fund in England, to fund local organizations (often run by people with disabilities themselves) who could provide information and help with managing payments, recruiting and employing personal assistants. Despite these measures, take-up remained low. While central government legislation and additional funding to promote take-up were undoubtedly important, local culture and practice among front-line staff and workload pressures restricting the time available for the more demanding tasks of encouraging people to use direct payment use were also influential in restricting take-up (Davey et al. 2007). To these barriers could be added resistance by social care service users to taking on responsibility for planning, organizing and the ongoing management of their own care services, particularly if they were experiencing illness, pain, cognitive impairments or fluctuating conditions.

From 1997, the Labour Governments built on these quasi-market foundations as part of a wider consumerist approach to public sector reform. Consumerism

was heralded as further increasing user control, continuing the earlier trajectory of squeezing provider and professional interests; and, by creating new opportunities for entrepreneurialism, enhancing efficiency in public sector markets. Consumerism of course also involves transfers of risk—not just from the state to the private sector but also to individual service users themselves. ‘The rhetoric of user choice . . . can be seen as a form of individual risk transfer. Choice has been put forward in a wider range of different services and processes . . . many of which are potentially liberating for service users but some of which raise concerns about risk, capacity and equity’ (Needham 2007, pp. 74–75).

Commentators have pointed out that the Labour administrations from 1997 to 2010 pursued the marketization of public services to a much greater extent than the previous Conservative governments—albeit tempered by frequent references to community, equality, responsibility and the social sphere (Needham 2007). These themes came together in discourses of co-production—the active involvement of users in the creation and delivery of the services they use:

By putting users at the heart of services, enabling them to become participants in the design and delivery, services will be more effective by mobilizing millions of people as the co-producers of the public goods they value . . . (Leadbeater 2004, pp. 19–20).

It was argued that co-production introduced new incentives for service users to optimize how the resources placed under their control were used and for providers to respond to individual demands, thus increasing cost-effectiveness. Addressing critiques of the individualism underpinning consumerism in welfare sectors, co-production was claimed to:

. . . create a new way to link the individual and the collective good; people who participate in creating solutions that meet their needs make public services work harder and help deliver public policy goals. Self-directed services work because they mobilize a democratic intelligence; the ideas, know-how and energy of thousands of people to devise solutions rather than relying on a few policy-makers . . . (Leadbeater et al. 2008, p. 81)

Social care has been at the forefront of implementing these ideas, extending the marketization of social care by devolving purchasing power—command over the public resources available for any individual to spend on social care—to individual service users themselves. As noted, this also involves devolving associated responsibilities and risks. Although, like direct payments, the following developments were initially promoted by and for disabled people of working age, they have subsequently been extended to all social care service users.

A 2001 policy statement on services for adults with learning disabilities, *Valuing People* (Department of Health 2001b) led to the development of an alternative approach to direct payments that also aimed to promote choice and control over social care. Supported by a social enterprise organization *In Control*, this approach gave service users a bigger role in assessing the level of social care support they needed (and correspondingly reduced the role of professionals in assessing levels and types of needs). Resources—personal budgets—were then allocated to individuals according to relative levels of need (rather than according to the value of in-kind services, as with direct payments). Individuals and their families were

given information and support in planning how to use these resources in line with their specific priorities and preferences. Whereas direct payments were generally used to employ personal assistants to help with personal and domestic care, *In Control* encouraged much greater flexibility in how personal budgets were used, including the purchase of a range of ordinary community-based services. For example, personal budgets could be spent on art classes or gym membership rather than attending a special day centre. *In Control* connected closely with the principles underpinning direct payments, but had a broader aim of ‘redesigning’ social care systems towards ‘self-directed support’ (Duffy 2004). The *In Control* organization was extraordinarily successful in promoting this approach to supporting adults with learning disabilities in many English local authorities.

This experience was picked up in a major policy statement published by the Prime Minister’s Strategy Unit in 2005. *Improving the Life Chances of Disabled People* contained a range of proposals designed to promote the social inclusion of disabled people, including the piloting of individual budgets (IBs). Unlike the *In Control* initiative, IBs were to bring together resources from a number of funding streams to which the individual was entitled—not just social care, but also housing-related support, equipment and adaptations and a special fund for people with very expensive support needs. The intention was to reduce duplicate assessments and increase choice and control for the service user, who would have more flexibility to use the full range of resources to which s/he was entitled according to her/his priorities and preferences. IBs could be managed in different ways—given back to a local authority care manager to purchase services on the user’s behalf; managed by the service user as a cash direct payment; managed by a third party such as a relative; or managed by a service provider. A standardized resource allocation system, based on the one developed by *In Control*, was recommended. Like *In Control*, individuals were to know how much money was available to them before planning how to meet their needs (and be responsible for managing that resource); and like *In Control*, IBs could be used to purchase conventional social care services, employ personal assistants, pay relatives and friends or buy mainstream goods or services. Individuals’ plans for using their IB were to be approved by a local authority care manager to ensure no undue risks were involved.

IBs were piloted in 13 English local authorities between 2005 and 2007 and an extensive multi-method evaluation of the pilots was undertaken (Glendinning et al. 2008). IBs were generally welcomed by their users because they offered more choice and control over daily life, but there were variations in outcomes between user groups. In particular, older people with IBs reported lower psychological well-being, compared to those receiving conventional services. Older IB users also reported lower levels of satisfaction compared to younger IB holders. There was no evidence, therefore, that IBs were cost-effective for older people. In addition, staff involved in piloting IBs encountered many challenges, including devising resource allocation processes and establishing legitimate boundaries for what IBs could be spent on. Despite the efforts of local service managers, efforts to integrate resources from different funding streams were largely unsuccessful; managers cited numerous legal, regulatory and accountability barriers that could only be reduced by central government

action. For a variety of reasons (Moran et al. 2011), central government departments failed to take the necessary steps to facilitate integration of funding streams.

Moreover, before the IB pilots and associated evaluation were finished, the Department of Health announced a three-year ‘transformation’ program in adult social care that involved the extension of personal budgets (PBs) to everyone receiving adult social care (Department of Health 2008). Significantly, PBs involve *only* social care resources—the ambitions of integrating funding streams and reducing multiple assessments had been abandoned. Like IBs, PBs can be deployed in different ways—as a cash direct payment; managed by a service provider organization and drawn on to pay for services as and when they are used; managed by a carer or other ‘third party’; or held by, and used to pay for services purchased by, the local authority.

Local authorities were given a specific grant to fund the necessary organizational changes to implement personal budgets and a target introduced to move all adults onto personal budgets within three years. However, progress has been slower. By March 2010, 18 % of adults (all ages) receiving social care had a personal budget; in-depth research in four local authorities found that between 13 and 59 % of older people had a personal budget (average 34 %), compared with an average 50 % of working age adults with physical disabilities (Audit Commission 2010). To support the wholesale implementation of personal budgets, local authorities have also had to transform methods for allocating funding to individuals and for managing financial and other risks; help local provider markets adapt to demands from personal budget holders for new services; and make available appropriate information and support for people to plan and manage their budgets.

Both the IB pilots and the PB program now being extended across all English adult social care involve the allocation of only local authority social care resources. Despite extensive collaboration between local health and social care organizations since 1997, leading to the creation of many joint local services for older people (see below), NHS resources were not included in the funding to be allocated through IBs and PBs (Glendinning et al. 2011). Instead, an experimental pilot program of personal health budgets (PHBs) was launched in 2009, supported by an extensive evaluation program. PHBs do not replace clinical treatments, but offer opportunities for more personalized and innovative ways of managing long term health problems that are not possible with conventional NHS services. Although the Coalition Government is committed to the long term future of PHBs, the extensiveness of the PHB program and the patient groups who are offered PHBs is likely to depend in part on the results of the pilot evaluation.

9.4 The Implications for the Social Care Workforce

Whether employed by local authorities or private organisations, care workers who provide direct ‘hands on’ care are predominantly low paid, low skilled and part-time women. Foreign-born people and those from black and ethnic minority communities and foreign-born workers are over-represented in the social care workforce, particularly in London. However, many are long term residents in England; temporary

migrant workers tend to be concentrated in the residential care home sector and in the relatively small market for live-in domiciliary carers.

Low pay is endemic in social care, even though front-line care staff were one of the groups to benefit most from the introduction of a National Minimum Wage in 1999 (Grimshaw 2002; Grimshaw and Carroll 2006). Skill levels are also relatively low, although these are slowly improving through workplace-based training and assessment programs. However, the introduction of direct payments and the extension of personal budgets may slowly lead to a more diverse, flexible and less regulated workforce in the domiciliary and community sectors. There are an estimated 200,000 personal assistants employed by older people using personal budgets (Skills for Care 2010). Personal budget-holders may recruit their care staff from among their own informal social networks, which may lead to an overall increase in the size of the home care workforce, albeit under much less formal or regulated arrangements.

Surveys of personal budget-holders report improvements in reliability and flexibility and lower levels of abuse from directly employed personal assistants than from agency home care staff. Personal assistants also report high levels of job satisfaction, although some complain about long hours or low pay. There are no requirements for personal budget holders to provide contracts or formal conditions of employment for their personal assistant employees, nor for personal assistants to have minimum qualifications. Indeed, personal budget holders tend to give low priority to formal qualifications, preferring to provide their own personalized, on-the-job training (Skills for Care 2008). Local authorities are beginning to develop systems to help personal budget-holders manage their employment responsibilities, but these are highly variable across the country (CSCI 2008).

9.5 The ‘Modernization’ of Social Care

Arguably, the drive first to create quasi-markets in social care, and subsequently to transform those markets into consumer-driven entities responsive to individual preferences and outcomes, have been the dominant features of reform over the past two decades. However, other goals and levers for reform are also apparent, particularly those aimed at improving the organization, delivery, efficiency and accountability of services themselves.

A discourse of ‘modernizing’ public services permeated the Labour government’s policies, particularly during its first term of office from 1997. The concept of ‘modernization’ is contested: some argue that it extends the imperatives of New Public Management beyond the marketisation reforms of the Thatcher era; others argue that ‘modernization’ is as much about transforming citizens in line with the requirements of neo-liberalism as with changing institutions. In practice, it is difficult to identify a distinctive and coherent ‘modernization’ reform program, not least because the features of social care services render simple managerial reform levers (economic incentives and penalties, performance targets) ineffective or inappropriate (Newman et al. 2008). Three ‘modernizing’ initiatives will be described here: improving

inter-sectoral collaboration ; intermediate care; and home care reablement. All aim to improve the efficiency and cost-effectiveness of services (as well, of course, as improving the quality of users' experiences).

9.5.1 Improving Collaboration Between Services

Barriers between health and social care services have long been identified as problematic, particularly in the prompt discharge of older people from acute hospital care and in de-medicalizing support for people with learning disabilities or mental health problems. A 1998 policy paper *Modernising Social Services* (Department of Health 1998) identified a number of areas for improvement, including better coordination between local social care, health and housing services. Subsequently, a plethora of measures was introduced to promote, incentivize and require collaboration between health and social care, including statutory obligations on NHS organizations and local authorities to work in partnership; 'ring-fenced' funding to support joint local services; national service frameworks that set benchmarks across both sectors; and the relaxation of legal barriers to closer organizational collaboration (see Glendinning et al. 2005). The latter allows pooling health and social care budgets for specific services; joint or lead commissioning by one sector on behalf of both; and/or the integration of health and social care staff and service delivery within a single management structure.

Many local collaborative developments have resulted, particularly in relation to services for older people. Individual assessments increasingly cover both health and social care needs (Department of Health 2001a). Joint strategic needs assessments and joint commissioning between local authorities and NHS Primary Care Trusts (PCTs) became widespread across many areas of adult services; collaboration and partnership are now mainstream activities for many managers and practitioners in both sectors.

Despite a lack of evidence of the benefits of collaboration for older people using services (Dowling et al. 2004), there is still an apparently strong belief in the potential efficiency gains. A Green Paper (consultation document) on the future of adult social care published in 2009 (HMG 2009) gave considerable attention to 'joined-up working' between different services and benefits.

... services that are not joined up can be very wasteful of tax-payers' money. For example, different organizations may provide duplicate services, and services that do not work well together can increase costs (HMG 2009, p. 68).

Meanwhile, other policy initiatives, such as the piloting of individual budgets (Glendinning et al. 2011), have served to undermine collaboration between health and social care. Moreover, a focus on this particular service intersection may itself undermine collaboration across a much wider range of services (Newman et al. 2008).

9.5.2 Intermediate Care

One area in which considerable joint developments between health and social care organizations have occurred is at the margins of hospital admission and discharge. These developments have aimed to improve the efficiency of the acute hospital sector by facilitating prompt discharge as soon as clinical treatment has finished; and to expand rehabilitation services to help reduce longer-term dependence on health and social care (Department of Health 2000). ‘Intermediate care’ is a generic term covering a wide range of short-term services aimed at preventing admission to hospital, supporting early discharge, and reducing or delaying needs for long term residential care. Since 2000, intensive pressures from central government on local authorities and NHS organizations, supported by additional targeted funding and financial penalties, have led to the widespread establishment of intermediate care services to support early hospital discharge (Godfrey et al. 2005), jointly commissioned and funded by NHS and local authority partners and employing a range of nursing, therapist and care staff. In some localities, joint-funded rapid response teams provide intensive domiciliary care to support an older person through a health-related crisis and avoid admission to hospital. In other localities intermediate care services are entirely hospital-based. Many are funded and delivered jointly by local NHS and social services organizations. They are generally free of charge at the point of delivery and offered for up to six weeks.

9.5.3 Home Care Re-ablement

Since 2000, most English local authorities have developed short-term, specialist re-ablement services within home care. Re-ablement has been described as an ‘approach’ or ‘philosophy’ within home care that aims to help people ‘do things for themselves’ rather than ‘having things done for them’, thus developing both confidence and practical skills to help them live independently.

Home care re-ablement services take different organizational forms. Some are funded and operated jointly with NHS partners. In other localities adult social care departments’ in-house home care staff are retrained in re-ablement approaches and teams are often strengthened by the appointment of occupational therapists (OTs), OT aides and other specialist staff. Easy access to equipment and assistive technology by re-ablement services is important.

There is widespread belief in the preventive benefits of home care re-ablement. A recent large scale, quasi-experimental study (Glendinning et al. 2010) found that re-ablement was indeed associated with a significant decrease in subsequent social care service use, compared to people using conventional home care services. However, these lower costs were almost entirely offset by the higher cost of the re-ablement intervention; after a year there was no significant difference in the costs of the social care services used by each group. Nevertheless, home care re-ablement was almost certainly cost-effective, because it was associated with marked improvements in outcomes for users.

9.5.4 *The Effectiveness of Modernization Initiatives*

These examples illustrate different attempts to improve the efficiency of long term care services, in particular by reducing barriers between health and social care sectors and by investing in new services at the interfaces between these sectors. However, there have been concerns that these developments—particularly the growth of intermediate care services—have been primarily driven by the imperative of improving throughput and efficiency in the acute hospital sector, rather than improving social care. Certainly the English Department of Health has claimed a ‘dramatic fall’ in the number of hospital discharges that were delayed because of previously inadequate post-discharge support services (Department of Health 2004). A review of evidence indicates that hospital-at-home schemes, providing intensive, specialist nursing and rehabilitation care in patients’ own homes, are flexible across a range of conditions and functions (Young 2009).

Yet, the effectiveness of these new service developments is itself influenced by wider external factors—particularly the extensive under-funding of social care services relative to need. Thus the evaluation of home care re-ablement services found their effectiveness was reduced when, as commonly happened, it was not possible to discharge users promptly at the end of a re-ablement episode because there was insufficient funding and capacity in the standard home care services that could provide longer-term support (Glendinning et al. 2010). Moreover, focused, intensive, short-term intermediate care and re-ablement services both demonstrate the most dramatic impacts on people with primarily physical disabilities or who are recovering from acute illness or surgery. Neither type of service is likely to generate significant improvements in outcomes for the growing numbers of older people with dementia and other cognitive impairments. More broadly, a wide range of other extrinsic factors—including labor market supply and demand, changes in local governance, reforms in other welfare sectors and ‘even changes to the accounting rules’ (Newman et al. 2008, p. 553) contribute to the overall effectiveness of modernization initiatives.

Meanwhile, since the mid-1990s, there has been growing concern about the increasingly high levels of need (on top of the assets and income tests) required to qualify for local authority-funded social care and the lack of investment in services for people with lower level needs—help with shopping, social activities outside the home, gardening and cleaning. The association of English local authorities has argued strongly it is inefficient for older people requiring only a small amount of support to remain independent to be denied access to assistance until a crisis occurs and they become eligible for very expensive services (ADASS/LGA 2003); this was endorsed by the Audit Commission (1997, 2000). An experimental Partnership for Older People Projects (POPPs) program ran from 2006 to 2008, involving some 470 local projects aimed at developing preventive approaches and shifting resources from acute to community and domiciliary settings. The POPPs program showed that every £ 1 spent led to an average saving of £ 0.73 on the per month cost of emergency hospital care (Windle et al. 2008). However, as time-limited local projects heavily reliant on charitable and voluntary sector contributions, the impact of the POPPs program was necessarily limited, particularly with respect to redirecting resources from acute hospital budgets.

9.6 Funding and Fairness

Section 9.2 outlined the fragmentation of policy and funding responsibilities for long term care for older people in England. Underlying this fragmentation are long-standing—and still unfinished—attempts to devise a fairer and sustainable approach to funding and provision. These attempts focus primarily on social care (and to a lesser extent the social security Attendance Allowance benefit); consistent with the institutional fragmentation described in the first section of this chapter, they largely exclude both the NHS role in long term care and the substantial contributions of informal carers.

There is widespread dissatisfaction with current funding arrangements, although public understanding and awareness is low:

It often comes as an unwelcome surprise to older people to discover that social care is means-tested and they are expected to rely on their own savings and income until their assets have fallen to the threshold set for state-funded care. It is a common complaint that the existing system penalizes those who have saved for their own old age (Wanless 2006, p. xxi).

Even without any reforms and based on current levels of support, demographic pressures are anticipated to lead to a near-doubling of costs by 2026. Without reform, access to publicly-funded care will become even more restricted to only the very poorest, who have the highest needs for care and are without any family support (Humphries and Forder 2010).

Over the past 15 years, numerous proposals, both from within and outside government, have proposed reforms to extend eligibility for state funded long term care and also to reduce some of the local variations in access and levels of provision. Longer-term sustainability, in the face of current high levels of unmet need, is an additional imperative.

One of the early measures of the 1997 Labour government was the establishment of a Royal Commission on Long Term Care (Royal Commission on Long Term Care 1999). Its main recommendation was that free personal care should be funded from general taxation on the basis of need only (as, indeed, was subsequently introduced in Scotland). However Commission members were divided over the affordability of this measure and this allowed the government to reject the recommendation and invest in intermediate care (see Sect. 9.3.2) instead.

Dismayed by this, a range of voluntary organizations, pressure groups and think tanks—not just restricted to those representing older people’s interests—continued to lobby for more extensive reforms (Joseph Rowntree Foundation 2006; Churchill 2008). Their activities were underpinned by extensive research, particularly into the costs of alternative reform options. Thus in 2006, the Kings Fund, an independent health charity, commissioned research into the funding and outcomes of current English arrangements, alternative funding models and the costs of these. This study (Wanless 2006) proposed a ‘partnership’ model, in which anyone assessed as needing care above a given level would be entitled to a minimum level of publicly-funded care; above the minimum, additional state funding would match private contributions. The main arguments for this approach were that it would

provide a basic level of state funding and encourage the contribution of private resources to the overall costs of care, but without the disincentive for personal savings that characterize means-tested eligibility systems.

These recommendations were not taken up by the English government. By this time, new evidence on the disparities of wealth enjoyed by the current and rising ‘baby-boomer’ cohorts, compared with younger generations, had appeared. Some £ 932 billion assets are estimated to be held by older people as a result of increases in home ownership and property values over the previous 20 years. Debates within and outside government shifted the emphasis from working age people as the main funders of long term care through general taxation to considering how to tap into the assets held by current and rising older generations (Lloyd 2010).

However by now two external factors seriously constrained scope for policy Manoeuvre: the growing international fiscal and economic crisis and the UK’s own financial deficit; and the anticipation of a general election in May 2010.

The Conservative-Liberal Democrat Coalition government elected in 2010 established a new Commission of Enquiry on the funding of care and support, chaired by a leading academic economist. The Commission’s remit was to consider the full range of possible funding models, including the respective financial contributions of individuals, the private sector and the state; and the implementation of different models, including the implications for local government and the NHS. The Commission reported in July 2011 (Department of Health 2011). It recommended a significant increase in the wealth threshold at which individuals become responsible for funding their own care, from £ 23,250 to £ 100,000; and that no individual should have to pay more than £ 35,000 for her/his care. These proposals covered older people only (care for younger people would remain largely free of charge), specifically for residential care. They effectively limited individual liabilities, thus creating an attractive market for the development of private insurance products, with the state being responsible for the highest risks and costs. The Coalition Government is committed to introducing new legislation on long term care in 2012. However, given the Government’s commitments to radical and rapid reductions in public expenditure and the consequent cutbacks in both public sector funding and services, it is very likely that the Commission’s proposals may be seriously modified. The prospects of radical reform—particularly any increase in public expenditure that might underpin a universal, tax-funded scheme—remains remote.

9.7 Conclusions

Over the period examined within this chapter, the coverage of publicly-funded adult social care has contracted significantly. Intensive home care services are provided only to those with the highest levels of need; many people are excluded altogether from publicly funded residential or domiciliary care because of modest levels of assets and/or income. With the introduction of quasi-markets, care services have become more fragmented; personal budgets shift responsibilities for managing resources and risks onto individual older people and their families.

At the heart of this failure is the challenge of finding a politically acceptable way of driving more money into the social care system.

The problems, and the options, for solving funding reform, have long been known; and prime opportunities to initiate reform . . . have been squandered. The failure to grasp this nettle is sadly indicative of the low priority given to social care by successive administrations (House of Commons Health Committee 2010, p. 67).

Current and rising cohorts of older people certainly do have substantial assets, mainly from property ownership. However, increased taxation, whether levied on current assets or inheritance, is widely regarded as political anathema. This option is even less acceptable, publicly and politically, in the context of the major cuts in public expenditure, and the anticipated widespread job losses and reductions in public services, resulting from the Coalition Government's rapid deficit reduction strategy.

Underpinning this political challenge is a highly complex and fragmented system of long term care, with separate central government responsibilities, funding streams and local service delivery organizations for health, social care and other services. Further instabilities arise from the division of responsibility between central government and local authorities for social care. Social security benefits for disabled and older people and carers are further separated—and these cover the UK as a whole, raising further challenges for any care-related reforms that are restricted just to England. In short, radical reforms to long term care raise challenging constitutional issues for the English and the UK state. Nevertheless, unless more funding is made available, fewer and fewer people will benefit from publicly-funded social care; more people will be exposed to catastrophic costs as they spend down their assets on privately-purchased residential or intensive domiciliary care; and family carers will carry increasingly unsupportable burdens. Given overall public spending cuts of 25 % or more over the next few years, these scenarios are very likely.

Against this background, the extensive quasi-market reforms and their extension to individualized funding through personal budgets is remarkable—but also, some might argue, a relatively low priority. These reforms have not been introduced in order to exercise tighter control over public spending on social care, but simply to alter the ways in which existing limited resources are allocated and used. However, as with earlier experiences of direct payments, the recent 'transformation' of personal budgets may not be wholly successful in delivering improved outcomes for service users. Both initiatives have taken a method of deploying social care resources that appears to work well for some social care service users (working age physically disabled people and those with learning disabilities respectively) and universalized this to all users, including frail and cognitively impaired older people. Moreover, there remain significant questions over how well the largely private market of home care and other service providers can adapt to meeting requests from newly empowered personal budget-holding users without incurring new transaction costs or being exposed to destabilizing financial risks.

References

- Association of Directors of Adult Social Services/Local Government Association (ADASS/LGA). (2003). *All our tomorrows: inverting the triangle of care*. London: Association of Directors of Adult Social Services/Local Government Association.
- Audit Commission. (1986). *Making a reality of community care*. London: Audit Commission.
- Audit Commission. (1997). *The coming of age: Improving care services for older people*. London: Audit Commission.
- Audit Commission. (2000). *The way to go home: Rehabilitation and remedial services for older people*. London: Audit Commission.
- Audit Commission. (2010). *Financial management of personal budgets*. London: Audit Commission.
- Care Quality Commission. (2010). *The state of health care and adult social care in England. Key themes and quality of services in 2009*. London: Care Quality Commission. Downloaded from www.cqc.org.uk.
- Carers UK. (2007). Carers save UK £87 billion per year. www.carersuk.org/Newsandcampaigns/News/1190237139. Accessed 5 Feb 2008.
- Churchill, N. (Ed). (2008). *Advancing opportunity: Older people and social care*. London: Smith Institute.
- Comas-Herrera, A., Wittenberg, R., & Pickard, L. (2004). Long-term care for older people in the United Kingdom: Structure and challenges. In M. Knapp, D. Challis, J. L. Fernández, & A. Netten (Eds.), *Long-term care: Matching resources and needs*. Aldershot: Ashgate.
- Commission for Social Care Inspection (CSCI). (2008). *The state of social care in England 2006–07*. London: Commission for Social Care Inspection.
- Commission for Social Care Inspection (CSCI). (2009). *The state of social care in England 2007–08*. London: Commission for Social Care Inspection.
- Davey, V., Fernández, J. L., Knapp, M., Vick, N., Jolly, D., Swift, P., Tobin, R., Kendall, J., Ferrie, J., Pearson, C., Mercer, G., & Priestley, M. (2007). *Direct payments: A national survey of policy and practice*. London: LSE, PSSRU.
- Department of Health. (1998). *Modernising social services*. Cm 4169. London: Department of Health.
- Department of Health. (2000). *The NHS Plan. A plan for investment, a plan for reform*. London: Department of Health.
- Department of Health. (2001a). *National service framework for older people*. London: Department of Health.
- Department of Health. (2001b). *Valuing people: A new strategy for learning disability for the 21st Century*. Cm 5086. London: The Stationery Office.
- Department of Health. (2004). Dramatic fall in delayed discharges. Press release 2004/0196, 17 May.
- Department of Health. (2008). *Putting people first: A shared vision and commitment to the transformation of adult social care*. London: Department of Health.
- Department of Health. (2011). *Fairer care funding: The report of the commission on funding of care and support*. London: Department of Health.
- Department of Health and Social Security. (1988). *Community care: An agenda for action*. London: HMSO.
- Dowling, B., Glendinning, C., & Powell, M. (2004). Conceptualising ‘successful’ partnerships. *Health and Social Care in the Community*, 12(4), 309–317.
- Drakeford, M. (2006). Ownership, regulation and the public interest: The case of residential care for older people. *Critical Social Policy*, 26(4), 932–944.
- Duffy, S. (2004). In control. *Journal of Integrated Care*, 12(6), 7–13.
- Ellis, K. (2007). Direct payments and social work practice: The significance of street-level bureaucracy in determining eligibility. *British Journal of Social Work*, 37(3), 405–422.

- Fernández, J. L., Kendall, J., Davey, V., & Knapp, M. (2007). Direct payments in England: Factors linked to variations in local provision. *Journal of Social Policy*, 36(1), 97–121.
- Glasby, J., & Littlechild, R. (2004). *The health and social care divide: The experiences of older people* (Revised 2nd ed.). Bristol: The Policy Press.
- Glasby, J., & Littlechild, R. (2006). An overview of the implementation and development of direct payments. In J. Leece & J. Bornat (Eds.), *Developments in direct payments*. Bristol: The Policy Press.
- Glendinning, C. (2007). Improving equity and sustainability in UK funding for long-term care: Lessons from Germany. *Social Policy and Society*, 6(3), 411–422.
- Glendinning, C., & Lloyd, B. (1998). The continuing care guidelines and primary and community health services. *Health and Social Care in the Community*, 6(3), 181–188.
- Glendinning, C., & Means, R. (2004). Rearranging the deckchairs on the Titanic of long-term care—is organisational integration the answer? *Critical Social Policy*, 24(4), 435–457.
- Glendinning, C., Hudson, B., & Means, R. (2005). Under strain? Exploring the troubled relationship between health and social care. *Public Money and Management*, 25(4), 245–252.
- Glendinning, C., Challis, D., Fernández, J. L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Stevens, M., & Wilberforce, M. (2008). *Evaluation of the individual budgets pilot programme: Final report*. York: Social Policy Research Unit, University of York.
- Glendinning, C., Jones, K., Baxter, K., Rabiee, P., Curtis, L., Wilde, A., Arksey, H., & Forder, J. (2010). *Home care re-ablement services: Investigating the longer-term impacts (Prospective Longitudinal Study)*. (Working Paper No. DHR 2438). York: Social Policy Research Unit, University of York.
- Glendinning, C., Moran, N., Challis, D., Fernández, J. L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Netten, A., Stevens, M., & Wilberforce, M. (2011). Personalisation and partnership: Competing objectives in English adult social care? the individual budget pilot projects and the NHS. *Social Policy and Society*, 10(2), 151–162.
- Godfrey, M., Keen, J., Townsend, J., Moore, J., Ware, P., Hardy, B., West, R., Weatherly, H., & Henderson, K. (2005). *An evaluation of intermediate care for older people. Final report*. Leeds: Institute of Health Sciences and Public Health Research, University of Leeds.
- Grimshaw, D. (2002). *Qualitative research on firms' adjustments to the minimum wage*. Manchester: European Work and Employment Research Centre.
- Grimshaw, D., & Carroll, M. (2006). Adjusting to the national minimum wage: Constraints and incentives to change in six low-paying sectors. *Industrial Relations Journal*, 37, 22–47.
- House of Commons Health Committee. (2010). *Social care* (Third Report of Session 2009–10, Volume 1, HC 22–1). London: House of Commons.
- Humphries, R., & Forder, J. (2010). Options for funding long-term care; the partnership model compared. *Quality in Ageing and Older Adults*, 11(4), 30–35.
- Joseph Rowntree Foundation (JRF). (2006). *Paying for long-term care*. York: Joseph Rowntree Foundation.
- Kasparova, D., Marsh, A., & Wilkinson, D. (2007). *The take-up rate of disability living allowance and attendance allowance: Feasibility study* (Research Report 442). London: Department for Work and Pensions.
- Laing and Buisson. (2005). *Care of elderly people: UK market survey 2005*. London: Laing and Buisson Publications Ltd.
- Leadbeater, C. (2004). *Personalisation through participation. A new script for public services*. London: Demos.
- Leadbeater, C., Bartlett, C., & Gallagher, N. (2008). *Putting people first. Facing the challenges of scaling up personal budgets*. London: Demos.
- Lewis, J. (2001). Older people and the health-social care boundary in the UK: Half a century of hidden policy conflict. *Social Policy and Administration*, 35(4), 343–359.
- Lewis, J., & Glennerster, H. (1996). *Implementing the new community care*. Buckingham: Open University Press.
- Means, R., & Smith, R. (1998). *From poor law to community care: The development of welfare services for elderly people*. Bristol: The Policy Press.

- Means, R., Morbey, H., & Smith, R. (2002). *From community care to market care? The development of welfare services for older people*. Bristol: The Policy Press.
- Means, R., Richards, S., & Smith, R. (2003). *Community care: Policy and practice* (3rd ed.). Basingstoke: Macmillan.
- Moran, N., Glendinning, C., Stevens, M., Manthorpe, J., Jacobs, S., Wilberforce, M., Knapp, M., Challis, D., Fernández, J. L., Jones, K., & Netten, A. (2011). Joining up government by integrating funding streams? The experiences of the individual budget pilot projects for older and disabled people in England. *International Journal of Public Administration*, 34(4), 232–243.
- Morris, J. (2006). Independent living: The role of the disability movement in the development of government policy. In C. Glendinning & P. A. Kemp (Eds.), *Cash and care: Policy challenges in the Welfare State*. Bristol: The Policy Press.
- Needham, C. (2007). *The reform of public services under new labour: Narratives of consumerism*. Basingstoke: Palgrave Macmillan.
- Newman, J., Glendinning, C., Hughes, M. (2008). Beyond modernisation? Social care and the transformation of welfare governance. *Journal of Social Policy*, 37(4), 531–557.
- OECD. (2005). *Long-term care for older people*. Paris: Organisation for Economic Co-operation and Development.
- Pearson, C. (2006). Direct payments in Scotland. In J. Leece & J. Bornat (Eds.), *Developments in direct payments*. Bristol: The Policy Press.
- Prime Minister's Strategy Unit. (2005). *Improving the life chances of disabled people*. London: Cabinet Office.
- Royal Commission on Long-Term Care. (1999). *With respect to old age: Long-term care—rights and responsibilities*. London: The Stationery Office.
- Schofield, P. (2007). Are there reasons to be worried about the 'caretelisation' of residential care? *Critical Social Policy*, 27(2), 155–180.
- Skills for Care. (2008). *Employment aspects and workforce implications of direct payments*. Leeds: Skills for Care.
- Skills for Care. (2010). *The state of the adult social care workforce in England 2010*. London: Skills for Care.
- Streeck, W., & Thelen, K. (Eds.). (2005). *Beyond continuity. Institutional change in advanced political economies*. Oxford: Oxford University Press.
- Wanless, D. (2006). *Securing good care for older people. Taking a long-term view*. London: Kings Fund.
- Windle, K., Wagland, R., Lord, K., Dickinson, A., Knapp, M., D'Amico, F., Forder, J., Henderson, C., Wistow, G., Beech, R., Roe, B., & Bowling, A. (2008). *National evaluation of partnerships for older people projects: Interim report of progress*. (PSSRU Discussion Paper 2612). Kent: Personal Social Services Research Unit, University of Kent.
- Young, J. (2009). The development of intermediate care services in England. *Archives of Gerontology and Geriatrics*, 49, S21–S25.

Chapter 10

Long-Term Care in Spain: Between Family Care Tradition and the Public Recognition of Social Risk

Gregorio Rodríguez Cabrero and Vicente Marbán Gallego

10.1 Introduction

The aim of this chapter is to provide answers, from an institutional perspective, (Pavolini and Ranci (2008)) to key questions concerning the transition in Spain from a residual long-term care (LTC) system, centered almost exclusively on the family, to a public one of universal coverage, which began in January 2007. This chapter will try to demonstrate the following hypothesis and views.

- *Why was the reform necessary?* The answer is manifold and it relates to different aspects: (1) cultural changes in terms of the *care responsibility culture*, which in turn were brought about by other sociodemographic changes (aging, changes in family dynamics, etc.); (2) the plural, family-based and multilevel structure of the organization, and provision of care in the public and private spheres (*social caring setting*), a structure, which has proven to be excessively intensive in terms of family care but deficient and disparate in terms of the supply and coverage of public and private services with public liability; and (3) political reforms and institutional inertias (*policy legacy and policy reforms*) in the LTC system.
- *Who took part in the reform?* The various stakeholders of the new Act (unions, employers, not-for-profit social action organizations, political parties, autonomous regions) never went so far as to forge ad hoc agreements or alliances among each other. However, a state of inertia led to a connection of beliefs, interests, and resources by the different social and political stakeholders, who more or less spontaneously formed a series of pressure groups in the LTC debate. In particular, third sector organizations and unions advocated the inclusion of the rights of and benefits for frail older people under the umbrella of social security, as well

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as their more active participation in personal social services by central administration. Yet, conversely, employers' organizations, most autonomous regions and the more nationalist political parties advocated financing LTC through taxes for a series of different reasons, which will be explained later in the chapter.

- *How has the reform been carried out?* The path to the reform has been gradual due to the accumulation of factors mentioned above. Yet the reform in itself did entail radical change. The path has been gradual insofar as regional and local social services policies have developed progressively, giving priority to social services for dependent people between 1992 and 2006. However, there is no doubt that the reform does entail radical change, which took place in 2006 with the substitution of an assistance right with a universally subjective right for all citizens with dependency.
- *Which LTC model has been adopted by the Spanish welfare state?* The Spanish LTC model is a complex one, which responds to the new generation of social rights emerging in the EU, where risk coverage is distributed among different institutional (multilevel) and social (individuals, families) stakeholders. Broad coverage is guaranteed, but with a relatively low degree of protection. Management is decentralized, and service provision is mixed; more than 80 % of providers operate in a context of growing competition between commercial and not-for-profit sectors. Social claims and demands are channeled through a wide-range system of participation by social and economic stakeholders. In short, it is a system of universal social protection, which is financially limited and subject to strict rules of cooperation, as well as some degree of institutional rationalization and coordination. All this means that its launch was accompanied by great political and financial tensions. These tensions are still to be resolved.
- *What have been the first notable effects in the few years following the implementation of the LTC reform?* The new system of social protection has had many effects: the extension of public coverage, the creation of social services employment, the broadening of the public network of social services, improvements and tensions in the cooperation among regions, innovative uses of social services, and attempts to develop cooperation between social and health services. All these innovations have occurred in the midst of limited financial resources, tensions between central government and autonomous regions, and an extremely uneven application of the system across the regions and boroughs.

10.2 Key Factors Concerning the LTC Reform in Spain (1986–2006)

The Spanish reform of December 2006, which established a new system of social protection for dependent persons, was the outcome of a series of progressive institutional, social, and cultural changes over a period of nearly 15 years (1992–2006). The Spanish Act 39/2006 on the Promotion of Personal Autonomy and Care for Dependent Persons (otherwise known as the Dependency Act) came into force on

1 January 2007 throughout Spain. This Act established a new system of social protection known as the SAAD—*Sistema de Autonomía y Atención a la Dependencia* or the System of Autonomy and Dependency Care.

The Act was the outcome of a long debate, which began around 1992 with the formulation of the First State Gerontological Plan and which continued through the so-called Toledo Pact for Pensions (1995), the Dependency White Paper (2005), Instituto de Mayores y Servicios Sociales (2005), and finally became a complex reform able to transform a system of residual social assistance and social security into one with a universal approach. Whereas in the early days of the debate the ideal model for LTC was considered to be the Bismarckian model of Social Security, the LTC system in the final Act came to be framed basically as a *sui generis* universalist or “social-democratic” program, though still connected to the social security system and the social assistance system of the Autonomous Regions. In fact, the new system is a streamlined version of the previous one, but it was transformed into a scheme of universal coverage based on a subjective right (as it is also the case with health and education) and on cooperation between central government and the regions, financed through taxation, social security contributions, and copayment by users.

In order to better understand the LTC reform, underlying social, historical and, above all, institutional factors must be taken into account. More precisely, two kinds of factors should be considered. Firstly, there are the historical–institutional factors—with a path-dependency effect—behind the reform. Secondly, there are factors connected to the “Europeanization” of the Spanish LTC system in the double meaning of, on the one hand, adopting new policies arising from the debate about the “European Social Model” and, on the other, introducing mixed forms of provision, which are tailored to traditional, culturally-embedded patterns of care.

Any effort to understand the social and institutional nature of the new LTC model, which came into being on January 2007, must begin with the analysis of the historical roots of the prereform model, which, as we shall see in Sect. 10.6 (“Impacts of the new LTC system”), is still indebted to both social security and the social services system. Until the end of 2006, this prereform LTC system was organized into two levels of formal care: the social security system and the personal social services system.

The social security system guaranteed an economic benefit to third-party carers of workers who were incapacitated due to accidents at work before the age of 65. Any serious incapacity suffered after that age was not recognized for such purposes. The system was, at the time, very restricted and was subject to rigorous medical and administrative controls. At the same time, since the Noncontributory Benefits and Pensions Act of 1990, the social security system has granted benefits to third-party carers of dependent persons with more than 75 % disability, who are incapable of working.

The personal social services system protected those in situations of dependency and more importantly the older people who had no means or informal support of any kind. Means testing and the verification of the absence of any informal support were the mechanisms of control for gaining access to a type of care, which in practice was residential, and whose financing and provision were the responsibility of the autonomous regions.

From 1985, two simultaneous changes facilitated the progressive transformation of a residual, residential-based social service system into one with a more universalistic and community-centered approach. Firstly, a major role was played by the progressive process of decentralization, which devolved to the regions' and municipalities' exclusive powers over social service provision. Regional social services legislation and the 1985 Local Government Act were factors, which enhanced the supply of social services. Secondly, the deep and rapid changes in social demand—due to female entry into the labor market and sociodemographic changes in the Spanish family—created even more pressure. These social changes pushed for the creation of new combinations of formal and informal care in which the public sector swiftly gained the upper hand, first as regulator, funder, and provider (approximately between 1985 and 1995) and then (from 1996 onwards) as regulator and funder of “social markets,” initially made up of NGOs and, in more recent years, also the commercial sector (Fantova 2008). Thus, thanks to the financial support from central government through statewide plans (Concerted Plan for Basic Municipal Services) and the wholesale transfer of the social security system's network of social services between 1985 and 1995, regional and local public administrations created a system of social services in each territory, in spite of the lack of a national legislative framework. The absence of such a framework created the basis for considerable diversification at the regional and municipal level in terms of LTC supply (Instituto de Mayores y Servicios Sociales (2009)).

Along with factors related to local authorities' choices (the creation of a public social service network) and households' needs (an aging population and changes in the family structure), two other phenomena help to explain the 2006 reform: (1) the progressive transformation of a means-tested system of social services, designed mainly for those on low incomes, into an LTC system for the whole population and, in particular, the urban middle classes who demanded quality social services (as well as universal health care); (2) the shift from a residential care-based model to a community care-based one, also as the result of pressures from the older population, who wished to live at home, care professionals, and carer families who, without renouncing informal care, were calling for institutional support (OECD (2005)).

Apart from the historical roots, the recalibration of the Spanish welfare state was also speeding ahead in more recent years in response to internal factors (the consolidation of the decentralization process and the diffusion of private provision) and external ones (the influence of the debate about the European social model in relation to LTC, as well as the influence of neoliberal ideology on public policy). There are four fundamental factors connected to these phenomena.

The first was the influence of the process of cognitive Europeanization of social policies.¹ The second was the need to rationalize and organize the care schemes already in existence under social security, autonomous regions and local councils, as

¹ We understand social policy Europeanization to be the growing influence of EU social protection and social inclusion policies and the LTC in its design, as shown in the NAPinclusion and the Joint Report from the Lisbon 2000 Strategy onwards.

well as to improve coordination with the health care service. The third was the growing social demand by households and working women with caring responsibilities, channeled through organizations representing older people and those with disabilities. The last was the role played by the Social Dialogue, in order to represent the demands of trade unions and of employers (advocating for the creation, respectively, of new employment and new business opportunities through the care sector). As a whole, the launch of the Spanish Dependency Law was the consequence of demand from professional groups (social workers, geriatric and gerontological professionals), pressure from NGOs for the disabled and older people, as well as the trade unions (under the umbrella of negotiations and Social Dialogue) and the leading role of regional governments in the roll-out of ad hoc programs of a different nature.

As a consequence of these historical and institutional factors, the configuration of the Spanish LTC system has its own peculiarities as shown in Sect. 10.6. These peculiarities combine the persistence of the past (a preference for cash benefits over services and for informal care over formal, or certain combinations where informal care is still central) with recent changes (universalization of care, the growing importance of integrated social- and health-care and the creation of private social service markets).

As previously mentioned, the Spanish LTC system was not radically transformed following its reform in 2006, though it did make a fundamental move away from the residual assistance tradition. Effectively, it universalizes a social benefits system for the entire dependent population. This system is governed by a Regional Board (*Consejo Territorial*), which lays down the basic conditions and the general content of the right to protection nationwide. It is a system whereby the State guarantees a minimum benefit which in turn guarantees the same minimum level of benefit nationwide. This minimum level is complemented by two further benefits, one of which is agreed by the State and the regions equally, while the other is left to the regions. In other words, the state does not guarantee the subjective right but only the basic conditions for its exercise on equal terms across the country.

If the Europeanizing tendencies of social policies and rising social demand are key explanatory factors of the new Spanish LTC model, other factors are also relevant, such as the economic rationalization of existing services; the coordination between administrations and health and social services; and the balancing of centrifugal trends in regional social service systems. Put another way, the Spanish LTC system is an attempt to find an answer to two sources of pressure simultaneously: the extension of the welfare state (on the demand side: families, unions, private sector, and NGOs) and social spending restraint and rationalization (on the supply side: public sector and financial sector). Pressure for the public sector to curtail social expenditure for dependency has come through the transfer of certain tasks (and relative costs) of personal care from the health care system to social services, which is cheaper than the former. The commercial sector has not opposed the roll-out of a public LTC system as long as it guaranteed the contracting-out of social services, as private enterprises have had a significant presence as suppliers.

10.3 Actors and Coalitions

The definition of the Reform's main goals, its institutional setting, the types of benefits, and the mechanisms of funding were each the result of a long and uneven process of negotiation among institutional actors (the social security system and health care), different layers of government (at national level, the autonomous regions and, to a lesser extent, the municipalities and provinces), social actors (NGOs advocating for older people and those with disabilities), the social partners (unions and employers' organizations), and professional actors (representing social workers, gerontologists, and geriatricians). These actors created a series of coalitions in defense of common interests (*advocacy coalition*; Sabatier and Jenkins-Smith 1999; Weible et al. 2009), built on the basis of different combinations of the beliefs, interests, and resources of the different actors involved. Table 10.1 illustrates schematically each of the different actors' positions (Marbán Gallego 2009). It should be kept in mind that these coalitions were "weak": in practice what happened was a gradual confluence of the interests of different social and institutional actors, rather than a series of deliberately designed alliances. Indeed, a process of social dialogue consolidation between the State, the trade unions, and business representatives has favored the restructuring of the Welfare State and the inclusion of the LTC public agenda.

As Table 10.1 shows, two key elements have helped in reaching a consensus between the main actors involved in the LTC sector. The first concerns certain basic aspects of the reform, on which there was a broad consensus: universal and equal access, social security entitlement for carers, the importance of prevention, training, quality service provision, and family support. The second concerns the scope of LTC social protection in terms of: the population covered, access conditions, the type of social benefits, and the role given to constitutional competences (competencies for the regulation, financing, planning, and evaluation of the LTC system); these issues were strongly debated by the various "coalitions" of actors involved.

With respect to the social protection framework and the sphere of constitutional competences, the main debate centered on the inclusion of LAPAD,² either within the social security framework or outside of it, financed through taxation as in the Nordic systems: its inclusion would thus give the central administration a more active role in the organization of social services. In this respect, Third Sector organizations and trade unions were in favor of including the LAPAD in the social security system, in order to better ensure nationwide equality of access, the spread of public services and of public accountability by the not-for-profit providers. Nevertheless, despite these shared beliefs, there was no genuine coalition between Third Sector organizations and trade unions for a variety of reasons, including their differences with regard to labor issues, a lack of communication, and an underlying struggle in terms of citizens' representation.

Meanwhile, the business representatives, the majority of the autonomous regions and the more nationalist political parties opposed the inclusion of LAPAD in the

² LAPAD: Act 39/2006, of 14 December, On the Promotion of Personal Autonomy and Care for Dependent Persons.

Table 10.1 Beliefs, interests, and resources of the main social actors involved in the LTC reform

	Unions	Employers' private commercial sector	Third sector	Autonomous regions (AR)
<i>Beliefs</i>				
Coverage	Universal public provision	Universal private provision	Universal mixed (public and private not-for-profit)	Universal provision (mixed: public-concerted private)
Scope of competence	Central administration (CA)	CA, AR, local councils (LC)	CA	AR
Protective frame	Social security	Finance through general taxation	Social security	Finance through general taxation
Family support	Complementarity, support and respite services, recognition of carers' rights by social security	Support and respite services, freedom to choose provider	Complementarity, support and respite services, freedom to choose provider; recognition of carers' rights by social security	Complementarity, support and respite services
Other	Importance of prevention, training, quality of service provision, health and social service coordination	Importance of prevention, training, quality of service provision	Importance of prevention, training, quality of service provision, health and social service coordination	Importance of prevention, training, quality of service provision, health and social service coordination
Interests	Employment creation, defeminization of care, equal access, extension of public services	Extension of service network, organizational growth, diversification of private finance	Employment creation, extension of service network, organizational growth, broadening of the rights of the elderly, the intellectually disabled and the mentally ill	Autonomy and preservation of competences in social security
Power resources	Social legitimation	Economic legitimation and pressure power in employers' social security contributions	Social legitimation, expertise	Economic legitimation, expertise, veto power

social security framework, who instead advocated it's financing through taxation. For these actors, its inclusion within the social security system would have given to central government the capacity to encroach on regional power over social services and erode their legitimacy in actual intervention. For the for-profit sector, its inclusion would also have entailed higher labor costs (in terms of employers' social security contributions), thus hindering economic growth. Ultimately, the decision to finally position the new system outside social security was due to opposition from business organizations, regions, and nationalist political parties, whose parliamentary presence was greater during the legislature in which the Act was passed.

That said, at least some of the decision originated from a social agreement pact signed in December 2005 between the government, trade unions (UGT and CCOO), and the employers' organizations (CEOE and CEPYME). In reaching the pact, pressure from the employers' representatives was decisive due to: their opposition to an increase in contributions; their arguing that the integration of the new LTC system in social security might have entailed a reform of the Toledo Pact (1995), the general thrust of which was to remove from the contributory system all that was not pure financial protection (pensions, unemployment, and family benefits).

When balancing up the results achieved by the different social actors, the conclusion is that the participation of the local actors in the LAPAD has been negligible despite their growing visibility as the Green Paper setting out its terms gradually became law. Instead, the autonomous regions achieved their principal goal of preserving their powers over social services before the central administration. Business organizations were unable to obtain any particular prominence for private initiative in the reform, although they did manage to avoid the inclusion of the act in the social security framework and to raise the profile of certain private financial products (for example, the inverse mortgage).

Third Sector organizations, whose demands were mainly channeled through organizations for older and disabled people such as CERMI, FEAPS, CEOMA, UDP, and the Social Action Platform of NGOs, did manage to have substantial changes introduced into the Act, such as the "particular" consideration of the Third Sector (Art.16.2) and the inclusion of the specific conditions of intellectual impairment and psychiatric/cognitive problems, duly reflected in the evaluation criteria.

10.4 The 2006 Reform: A Universal Subjective Right

10.4.1 Basic Features and Main Goals of Act 39/2006

In force since January 2007, the Dependency Act has developed a universal subjective right for all those who, regardless of their age, can demonstrate that they have been residing in Spain for at least 5 years and have at least a certain degree of dependency (moderate, severe, major) as defined according to the terms of the Act. The level of dependency is determined according to the frequency and intensity of assistance required (intermittent support at least once a day—moderate; extensive support two

or three times per day—severe; indispensable and continuous support several times a day—major). The level of dependency is assessed by a qualified professional who carries out interviews and direct observation of the potential beneficiary in their everyday environment.

As far as benefit types are concerned, the Act prioritizes services over cash benefits: if services are not feasible, then an economic benefit linked to the provision of the service is assigned (Art. 17). Other “one-off” cash benefits include economic benefits for care personnel (for those with major dependency; Art. 19) and benefits for family or nonprofessional carers (Art. 18), in which case the family carer has to be registered in the social security system (RD 615/2007, 11 May).³ Funding is through general taxation, with central administration financing the common basic coverage and the regions also matching a similar amount. The remaining part is funded through copayment by the beneficiary in accordance with their income and wealth.

The timeframe for the implementation of the Act runs from 2007 to 2015. During this period, recognition of the right to access to the different benefits will be increased progressively, from a greater to a lesser level of dependency. The Degree III Dependent persons Act was expected to be recognized in 2007, with Degree II in 2008 and 2009, and Degree I from 2011 onwards. The Spanish LTC reform is quite complex given its ambition to address various goals at the same time:

1. Social protection and care goals (guaranteeing a minimum of protection nationwide; support for the care recipient’s family, improving service quality and social service network nationwide; and promoting personal autonomy).
2. Institutional goals (cooperation between administrations; the participation of social and economic actors into policy planning; equal conditions nationwide; and the reconciliation of family life, informal care, and employment).
3. Economic goals (job creation; financial cooperation between central and regional governments; copayment in accordance with income and wealth; and creation of social markets). This multiplicity of goals has generated considerable institutional and financial conflicts among administrations, between those who prefer cash benefits rather than services and vice versa (with a majority in favor of the former) and between private and state providers (over the cost of services and the limited desire for developing the social services).

10.4.2 Did the Reform of Dependency Care Social Policy Occur Abruptly or Gradually?

In recent decades, the debate regarding the reasons behind changes in institutions and public policy has been very productive. According to Streeck and Thelen 2005, these changes may come about abruptly, but also through a “gradual transformation”

³ Social Security contributions for the family or nonprofessional carer are financed by the State and they are taken into consideration in the social insurance records of the carer.

process. Spain's LTC policy can be described as an unbalanced combination of both. On the one hand, the 2006 reform was the result of the accumulation and convergence of political factors (a new socialist government from 2004), sociodemographic ones (aging), the European context, the diversity of reforms mentioned, the rising consciousness among the professional classes, experts, social actors, and society: each of these factors played a role in the move from gradual reforms of LTC policy in Spain to the 2006 deep (abrupt) change.

It should also be considered that LTC policies have historically been seen as a low priority by successive governments, including in particular the Conservative People's Party, in office between 2000 and 2004.

Until 2001, social movements' and unions' sole priority was the generation of employment and the improvement of the public pension system. In the case of Spain, the new LTC policy in 2006 is a combination of two factors: the accumulation of practices and previous institutional reforms in LTC, together with the reshaping of the State-level political agenda. A central role was played by the accumulation of regional LTC programs, even when experimental and sporadic, between 1992 and 2001. Moreover, from 2001, the LTC policy fully entered the Social Dialogue agenda between Government, trade unions, and business organizations and, finally, from 2003, it became a relevant element in the political agenda following the renewal of the Toledo Pact in 2003.

10.5 The Pillars of the Spanish LTC System: Accessibility, Social Benefits, Governance, Finance, and Quality of Care

The Spanish LTC system is structured around five pillars, which, in a way, represent the different forces, which underlie the reform process (Rodríguez Cabrero 2007): (1) a universal right to long-term care; (2) a system of benefits, which favors service provision over cash benefits; (3) a system of governance in which the decentralization and cooperation of the various public administrations are combined with forms of institutional participation from social and economic actors; (4) a mixed finance model based on general taxation, social security contributions, and users' copayments; and (5) a system of care quality control. Table 10.2 synthesizes these five pillars: system access, types of benefits, governance, finance, and information and quality.

Access to the system of protection is based on the subjective social right to minimum or basic (limited) protection, which takes the form of a package of social cash benefits and services. The workload is shared between the autonomous regions (which assess the condition of dependency) and the municipalities or local organs of government (which assign the benefits through the Individual Care Scheme). While the assessment process is clearly defined, the assignment of cash benefits or services is a decision taken by social workers in partnership with the care recipient and their family/carers. The pressure coming from limited public resources, the choices of care recipients themselves, and differences in regional or local policy have led to a wide range of care models.

Table 10.2 Levels of protection, system of benefits and support for autonomy, financing, governance, and quality checks in the dependency act 39/2006. (Adapted from Act 39/2006)

Levels of protection (Art. 7)	System of benefits (Chapter II)	Financing (Chapter V)	Governance	Quality information and training
Minimum protection guaranteed by state	Social services as per catalogue (Art. 15)	General taxes (Art. 32), the state will provide finance from 17 Jan 2007 to 31 Dec 2015	Governance of SAAD: territorial council as instrument of cooperation between the central state administration and the autonomous regions, this council defines the assessment criteria, protective intensity, amount of benefit, joint schemes, and assessment, local institutions may take part (Arts. 8 and 12)	Common accreditation criteria for centers and SAAD quality schemes devised by the territorial council (Art. 34)
Protection agreed between state and autonomous regions	Economic benefit linked to service (Art.17)	Copayment in accordance with beneficiary's economic capacity (Art. 33), distinction between care, maintenance, and hotel services	Advisory bodies: mixed advisory committee of state, autonomous regions, local bodies, unions and employers' organizations, state council of the elderly, national council for disability, and state council of social action NGOs	SAAD's information system (Art. 37)
Additional protection on initiative of autonomous regions	Exceptional economic benefit for nonprofessional carers (Art. 18) Economic benefit for personal care (Art. 19)	Fiscal stimulus of private instruments to enable cofinancing of services (seventh additional disposition)		Training and qualifications for professionals and carers (Art. 36)

A second formal characteristic of the Spanish LTC system is the (theoretical) priority given to services over cash benefits, the latter being considered as “exceptional.” One of the system’s strategic goals is to expand social services in general and, above all, LTC services. Union pressure towards generating employment in social services and the expectations of both commercial and nonprofit providers have together favored a model of care services, which has come into conflict with the fact that most citizens prefer cash benefits. Meanwhile, the LTC system is set in a way that should foster more the preference of nonprofit providers over commercial ones, although this is more rhetorical than real: the commercial sector is gaining ground in social service provision, above all in urban areas where economies of scale can be generated.

The governance of the Spanish system is highly complex, requiring for its effective functioning high levels of institutional cooperation and loyalty between the State and regions. This is because the Spanish LTC is based on the “sharing out” of competences between the State and regions. The State has the power to regulate the basic conditions, which guarantee the equal exercise of the right nationwide and, to that end, it finances a minimum benefit for each beneficiary in accordance with the grade and type of dependency. For their part, the autonomous regions have exclusive powers over social services and accordingly guarantee funding which is at least equivalent to state funding. This does not cover the total cost of benefits, which is further funded by the regions and through copayment from beneficiaries subject to means testing. This model of governance causes tensions in practical terms since it is a kind of *sui generis*, social federalism, which requires a formal and complex agreement for the development of each new piece of the LTC system.

In this new model of governance, local government has a voice but no vote, being subordinated to the autonomous regions, even though the municipalities are the gateway and they play a key role in financing community services. From the very beginning, this integration of local government—formally an institutional subordinate to regional power—has fueled the debate, with local levels demanding the institutional visibility, which corresponded to them in the SAAD. The system of governance is based on advisory bodies such as the tripartite Mixed Advisory Committee as well as social organizations such as state councils of the elderly, the disabled, and social action NGOs.

The system’s fourth pillar is financing, the aim of which is to guarantee SAAD’s self-sufficiency and sustainability (Montserrat Codorniu 2009). As stated, the state guarantees funds to the autonomous regions to develop the minimum level of protection, where both the national and regional governments contribute equally towards the remaining cost thanks to an annual agreement (*convenio*). The users participate in funding through copayments. In the context of the current economic and financial crisis, SAAD’s guaranteed funding is inevitably a focus for public debate. The Agreement of the State, between Central Administration and Autonomous Communities in September 2009 has included LTC as part of the guaranteed welfare provision for all Spaniards at the same level as health care and education.

The last key element of the LTC 2006 reform is service quality improvement. This goal is achieved through the accreditation of centers and services, and the

Table 10.3 Changes in the Spanish LTC system (2005–2011)

Date	Reforms
January 2005	White paper on LTC
December 2006	Law on the promotion of personal autonomy and care for dependent persons
January 2007	Introduction of SAAD (system for autonomy and care for dependency)
April 2007	RD 504/2007 scale of assessment of the situation of dependency
May 2007	RD 614/2007 minimum level of protection
June 2007	RD 727/2007 benefits in cash and intensity of services. Updated every year
May 2007	RD 615/2007 regulation of affiliation, registration, and contribution to the social security by nonprofessional carers
February 2011	RD 174/2011 new scale to assess dependency
<i>Calendar of LTC Act application</i>	
January 2007	Entitlement to dependency benefits to degree III (major dependency) levels 2 and 1
January 2008	Entitlement to dependency benefits to degree II (severe dependency) level 2
January 2010	Entitlement to dependency benefits to degree II (severe dependency) levels 1
January 2011	Entitlement to dependency benefits to degree I (moderate dependency) level 2
January 2013	Entitlement to dependency benefits to degree I (moderate dependency) level 1

training of professionals working in the sector, given its labor-intensive characteristics. Table 10.3 shows the schedule of LTC reform in Spain from 2005 to the present day. Please note that social benefits, both in terms of services and monetary benefits, have been updated annually according to the previous year's rate of inflation.

10.6 Socioeconomic Impacts of the 2006 Spanish LTC System Reform

Year 2010 saw the institutional assessment of the results following the first years of the implementation of the 2006 Act. The impact of Spain's LTC system may be assessed on various levels in accordance with the five pillars of the Act described above: coverage, social benefits, governance, financing, and system quality. With barely 4 years of activity—the new system started to provide coverage in summer 2007—any impact assessment must be tentative since the system has yet to reach

Table 10.4 LTC services' coverage before and after the 2006 reform and the diffusion of cash benefits. (Adapted from *Instituto de Mayores y Servicios Sociales* [IMSERSO] and social security)

	Services ^a				Cash benefits ^b
	Residences	Day Centers	Home care	Tele-aid	
1999	2.99	–	1.67	0.72	73,000
2002	3.34	0.26	2.75	1.45	74,600
2004	3.66	0.54	3.14	2.05	78,100
2006	4.00	0.64	4.05	3.50	78,300
2008	4.44	0.83	4.69	4.72	151,000
2010					311,000

^aService coverage corresponds to persons over the age of 65.

^bScale of cash benefits beneficiaries unit 2006 belong to the social security contributions and assistance system. From 2007, beneficiaries belonged to a new system. In both instances, the data refer to “all” ages.

“cruising speed,” given the fact that the period for its implementation runs from 2007 to 2015.⁴

In terms of coverage, there can be no doubt that the new system has been a success when analyzed in terms of the increase of beneficiaries: by 1 September 2010 the degree and level of dependency of 1,476,694 people had been assessed and benefit entitlement had been determined for 1,031,676 people, with 622,056 people actually receiving social benefits. The difference between the total number of actual beneficiaries and of those with a right to benefit is due to slow bureaucratic procedures and to the fact that only those with degree II and III dependency can receive benefits. From 2011, those with grade I of dependency (some of whom are among the 1,031,767 people entitled to benefit) will start to receive benefits as well. Consequently, the coverage level of the new system is growing fast. The sociodemographic profile of beneficiaries is very similar to those elsewhere in Europe: 67 % of beneficiaries are women and 57 % are over the age of 80.

When analyzing the characteristics of coverage in greater depth, we see in Table 10.4 that, between 1999 and 2008, the increase was widespread among different types of provision: residential care coverage for the over 65s shifted from 2.95 to 4.44 %; day centers coverage from 0.26 to 0.30 %; home care from 1.67 to 4.69 %; and tele-aid from 0.72 to 4.72 %. Also, in relation to Social Security contribution and assistance cash benefits, a trend of rising coverage can be detected.

If we analyze the type of social benefits granted in these first years of the reform implementation, the results show a divergence between the theoretical legal provision and the actual role played by cash benefits, which should have been only an “exception.” As shown in Fig. 10.1, cash benefits amount to around 50 % of all benefits. This result is not too surprising given that there is: (a) a cultural predominance and preference for an informal and family care model, traditionally based on household

⁴ Several assessments on Spanish long-term care are at disposal at websites: *Asociación Estatal de Directores y Gerentes en Servicios Sociales* (2009); *Grupo de Expertos* (2009); also *Rodríguez Cabrero* (2009).

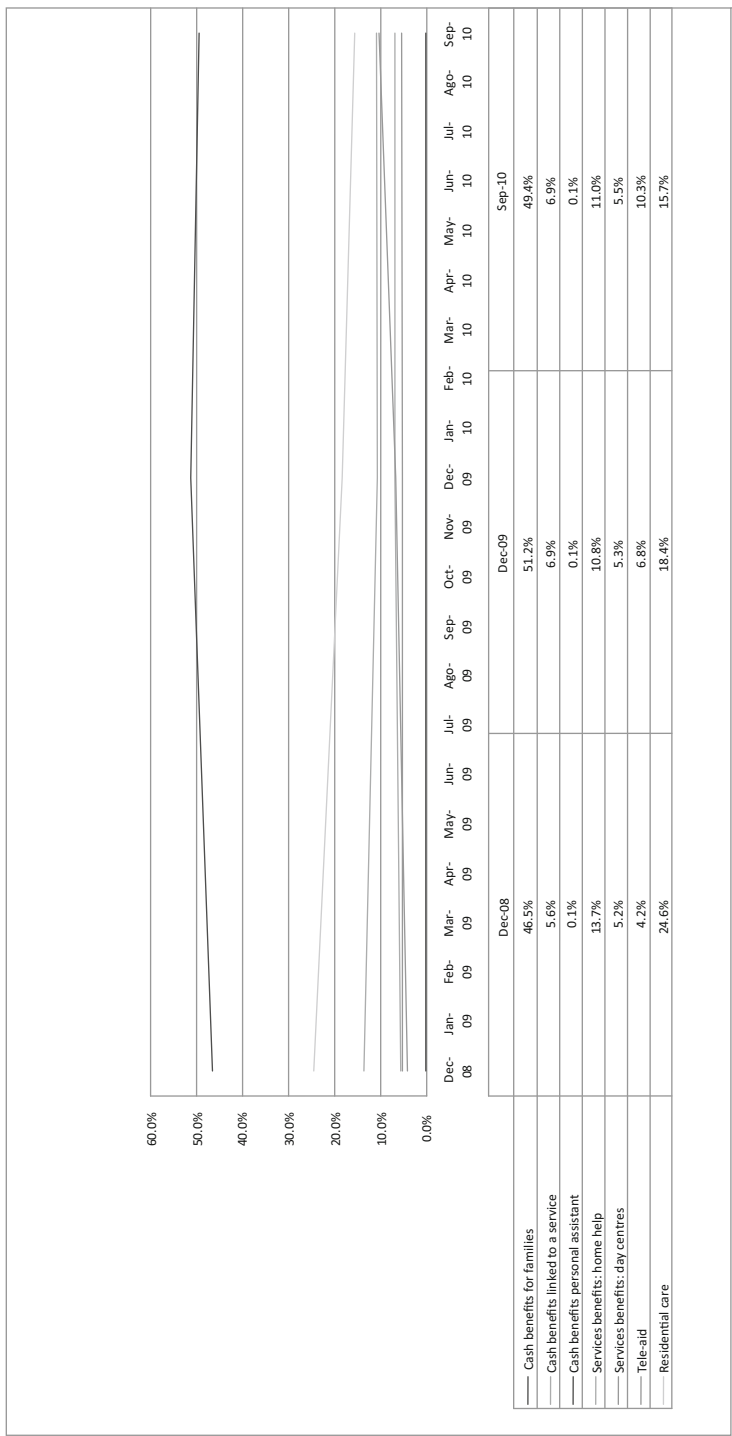


Fig. 10.1 Evolution of the proportion of cash benefits and services in relation to the total amount of benefits 2008–2010 (%). (Adapted from SAAD-IMERSO)

members (mostly women) as carers and today on immigrant care work, particularly from Latin American women; (b) a large group of women over the age of 50 who are carers, also because they have no employment perspectives in the formal labor market, especially in rural and semiurban areas; (c) a shortage of LTC services, as is evidenced in Table 10.4, which, despite the rapid growth of public and private social services over the last 20 years, is still insufficient to meet the demand in society, with the result that cash benefits are often preferred; (d) cultural preferences in the urban middle classes, who demand a wide and free choice of benefit types and, as a whole, prefer cash benefits. Available statistical information confirms that, following 4 years of application, the preference for cash benefits has increased.

In addition to these structural explanations, the role of the autonomous regions should also be highlighted. The regions favored the diffusion of cash benefits as they are easier to manage and are cheaper in comparison with services, especially in a time of economic and financial crisis, which has led to greater social spending restraint and a consequent postponement of investment in LTC services. However, even if cash benefits are playing a bigger role than the one foreseen in the 2006 reform, the contribution of the Spanish LTC system to job creation has been notable, with a yearly average of 63,021 new jobs created between 2007 and 2009 (a total of 189,063 new employees in 3 years; Sosvilla Rivero 2010).

In sum, the Spanish care is a mix of the typical LTC European model,⁵ with female carers taking a leading role in care networks, although men are slowly beginning to participate as well. There is also a relative trend towards substituting public services with cash benefits so that the care recipient is able to decide how to satisfy their needs (personal budgeting) and, when appropriate, where to contract the service. Finally, there is a general shift from residential care to community care. All these changes are taking place under a public spending restraint policy and a redistribution of the relative powers of the main institutional and social actors. In the case of Spain, the proportion of informal care for frail older people (aged 65+) has barely altered between 1993 and 2010, with women still bearing the burden of informal care responsibilities. At the same time, Spanish society is gradually realizing that there is a need to socialize risks, but not at the expense of eroding the centrality of informal care and, above all, of family control.

As far as governance is concerned, it must be emphasized that the new model is based on a structure of powers shared between the state and the autonomous regions, the latter being the territorial level of power, which is really in charge of running the system. Bearing that in mind, there is no national social services legislation, which sets basic rules for the operation of the social service system as there is for the health care and education. Moreover, given the fact that there are also important ideological differences between the different regional governments, it is no surprise that, to date, there is scarce cooperation between the State and the regions, which in turn has led to different speeds in the implementation of the new system.

⁵ By LTC European Social Model, we refer to a mix of trends towards universal coverage of dependency risk, decentralisation of management, combination of services and monetary benefits, and the participation of the users in cost financing through copayments.

The heterogeneous governance and implementation of the SAAD at the territorial level are not only due to financial and political factors. Rather, the roots of the differences can be traced back to the historical evolution of the different regional social services systems having their own social service traditions and models, which are shaping the implementation of the new LTC system. These traditions are still in many senses the decisive factor when it comes to individual regional governments decide which LTC should be applied. Local social services traditions play often a more relevant role than the type of government or ideological orientation. Regional governments with different political majorities often use the same approach in applying the new system as they share quite similar social service set-ups.

In addition to political differences and service infrastructures, there are two further and no less important problems associated with the governance of the system: the flow of information from regional to central government about how LTC beneficiaries are attended and the benefits are provided; and the opacity regarding the participation and financing of the municipalities in the care system. The great heterogeneity of SAAD in terms of access, benefit type, and quality is also affected by financing. The method of financing dependency is highly complex given that the State finances 50 % of the “new” social benefits created as in January 2007, but not the cost of the provision that existed previously in the care system. This means that, in practice, more than two-thirds of the total cost falls to the Autonomous Communities or regions. Moreover, state financing for the new LTC system is not always used by the regions for this purpose but for funding preexisting benefits (such as residential care): such a situation has slowed down the expansion of the new system.

The State guarantees a degree of equity by means of an equal minimum per capita benefit nationwide, as well as some territorial redistribution on the basis of the benefit agreed with the regions in accordance with criteria of territorial dispersion, population size, and number of service users. But the final word regarding where benefits go rests with the regions, which have exclusive decision-making rights in this regard, as is demonstrated by, for example, different yardsticks for assigning benefits and different forms of copayment by beneficiaries.

Financial restrictions and the social and institutional preference for cash benefits has led to increased competition between the commercial providers and NGOs to control service contracts, and this is changing the face of the traditional structure of social services private provision. Finally, the development of SAAD is not improving the coordination between social and health care services. This lack of coordination means that the implementation of the Act has been limited to the social care system. An explanation for this outcome is related, on the one hand, to the different levels of development, organization, and professional practice by health care and social services, on the other, to the lack of steering capacity by the national ministries involved in LTC issues, including in particular the Department of Health.

10.7 Conclusions

The Spanish LTC system (SAAD) is relatively new and therefore only tentative conclusions about its functioning can be drawn. Firstly, like most of the models in place in European welfare regimes, the Spanish LTC model is one of shared responsibility between the dependent persons, their family, and the public sector, with an aim of enhancing the quality of life of both the care recipient and of their carers. It is a model, which favors the freedom to choose between a limited set of different care arrangements and which seems to foster a new ethos of joint responsibility, whether of state and family or of men and women. Secondly, the SAAD is the outcome of a convergence between deep social and demographic changes, the needs of new generations of working women, the growing Europeanization of social policy, and the mobilization of social and institutional actors in favor of the reform (particularly the Third Sector and Social Partners through Social Dialogue). Thirdly, it is also a care model, which replaces the social assistance logic with a universal approach built around an institutional set-up, in which state and autonomous regions are obliged to cooperate. This situation often creates tensions between the various actors and it has so far caused territorial heterogeneity and inequalities in terms of coverage, benefit types, and the social impact of the reform. In relation to this last issue, it seems clear after some years of implementation that different historical traditions in social care models at the local level are shaping the nature of regional policies far more than ideological stances. Finally, the reform has had a significance in terms of the coverage of the dependent population, even if this coverage has often increased more because of cash benefits than services. This circumstance, criticized by unions, professional associations, and providers, is the result of the continued existence of a social structure of informal care (which the current economic crisis has partly reinforced), the limited supply of social services, and public spending conservatism, which has diminished investment in social service infrastructures. Care recipients' preference for cash benefits is also backed up by the offer of relatively cheap migrant labor to which frail older people and their families often resort.

Looking at the future, the Spanish model will face major challenges in the future: a more effective governance; the need to improve equity across the nation and to guarantee enough funding in order to increase the supply of services; a boost to social health service coordination and greater institutional weight to local government, insofar as it provides services in the community. From our analysis of the impact of Spanish LTC, we deduce that its future evolution will depend on the development of a mixed model whereby the link between family help and individual responsibility on the one hand and the socialization of risks on the other will be keystones of a system characterized by a highly decentralized model of regulation and provision.

References

- Asociación Estatal de Directoras y Gerentes en Servicios Sociales. (2009). Desarrollo e implantación territorial de la Ley de Promoción de la Autonomía Personal y Atención a las Personas en Situación de Dependencia; III Dictamen. Retrieved from <http://www.directoressociales.com/>
- Fantova, F. (2008). *Sistemas públicos de servicios sociales. Nuevos derechos, nuevas respuestas*. Bilbao: Instituto de Derechos Humanos. Universidad de Deusto.
- Grupo de Expertos. (2009). *Informe final del grupo de expertos para la evaluación del desarrollo y efectiva aplicación de la Ley 39/2006, de 14 de diciembre de Promoción de la autonomía personal y Atención a las situaciones de dependencia*. Madrid: MSYPS (IMSERSO) y Congreso de los Diputados.
- Instituto de Mayores y Servicios Sociales [IMSERSO]. (2005). *Libro Blanco de atención a las personas dependientes en situación de dependencia en España*. Madrid: Imserso.
- Instituto de Mayores y Servicios Sociales [IMSERSO]. (2009). *Las personas mayores en España. Informe 2008*. Madrid: Ministerio de Trabajo y Asuntos Sociales.
- Marbán Gallego, V. (2009). La atención a la Dependencia. In L. Moreno (Ed.), *Reformas de las políticas del bienestar en España* (pp. 207–238). Madrid: Ed. Siglo XXI.
- Montserrat Codorniu, J. (2009). Evolución y perspectivas de la financiación del sistema para la autonomía y atención a la dependencia. *Documentación Administrativa*, n° 276/277.
- OECD. (2005). *Ensuring quality long-term care for older people, Policy Brief*. Paris: OECD.
- Pavolini, E., & Ranci, C. (2008). Restructuring the Welfare State: reforms in long-term care in Western European countries. *Journal of European Social Policy*, 18(3), 246–259.
- Rodríguez Cabrero, G. (2007). El marco institucional de la protección social de la dependencia en España. *Estudios de Economía Aplicada*, 25(2), 343–372.
- Rodríguez Cabrero, G. (2009). El desarrollo de la política social de promoción de la autonomía y atención a las personas en situación de dependencia en España (2007–2009). *Gestión y Análisis de Políticas Públicas*, 2, 33–58.
- Sabatier, P. A., & Jenkins-Smith, H. (1999). The Advocacy Coalition Framework: an assessment. In P. Sabatier (Ed.), *Theories of the Policy Process* (pp. 117–168). Boulder: Westview Press.
- Sosvilla Rivero, S. J. (2010). *Estimación del efecto del establecimiento del sistema de autonomía y atención a la dependencia sobre el empleo en España*. Madrid: Mimeo, UCM.
- Streeck, W. Y., & Thelen, K. (eds.) (2005): *Beyond continuity: Institutional Change in advanced political economies*. Oxford: Oxford University Press.
- Weible, C. M., Sabatier, P.A., & McQueen, K. (2009). Themes and variations: taking stocks of the Advocacy Coalition Framework. *The Policy Studies Journal*, 37(1), 121–140.

Chapter 11

Long-Term Care Italian Policies: A Case of Inertial Institutional Change

Giuliana Costa

11.1 Introduction

Even though the Italian social protection system has undergone some reforms over the last 2 decades (Ascoli 2011; Ranci and Migliavacca 2011), long-term care (LTC) issues have been systematically neglected over the same period. Welfare reforms in the 1990s focused mainly on the redesign of pensions schemes—including a shift to a contributory system—and partially on health policies, where instruments reflecting a “New Public Management” approach (i.e., adopting market-based principles; Ferlie et al. 2005; Jessoula and Alti 2010) were introduced. It is only since the beginning of the new millennium that LTC has entered the public reform agenda, when several national reform proposals were first mooted. However, the only public action specifically directed to address care needs over the last 10 years was the creation of a very modest and temporary “National Fund for Dependency” in 2007. Since then, two other measures have also indirectly offered some assistance to those with caring needs: the establishment of a national contract for homecare workers (including personal assistants) and the “regularization” (i.e., legalization) of migrants who wished to work as personal care assistants in 2009, as will be explained later on.

Sociodemographic trends clearly indicate that a new set of risks related to dependency and care needs has emerged in Italy. Indeed, the number of individuals and families affected by dependency is increasing. Nevertheless, LTC policies have not undergone explicit institutional change through legislation at the national level. The ongoing decentralization of social policies in Italy, even if potentially innovative in terms of responsiveness to growing social demands, has not been able to keep pace with growing LTC needs, which remain partially unmet.

This chapter sets out to describe and discuss the main features of the Italian “care regime” (Ranci and Pavolini 2008) and the LTC policy arena, clarifying what the opportunities and constraints for national and subnational LTC reforms have been. The central argument of the chapter is that a substantial inertia (in the context of huge societal transformations) characterizes this policy arena (Ranci and Pavolini 2011)

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and, as a result, the LTC field has undergone only an “incremental institutional change” (Streeck and Thelen 2005). This interpretation of LTC policies trends is based on two interlaced phenomena. First, the core support tool for LTC needs in Italy consists of a cash transfer, which was introduced 30 years ago. It was originally devoted to adults with disabilities, but it is now almost completely used by severely dependent older people without any recalibration of its design. Second, Italian families are responding to the care needs of older relatives via a huge private care market that has developed without any substantial public-specific regulatory intervention to qualify, formalize, or finance it. The lack of any steering actions during the emergence and consolidation of the private care market, together with the absence of any additional public support for those with LTC needs, can be interpreted as an ongoing, partial, and gradual institutional change process. As a result, the Italian LTC system has evolved from a “familialistic” model to one where those with caring needs are obliged to simply “cope” through a mix of public and private resources within an overall “marketization of care” trend (Bettio et al. 2006).

11.2 The Italian Care Regime: Overloaded Families, Private Solutions, Public Absence, and Caregiving Gaps

Along with other southern Europe countries, Italy’s care regime has been defined as “familialistic” since comparative studies have pointed out the strong role of family in the organization, provision, and financing of personal care (Bettio and Plantenga 2004; Naldini and Saraceno 2008; Ranci and Pavolini 2008, 2010). As a large body of research has shown (Eurofamcare 2006, Fujisawa and Colombo 2009; Österle 2001), care in Europe remains a “family matter”: most care work is provided by family members and families have, even when public or private services are available, a pivotal role in care arrangements. What is peculiar to Italy and other Mediterranean countries is the assumption that families “are always there” and that they will provide all kind of resources, including care (Saraceno 2002).¹ Moreover, an “implicit familism” (Saraceno 2010) is in place because the welfare system assigns significant caring responsibilities to families: the State intervenes only in limited, urgent cases. The scarcity of public services thus feeds back into the traditional Italian “care responsibility culture” (Titmuss 1973), whereby it becomes very difficult for family members to opt out of caring (Costa 2007a; Lewis 1993).²

If we analyze the caring arrangements of Italian families that have at least one older person, the extent to which care is a family issue becomes clear. Throughout all age groups (65+) and for a range of caring needs (from not dependent to severely dependent), most help and services-in-kind are provided by family members (*Istituto*

¹ As shown by Groppi (2010), this assumption is historically constructed: the “ideology of blood” is the outcome of a continuous negotiation between family and collective responsibilities with the intervention of the State or tribunals throughout the Modern Era.

² See how the responsibilities towards relatives stated in the Civil Italian Code are heavier as compared to other countries (Millar and Warman 1996).

Table 11.1 Percentage of Italian families with older people per type of help received (2009). (Adapted from ISTAT 2010)

Kind of family	Families that receive help	Informal	Private	Public	Mixed help	Families that do not receive any kind of help
With 65+	29.2	16.2	14.0	7.9	7.5	70.8
With 65+ ^a	49.6	29.6	22.9	22.0	20.1	50.4
With 65+ ^b	31.1	17.6	14.6	6.0	6.4	68.9
With 80+	45.0	26.0	23.6	13.2	14.8	55.0
With 80+ ^a	61.5	37.1	31.9	27.6	28.0	38.5
With 80+ ^b	43.9	25.4	22.2	9.2	11.2	56.1

^aSeverely dependent^bDependent**Table 11.2** Caring arrangements of severely dependent older people receiving the IdA living at home and number of hours per week of care (2008). (Adapted from DaRoit 2008)

Caring arrangements	Percentage of severely dependent older people living at home	Number of hours/week of care received
Only informal care provided by family caregiver	39.8	90.7
Only public care services	0.8	13.9
Only private services	3.3	66.0
Informal care + public care services	11.3	92.9
Informal care + private services	29.6	119.5
Public care services + private services	1.8	103.3
Informal care + private service + public services	13.4	121.3
Total	100.0	102.4

Nazionale di Statistica [ISTAT] 2010; see Table 11.1). Along with this preeminence of family care, it is important to point out that a large part of the dependent older population, almost 40 % of families with an individual aged 80+, do not receive any kind of formal or informal help. The amount of help drops for those younger than 80 or with less severe autonomy limitations.

If we focus on highly dependent individuals aged 65+ who receive the LTC allowance “*indennità di accompagnamento*” (described in further detail in the next section), Survey data show that only 5.9 % of beneficiaries cannot rely on informal family care: the vast majority are assisted exclusively by a family caregiver or by a combination of informal care and public or private services (Da Roit 2008). In particular, see Table 11.2:

- Around 40 % of beneficiaries are only helped by family care givers for a total amount of 91 hours per week (an average of 13 hours per day!).
- Another 30 % are able to mix family care with private provision (mostly migrant care workers); this mix assures the highest number of care hours per week (119.5).
- Only 13.4 % of beneficiaries are able to rely on informal, private, and public resources.
- In general, public LTC services reach only a limited number of highly dependent individuals in receipt of an allowance (27.3 %), whereas almost half of the households utilize private paid care (47.9 %).

Some scholars have argued that the emergence of the private care market, made up of mainly foreign migrants, changed the nature of the Italian model of care with a “transition from a ‘family’ to a ‘migrant in the family’ model” (Bettio et al. 2006, p. 272). In fact, the gap between the expanding demand of care services, the modest public LTC service provision and the reduced capacity of families to care on a long-term basis (as will be clarified further on) has largely been filled by low-cost care work provided by migrants. Carers are mainly women from less developed countries:³ An old Italian word—“*badante*”—has been revived specifically to name those who “care/mind for” someone on a long-term basis. The growth of this private market is due to many different factors: the availability of a large immigrant female labor force, the scarcity of and difficult access to public personal care services, the traditional preference for caring at home, the increase of the female employment rate in the country, and finally, the availability of an adequate income by a significant proportion of the current generation of Italian pensioners (Da Roit 2007; Spanò 2006). Hiring a personal assistant is less expensive than other caregiving solutions and is also more flexible than availing of more formal services, be they private or public. Often, migrant workers in this field offer care 24 hours a day and are able to monitor the daily lives of frail older people at home. Employing a “*badante*” has turned out as a common, relatively reliable and “ready-to-go” arrangement, even for nonaffluent households. In general, migrant care workers are employed through the “gray” market without proper employment contracts being signed: therefore households can pay as little as € 700–1,200 per month for a “*badante*” (Pasquinelli and Rusmini 2010). Supply has also increased the demand in Italy (Colombo 2005). As shown in Table 11.1, more than 14 % of families with an older relative (aged 65+) employ a personal assistant and the percentage continues to grow within the older population. According to recent estimates, Italian families are spending around € 9.5 billion a year to pay for personal assistants (Pasquinelli and Mesini 2010).

However, if we consider the overall burden of care towards older people, it is clear that even with the entrance of “*badanti*” into the sector, a significant proportion of care is still provided by family members. Empirical evidence shows that personal assistants do not completely replace families in their caring activities. Instead, they are complementing them (Eurofamcare 2006; ISTAT 2010). Families provide the bulk of personal care and domestic help as well as health and psychological assistance. They also have a crucial organizational role in monitoring financial aspects and in coordinating different kinds of care resources. As already stated, the centrality of families (and private assistants) in care arrangements can be at least partly attributed to the low level of public provision of services and by weak entitlements related to caring needs (see next section). In Italy, care policies do not rely on actual, clear eligible rights. To be cared for is an “incomplete right” (Knijn and Kremer 1997; Leira 1993) because obtaining personal help is not legally enforceable.

³ Typically, migrant care workers come from a relatively limited number of countries and geographical areas, which have changed over the last 15 years due to different migratory waves. Most of those nowadays working in Italy come from eastern Europe (mostly Ukrainians, Moldavians, and Rumanians). They are largely middle-aged women, often highly educated and ready to live at the home of the cared person in order to save money.

11.3 The Shaded Perimeter of the Long-Term Care Policy Arena

Like many western countries, LTC policies are not defined as a specific arena in the Italian welfare system (OECD 2011); instead, they are spread among different, uncoordinated policy fields and national, regional, and local agencies. Available data reflect this fragmentation and dispersion (Chiatti et al. 2011) and in turn make it quite difficult to obtain a clear, overarching picture of LTC interventions. Furthermore, LTC needs are not defined by any national law, which set out common criteria. Instead, each regional government has defined care needs in different ways and in different contexts, sometimes within regional laws, sometimes simply through administrative norms (Pavolini 2004). Differentiation in what is considered “dependency” in old age also exists at the local level. Only “severe handicap,” “civil invalidity,” and “being in need of the *indennità di accompagnamento*” are conditions defined by national laws, though dependency is assessed locally (by the “*Aziende Sanitarie Locali*” (ASL) the Italian local health services).

The Italian welfare system is strongly dualistic and is financially imbalanced in favor of cash transfers. Indeed, social assistance represents approximately 80 % of total public spending on social welfare. Cash transfers are normally regulated at the national level, while the few in-kind services are locally designed and provided. Dependence as a condition of LTC support is supported by the public system mainly through social care policies and partly by health policies, two arenas that in most regions are not integrated; as already underlined in the previous paragraph, home health services are organized by local health agencies, whereas social services are delivered by the municipalities. Homecare and residential services started to be developed by some municipalities in the 1970s outside of any national law or regulation. In the following decade, after the foundation of the National Health Service (NHS; law 833/1978), these services were strengthened in some areas of the country with different levels of integration between medical and social provision. The *National Plan for the Elderly* was delivered in 1992 but it was never fully financed, leaving the evolution of LTC services at the discretion of the regional governments and the local municipalities, which were responsible for the provision of those services. Thus, providing for those with disabilities and/or dependence has never been a specific national policy objective.

LTC services with a high health component are tax-funded (under the National Health Service). Only residential homes, which are organized and/or delivered by the ASLs and managed by the regional governments, are partly copaid by users. These homes offer not only residential facilities with different levels of medical services, but also day care centers. All service users also have access to the assistance provided by general medical practitioners. Residential services are offered largely to the oldest, most dependent older people, or to adults with the most severe disabilities, who are generally coming to the end of their lives: a reason why they are considered nowadays as a “last option” to be used when all other arrangements are exhausted (Da Roit 2007). On the contrary, home health services cannot be fully considered LTC

Table 11.3 Coverage by the Italian LTC system (2008–2011)

Percentage of more than 65 receiving	Italy	Center-northern Italy	Southern Italy
Attendance allowance (IA; 2011) ^d	11.6	10.4	14.7
Social home care (2008) ^b	1.6	1.5	1.8
Nursing home care (2009) ^a	3.7	4.3	2.2
Residential and day care (2009) ^c	2.5	3.0	1.2

The figures of social home care (run by local authorities) and nursing home care (run by the NHS) cannot be simply added together because they partially refer to the same beneficiaries

Own elaboration from:

^aMinistero della Salute 2011

^bISTAT 2011

^cISTAT 2012

^dINPS 2012

supports because they are organized to provide medical, nursing, and physiotherapy interventions solely on a temporary basis for just few hours per week. The ASLs are responsible for assessing the degree of care needs of those who live in their area through a multidisciplinary team, to set a “personal care plan” for them. Normally, the evaluation processes are built on validated international multidimensional schemes.

Public support for LTC is funded through taxes and is managed directly both by the municipalities and by the central State. The municipalities offer mainly services in kind and, in the last 10 years, modest cash allowances. Social services in kind for LTC provide only a very modest level of coverage (see Table 11.3) and they are also locally fragmented. They consist of home care services, residential services, and day care centers. Homecare and residential care are normally means-tested because users contribute; day care centers are mostly accessed on a free basis. Each territory offers a very different care model in terms of the numbers of home visits, the qualifications of the staff, the number and kinds of services provided, and integration with other services. Eligibility criteria (including economic ones) are not homogeneous and are defined at the municipality level, in some cases following regional regulations. Municipal cash transfers are provided to maintain frail older people at home and are normally an alternative to services in kind. They consist of allowances devoted to family caregivers or to pay for private assistants on a strictly means-tested basis. Their amount varies from € 200 to 500 per month (Pasquinelli and Rusmini 2009) but their coverage rates are still very low, less than 1 % of the target population.

The main and most widespread support for LTC is the “*indennità di accompagnamento*,” a disability benefit regulated by the central State, managed and paid directly to the recipients from the National Institute for Social Security (INPS). It is an allowance devoted to those who are assessed as completely dependent on a long-term basis by local health medical commissions, independent of their age and economic status. It is the only universal measure in the Italian welfare system especially designed for those who are severely dependent (in this case dependency means being completely unable to perform the basic activities of daily living without help). It consists of a flat rate allowance of € 480 per year (2010) and it is not graduated in

relation to different care needs. It can be used freely and there is no public control over its use. The medical commissions, which are the gatekeepers to access this measure, do not take into account any possible mismatch between the available resources (other economic means, family help, networks) and needs. Indeed, empirical research shows that it is frequently used to pay for some form of care, in most cases to integrate the cost of private assistants (DaRoit 2008).

Table 11.3 synthesizes the main figures related to the functioning of the Italian LTC system. The coverage level of the *Indennità di Accompagnamento* among the older population was equal to 11.6 % in 2011.⁴

It can be estimated that around 4.5–5 % of the older population in Italy benefits from public home care programs (1.6 % of home care provided by local authorities and 3.7 % by the NHS) and 2.5 % have access to residential care. Data for other European countries are different and often higher (see Chap. 2). Yet, if we differentiate between the coverage of LTC services in the center–north of Italy and in the south, we can see that the availability of services in the center–north is closer to central Europe (3 % coverage in residential care and around 5.5 % in home care), whereas the situation is dramatically lower in the south (1.2 % coverage in residential care and around 3.5 % in home care). The territorial divide in LTC availability is quite a specific and worrisome feature of the Italian system: also in LTC, as in other welfare services, we can describe the situation as consisting of “two different welfare regimes” (Pavolini 2011).

Other Italian LTC policies are even less well developed. There are no specific fiscal benefits for LTC expenses: a modest amount of contributions paid to regularly hired personal assistants can be rebated (around € 1,500 per year) and only 19 % of expenses devoted to buy vehicles and technological devices for disabled people can be deducted from the total amount of gross payable taxes. On the contrary, health costs are generally favored as they can be fully deducted from taxable income. No figurative contribution schemes are in place for those who leave their employment to care for someone on a permanent basis. The only benefit provided for working caregivers is 3 days’ parental leave per month, offered to close family members who care for someone who has been defined as severely disabled according to the criteria reported in a national law (104/1992), assessed by ASL medical commissions.

According to available data in 2008, public spending on LTC represents 1.18 % of total GDP, around € 18 billion: 0.49 % of GDP is made up of NHS LTC spending; 0.56 % for the provision of the IdA; and 0.13 % for social care spending by the municipalities (Chiatti et al. 2010). Public spending on LTC grew by a modest 0.13 % from 2004 to 2008. Private spending on LTC (what families pay for personal assistants) has been estimated at around 0.59 % of GDP, equivalent to half of the total public spending on LTC (Pasquinelli and Rusmini 2009).

⁴ Author’s own calculation, based on the data provided on the INPS website.

Box 11.1 The Italian LTC panorama: actors, services and provisions, and funding

LTC actors	LTC services and provisions	Funding LTC
Ministries and national agencies regions ASL	Health home services (ADI) Social home services (SAD)	NHS (general taxation) regions Municipalities (general taxation and local taxation), INPS (general taxation), users private resources
Municipalities	Residential services and day care centers (with different degrees of medicalization)	
Families	Cash transfers	
Third-sector organizations, for-profit organizations	Mediation services, tax credits	

11.4 Drivers for LTC Reforms

The ageing of the population, the shrinking care capacity of households and the rising social costs of LTC in old age represent potential driving forces for institutional changes in the Italian LTC system. Italy has one of the oldest populations in the world and, along with Germany, its ageing rate is the highest in Europe. The proportion of the 65+ population is, according to ISTAT (2009), 20.1 %, a value that grew by 37 % in the last 20 years and almost doubled in less than 50 years. In the early 1990s, there were 8.7 million older people living in Italy, which had risen to 11.9 million by 2008; a net increase of 3.2 million individuals (see Table 11.4). The ageing of Italy can be better understood by analyzing the evolution of those aged 74 and over: they represented around 3.9 % of the population in 1971 but 9.6 % at the end of last decade. Even if the “compression of morbidity” scenario (Baltes and Smith 2003) partially holds true for the Italian case (the older disability rate decreased from 21.7 % in 1994 to 18.8 % in 2005, see Table 11.4), the absolute number of dependents has grown and the qualitative composition of dependency has changed: the severe dependency rate (defined as being confined at home) is increasing. So, even if disability rates are decreasing for the whole population, the number of dependent individuals is growing and dependency, when present, is getting more severe.

These figures should be considered jointly with those related to demographic dynamics and structural changes in the female participation in the labor market. Analyzing the life course of three generations of Italian women at the age of 40 (see Table 11.5), it is clear that couples are having fewer children, usually at a later age, and more generations coexist for many years (ISTAT 2011).

More than 60 % of 40 year-old women are now in employment; this figure has doubled in 30 years. Nowadays, 51.9 % of the so-called “caring pool,” represented by women aged 40–59, is in the labor force, compared with 39.5 % in the early 1990s. As household division of labor between men and women has not changed significantly over the same time period, care work by families, and particularly by women, can

Table 11.4 Ageing and dependency in Italy. (Adapted from Ranci and Pavolini 2011 from ISTAT [different sources])

	The 1990s	The 2000s	Variation over time	
	(1993/1994)	(2005/2008)	Absolute	Relative (%)
Number of older people (millions)	8.7	11.9	3.2	+36.7
Number of older people more than 74 (millions)	3.7	5.7	2.0	+54.0
Number of dependent older people (millions) ^a	1.8	2.0	0.175	+9.4
Number of dependent older people with severe limitations (millions)	0.7	1.0	+0.3	+35.6
Number of dependent older people with less severe limitations (millions)	1.1	1.1	-0.0	0
Disability rate among older people (standardized): general	21.7	18.8	-2.9	-13.4
Disability rate among older people (standardized): severe limitations	8.8	9.3	0.5	+5.7
Disability rate among older people (standardized): less severe limitations	13.3	10.3	-3.0	-22.6

^aThese numbers do not include older people living in residential settings

Table 11.5 Projected indicators for three generations of women at 40 years old. (Adapted from ISTAT 2011)

Year of birth	Average number of children	Average age at first child	Percentage of women who do not give birth	Average number of years coexistence with an older parent	Percentage of 40-year-old women in the labor market
1940	2.0	25	13	12	30
1960	1.7	27	13	18	50
1970	1.4	30	20	22	62

thus no longer be taken for granted. More Italian adult women are employed and are staying longer in the labor market because of the worsening of eligibility criteria for pension schemes and their late entrance in paid activities: this situation lowers their will and capacity to provide personal care, at least on a full-time basis. Even if families are “still there,” their caring capacity has clearly decreased in quantity (Eurofamcare 2006): from 1998 to 2009 the total number of hours dedicated to adult personal care adults decreased from 759,000 to 730,000 (ISTAT 2010).

The last crucial aspect related to the growing demand for a wider reform in the LTC Italian system is the increasing economic impact of LTC needs. This kind of need has been identified as the second cause of household impoverishment after unemployment (Centre for Economic and International Studies [CEIS] 2009), not only because of out-of-pocket spending (to buy private services or to copay for public-regulated ones) but also due to costly family rearrangements. As a matter of fact, LTC

needs are facilitated less and less by health services, which are focused increasingly on acute conditions. The introduction of hospital reimbursement mechanisms, which has accelerated the discharge of patients, is a good example of the process that sees the embedding of LTC more and more into the social arena, delegating caring responsibilities to families and municipalities. Last but not least, it has been estimated that 2 % of the older population remains excluded from the IdA (Ranci et al. 2008), because, even if they are frail, they do not fit eligibility criteria, which are designed to facilitate physical impairment rather than cognitive or mental disorders.

11.5 Institutional Reform Attempts and Substantial Inertia: The National and Regional Levels

Many LTC reform proposals have been advanced since the “*Commissione Onofri*” was set up by the left-wing government to reformulate the Italian social protection system in 1997. This commission suggested redesigning invalidity pensions and benefits for dependent people with the creation of a ring-fenced “National Fund for Dependent People.” This proposal was never put into practice and LTC issues were sidelined by government priorities until the beginning of this millennium when an important Act (328/2000) reframed the whole assistance system in Italy. Between 2001 to 2006, LTC issues received more attention from the Center–Right government with many technical and political (even bipartisan) proposals to innovate and fund the system (Gori 2008). Most of them focused on the following policy priorities: providing universal coverage for LTC costs (even with the introduction of homogeneous copayment formulas throughout the country), ensuring more coordination between health and LTC policy arenas, widening the take up rate of services, and developing more home care arrangements (in line with other countries in Europe; see OECD 2011). Some proposals were devoted only to those aged 65+, others to dependent people in general. Some of them intended to modify and to incorporate the available economic resources into a single fund on assignment to the IdA. However, none of the proposals were implemented mainly because of the absence of consensus on how to finance new schemes and because of veto players who resisted reforming the IdA, as will be clarified later.

Meanwhile, incentives for the development of national programs and ring-fenced resources decreased. In Italy, as in a large number of European countries, devolution, rescaling, and subsidiarization processes of public policies have been enforced in the last 2 decades (Kazepov 2008). The decentralization has not been supported either by the transfer of consistent national resources or by an increase in fiscal autonomy by regional governments. The redesign of the institutional architecture of competences towards welfare policies started with the above mentioned Act 328/2000. This law assigned precise duties to all levels of government (regional, provincial, and the municipalities), set specific instruments for social planning and created the National Fund for Social policies (FNPS) to finance basic services, which should have been offered all over the country, acknowledging the strong territorial differences in terms

of social infrastructures. A few months after the enforcement of the law (in 2001), a Constitutional reform delegated most of the responsibilities for social care to the regional governments and moved towards a more federalist structure of the Italian State. Regional governments now hold exclusive jurisdiction over social assistance policies, leaving to the central State the responsibility of fixing the “basic levels of provisions concerning the civil and social rights that must be ensured all over the national territory” (Art. 117, comma m, Title V of the Italian Constitution). Previously, regions already had large planning capacities in several matters but were strongly checked by (and dependent on) the central government through a system of fund transfers linked to specific aims (Arlotti 2009; Brosio 2003). The Constitutional reform attributed new tasks to the regional level. Such attribution of competencies has, nonetheless, been adequately supported neither by tax levy⁵ nor by the fixing of the mentioned basic levels of provision, meant not only to protect the universal rights of citizenship but to ensure, at least up to such minimum levels, the funding of social policies by the central government. The resources of FNPS supposed to ensure the funding of social services are therefore transferred to the Regions without any central control over their final destination.⁶ One of the consequences of the devolution enforced by the Constitutional amendment is that each region uses the assigned resources in accordance with its own standards and programs, eventually adding different amounts of their own resources and allocating them to the municipalities.

Such a standoff has to some extent been filled by regional initiatives. However, such initiatives have not been consistent and, in the decade following the constitutional reform, many regions—especially in the southern part of the country—have not been able to clearly define their own social care policies. This inertia towards LTC social policies can be attributed to many reasons. The first is that most available resources come from the municipalities (70 % on average; ISTAT 2009) while the funding from regional and national governments (like those of the FNPS) is more modest. Limited regional resources imply a low capacity to condition local rules. Another reason is related to very strong territorial differences, mainly between northern and southern Italy, both in terms of economic development and LTC services coverage rate (see Table 11.3; Costa 2009).

In 2007, the left coalition Government led by Prodi tried to introduce a reform for LTC, but the legislature was prematurely concluded and only a very modest National Fund for Dependency was created with the allocation of € 500 million (later increased to € 800) for a 3-year period (2007–2009). Thanks to an agreement signed by the regions, the Fund was confirmed for 2010 with an allocated budget of € 400 million but it has been completely cancelled for 2011 and onwards, in the context of a massive reduction of funding for all social policies (not only LTC ones)

⁵ This is particularly crucial for social assistance policies because most of the regional resources are used to finance their health services. In any case, it is important to know that from 2001 onwards, the central State had systematically limited the mentioned Region’s fiscal autonomy.

⁶ The only exceptions are the funds related to the National Fund for Dependency (see later) and the Plan for preschool services, both implemented with the general annual budget law of the State of 2007.

due to austerity measures. Some regions decided to develop their own social policies in favor of dependent people, creating their own Funds in order to enlarge the coverage rate of territorial services, diversify the offer of services, or redesign the body of regulations (Cembrani et al. 2010). However, quite often the amount of resources in these regional funds was not able to overcome the shortcomings of the local LTC system.

11.6 Factors Leading to Institutional Reforms: The (Relative) Success of the “Indennità di Accompagnamento” and of Migrant Personal Assistants in Italy

We will now discuss the main elements and processes that have played an important role in creating the inertia surrounding LTC policies in Italy (Ranci and Pavolini 2011). They are basically related to the role played in the whole system by the IdA and the consolidation of a private and unregulated care market, as we have already shown. Paradoxically, the existence of the IdA can be considered as a factor leading to the inertia in the creation of wider institutional reforms of LTC in Italy. This cash transfer was launched in 1980 to compensate for the loss of economic income among those who were unable to work. After 8 years, it was extended to those aged 65+. Since then, an exponential growth in its coverage rate and a progressive ageing of its beneficiaries has developed. By means of demographic and epidemiologic changes, the IdA has completely changed its scope and use over the last 20 years, though there has been no revision of its eligibility rules, targeting, or the amounts granted. As shown in Fig. 11.1, the increase in the take up rate grew exponentially at the beginning of the 1990s, almost completely due to the entrance of older beneficiaries.

As shown in Fig. 11.2, the coverage rate of IdA rate among older people was 11.6 % in 2011, after rising rapidly in recent years (it was 6 % in 2000). In the same period, homecare and residential care did not increase by as much. The huge growth of IdA can be explained first of all by demographic ageing and, more specifically, the growth of the population aged 75+. In fact, the actual distribution of beneficiaries by age reveals that the IdA is mainly distributed to the very old: more than 50 % of the recipients are aged 80+. Other factors can explain the “success” of the IdA: a growing welfare consumerism, the lack of other public supports for LTC, the absence of universal income supports in the Italian welfare system, the availability of migrant women to perform caregiving tasks, and the separation of the IdA gatekeepers (regional governments, through their ASLs) and financers (the National State, through the INPS; Gori 2010).⁷

Despite being a universal measure provided to those who are assessed as dependent on the basis of (in theory) nationally defined criteria, there are markedly

⁷ From 2011 onwards, the INPS imposed the presence of their own doctors in the Commissions to assess the needs of applicants in order to control the whole process from IdA applications to their payment.

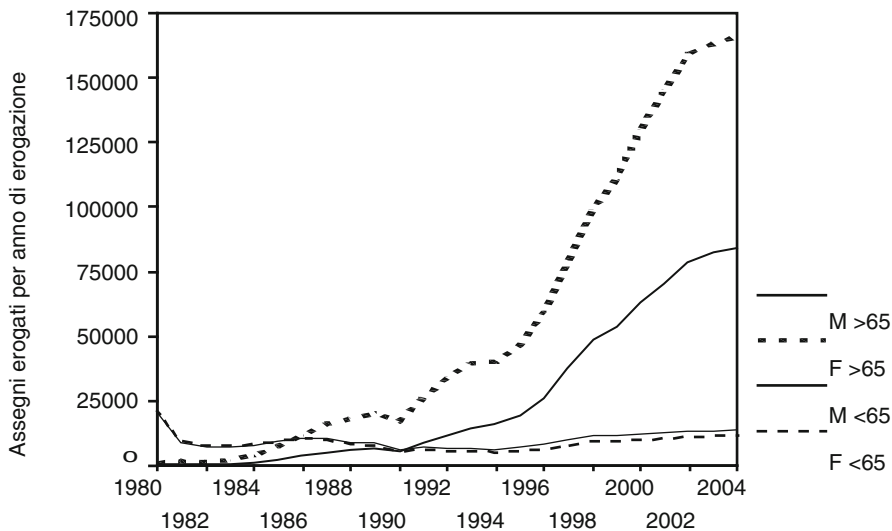


Fig. 11.1 Evolution of new yearly provisions per gender and age at the beginning of provision. (Adapted from INPS data, Ranci et al. 2008)

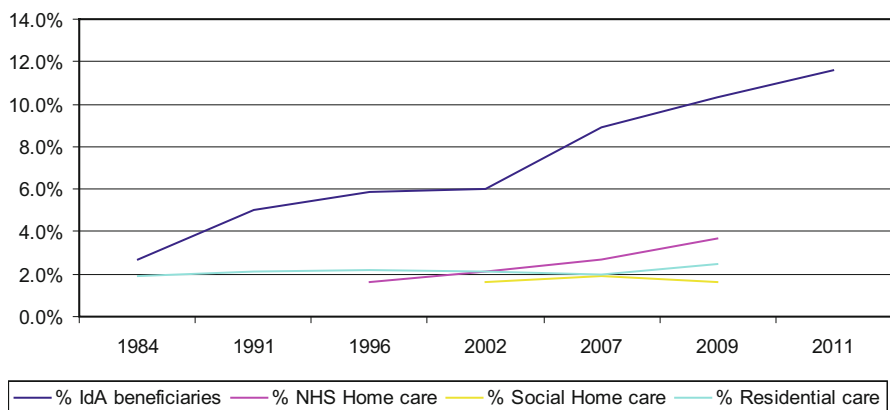


Fig. 11.2 In-kind services and cash programs for frail older people in Italy 1984–2011. (Adapted from Ranci and Pavolini 2011)

different take up rates of the IdA in different regions, which are not explained by differences in dependence rates (Table 11.3 already showed some of these features comparing northern and southern Italy). Calabria (15.6%), Campania (15.0%), Sardinia (13.9%), and Umbria (18.2%) are among the regions with relatively high take up rates. Between 2006 and 2010, the older population grew as a whole by 4.3%, while older IdA percipients increased by 32.8% (25.1% among those aged 65–79 and 36.4% among those aged 80+). It appears that some regions are using the IdA

more than others, as epidemiologic data cannot explain this level of heterogeneity. The last government, in power from 2008 to 2011, was relatively convinced that this heterogeneity in the territorial diffusion of the IdA was related to opportunistic patronage behaviors⁸: on different occasions during parliamentary hearings, the Minister for Labor and Social Affairs illustrated the strategy of the government in order to limit abuses in access to IdA through stricter control measures (including introducing sanctions for doctors working in the needs' evaluation commissions). Recent actions went in that direction with a massive campaign of controls performed by INPS during 2010–2011 on beneficiaries all over the country in order to cast some light on what seemed to be an uncontrolled device.

Italy spends more than € 12 billion on IdA (mostly for older people). Recent estimates indicate that economic resources assigned to the IdA can assure levels of coverage that are not far from those dedicated to LTC in other European countries (Ranci et al. 2008). Such an amount of resources cannot be ignored in reform hypotheses. In a context of budget restrictions, high fiscal pressures and “permanent austerity” (Pierson 2001), it is hard to finance a wider reform for LTC without including these huge (and growing) resources. At the same time, it is not easy to “touch” (a word frequently used in the current Italian debate) the IdA. Empirical research shows that most recipients spend the “*Indennità*” on some kind of care support (Da Roit 2008) and that the freedom of use they enjoy is highly appreciated. In a context of scarcity of public provision for LTC needs and of fragmentation and discretion in its management, the IdA constitutes the only certain and available public support for “ageing in place” (OECD 2003). For this reason, organizations for older people and those with disabilities formed longstanding advocacy coalitions (Sabatier and Jenkins-Smith 1993, Sabatier and Weible 2007) that have blocked any attempt to review and integrate this measure within other schemes, even continuing its pressing action for increasing public investments in LTC.⁹ Finally, pensioners' trade unions and umbrella organizations for people with disabilities (*Federazione Italiana Superamento Handicap*, FISH and *Federazione Associazioni Nazionali Disabili*, FAND) lobbied in the same direction throughout the decade, united by the same objective. Adults with disabilities obtained much more than severely dependent older people in terms of services in kind (with growing coverage and diversification) but organizations for dependent people as a whole prevented the violation of what is considered as an inalienable right. As confirmed by some policy makers, observers, and activists,¹⁰ “nobody wants to risk the certain for the uncertain even if the limits of the IdA are evident to everybody.” As a matter of fact, the IdA is a flat rate amount, it can represent a good economic compensation for those who have less severe caring needs but it is insufficient for those who are completely dependent. Furthermore, no form

⁸ Italy has a quite long story of patronage practices in the use of public benefits (see Paci and Ascoli 1984).

⁹ As stated by Kingston and Caballero (2009), “existing institutions can affect the configuration of interest groups and their bargaining power, and groups with a vested interest in the status quo may attempt to block subsequent institutional change” (p. 173).

¹⁰ Interviewed for this research.

of case management is organized around it: those who cannot rely on family helps are left alone to organize care responses by themselves. In this sense, the societal resistance to change the IdA regulation and functions can be seen as a constraint for reforms.

As illustrated before, Italian households are nowadays—and have been in the last 10 years—massively helped by immigrant women in assisting dependent individuals at home, mostly older people. These “private to private” arrangements have been called a “hidden welfare” (Gori 2002) because “it has worked” for many years without any public effort in terms of regulation. The relative success of this solution has not been addressed either by explicit or by specific LTC or family policies. At the same time, migration policies were not specifically designed for care workers, despite their growing numerical importance. The issue of the “*badanti*” has entered the Italian public debate very slowly, when they were already quite widespread and in a historical moment when the accelerated ageing of the population and the social risks involved came to the fore in the public agenda (mainly related to the pension system sustainability).

At the beginning of the 2000s, the Italian government was obliged to acknowledge the important social role played by the migrant care workers, thanks also to the lobbying made by an active advocacy coalition, consisting of a number of Catholic organizations as well as NGOs with a left-wing political orientation (Van Hooren 2008). But this acknowledgment deployed its effects only via migration policies through the introduction of preferential regular entrance conditions for care workers. No other support was introduced at the national level. To fully understand the implications of this reorientation in terms of gradual institutional change, it is important to briefly describe how immigration policies have been used in Italy. They are traditionally based along two different approaches. The first and more important one is immigration “amnesties” that have the aim of regularizing the legal position of illegal migrants already present in the country. Such amnesties occurred in 1986, 1990, 1995, 1998, 2002, and 2009. The second one is the definition of migrants incoming fluxes, defined year by year.¹¹ In the Bossi-Fini law of 2002, passed by a right-wing government, special and favorable conditions were set for the first time to regularize care workers, accepting the regularization of those who could prove to be at work in an Italian family. Fluxes for those who apply to enter in the country regularly as home or care workers have been widened as well. The acknowledgment of the importance of private assistants in coping with care needs (abundantly supported by media between 2002 and 2009) pushed the right-wing Berlusconi government to launch a special amnesty law in 2009 only for migrants who worked as carers. On this occasion, care issues were put on the agenda calling for public responsibilities once again (and more than in 2002) through a vivid debate on immigration policies. About 500,000 demands of regularization/legalization were expected but only 295,000 were presented and only 114,000 by carers and the families who hired them

¹¹ According to the present legislation, these regular fluxes are defined at national level by a decree every year (but based on a 3-year timeframe), with the help of local institutions and according to market needs.

(Pasquinelli and Gori 2009; Pasquinelli and Rusmini 2010). The context in which this special amnesty law occurred was the approval of a strongly contested security law to criminalize families and enterprises hiring undocumented immigrants. It has been estimated (Pasquinelli and Gori 2009; Pasquinelli and Rusmini 2010) that after the 2009 amnesty law, there were around 750,000 migrant care workers employed in Italian families, 46 % documented and with a formal contract, 28 % documented but without a formal employment contract, and 26 % undocumented and without any formal contract, which means that almost a half of the market is illegal.

Even though it has been argued that 2002 was a turning point year in policies towards “migrants who care” (Van Hooren 2008), the immigration policy pursued by the Italian government, based on ex post calls to regularize rather than a clear ex ante plan has helped the perpetuation of an irregular and cheap labor market because undocumented migrants cannot be hired with regular contracts (Bettio et al. 2006; Costa and Pavolini 2007). This policy to some extent fuels irregularities in the market. As a matter of fact, employed workers and employing families wait for amnesties to eventually regularize their position, because the present legislation encourages a sort of “abuse by necessity” (Ambrosini 2007). This is due to the fact that regular channels to include immigrants are quite ineffective in the care market, where face-to-face relationships are crucial. Because of Italian immigration laws, it is not possible to legalize the presence of an undocumented person if she or he is already in the country, employed or not. She or he must return to his/her country and await a call from his/her employer in order to stay in Italy and apply for a permanent residence and a work permit. Such a possibility has to be fitted into the formal immigration fluxes that are far from being sufficient to meet all the received applications. The only way to have a regular residence permit is therefore rather complicated and it is far from likely to ensure success.¹²

No efforts have been invested in connecting the IdA with this private market even if it is known that public money from the IdA feeds elusive and irregular practices. The only investment in the regulation of the specific market of care was the introduction of a *National Work Contract for Homecare Workers*, applicable also to care workers who are involved in other LTC activities, designed to fix minimum salaries and basic contributions, protection, and work conditions. However, this attempt to legalize such workers has had only limited success because, on one hand, there are still limitations related to regularly hiring an undocumented carer and, on the other, there are few incentives to formalize their employment: controls are quite modest and tax rebates on household services and personal care are very modest and not generous enough to compensate for higher costs emerging from the correct application of contracts, especially for carers working on a cohabitation basis.

The national inertia has been in some way filled by some regional and local administrations, which developed local policies trying to support care workers and family’s needs (Costa 2007b). The most evident aims of these policies are the qualification

¹² In the Conference State/Regions, there are nowadays some proposals to separate fluxes for personal assistants from those devoted to other sectors applicants. This can be considered as another attempt to support what is considered to be a fundamental component of the Italian welfare system.

of care work and the improving of contractual relationships. To do so, they created special “public agencies” where families can find the right “migrant carer”; they created registers of “migrant carers” with certified personal and professional standards; they developed training courses devoted to those who wanted to be a personal carer; they tried to integrate personal assistants work with the support provided by formal services; and they provided means-tested allowances for those who hired personal assistants with a regular contract, paying part of or all their contributions costs¹³ (Costa 2007b; Pasquinelli and Rusmini 2010). These local attempts to regulate and qualify the private market are very innovative and interesting but they are poorly funded and affect only a very small number of migrant carers and households.

In conclusion, it can be stated that public choices towards the regulation of this market over the last 10 years have been affected both by: (a) the rising demand of (cheap) care by Italian households and (b) the public sector that partially avoided the rising pressure for LTC services. The absence of explicit steering actions towards the emergence of a private and nonregulated care market can, to a certain extent, be interpreted as an intentional effect. In this sense, the success of the private market can be considered until now as an inertial factor in respect of a more compelling (for public finances) reform in LTC. But many observers argue that the “private way” for LTC needs is not sustainable for the future: in the next 20 years Italy will experience a shortage of people available to be home carers as this kind of activity will not be attractive enough for future migrant generations (Costa 2004; Mesini 2008); pensioners will get relatively lower benefits due to pension reforms and, last but not least, it should be remembered that the demand for personal carers is very elastic in relation to revenues (Ranci et al. 2008), which implies that inequalities in their use will be more manifest and perhaps no longer avoidable at a political and collective level.

11.7 Missing Reforms, Inertia, Future Trends, and Institutional Change in LTC

Huge social reorganization has occurred around LTC needs and dependency in Italy in the last 15 years. However, this occurred in the context of institutional inertia; thus, the LTC service provision system is nowadays almost the same as 2 decades ago. Trends in the different coverage rates show that the only public support that has accompanied the demographic and care needs evolution is the IdA. Moreover, the Italian care regime has been profoundly redesigned by the emergence of a private care market and the use of migrant care workers. The model of care experienced a transition from being “family-based” to a more mixed one, with migrants often living in the family home (Bettio and Simonazzi 2006).

¹³ The Regions that have activated special cash allowances to support the regularization and qualification of personal assistants are Abruzzo, Emilia-Romagna, Friuli-Venezia Giulia, Veneto, Sardinia, and Valle D’Aosta. Their amount, duration, and economic eligibility criteria are very different.

Using the institutional change literature, the evolution of LTC policies at a national level in the Italian case can be interpreted as a case of partial and probably not foreseen “gradual transformation” (Streeck and Thelen 2005). This is because, institutions, to remain as they are, require active maintenance. They need to be reset and refocused and even in certain contexts more fundamentally recalibrated and renegotiated in response to changes in the political and economic environment in which they are embedded (Streeck and Thelen 2005). The disjuncture between social programs and changing profiles of social risk can result from natural trends or from political cultivation. How then can we interpret the Italian case? To what extent can the lack of strong and effective steering action towards LTC issues be intended as unintentional or rather as the result of rational action? Whatever the answer to these questions, it is evident that the existence of the IdA and the availability of (cheap) migrant female labor have led to the avoidance of further public investment into LTC.

Since LTC issues entered the public agenda, many projects have been drawn up to radically or partially reform the actual public system to support dependent people. Some of them planned to link the IdA (the bulk of resources devoted to dependence) to the services system, including the caring activities provided by migrant workers. Political instability as well as budget constraints and the action of advocacy coalitions have undermined any attempt to change the IdA regulation and at the same time have worked out an original (but problematic) solution to the need to use migrant workers to guarantee caring activities on a long-term or on an extensive basis. In the Italian case, it can be stated that some sort of universalism in cash programs (the IdA) has therefore paradoxically prevented any radical change in LTC policy. The societal rationale of not losing or even weakening eligible rights has made it very difficult to enlarge and differentiate public support for LTC needs in older age and has also led both public and private actors to focus on private solutions to the unmet care needs.

References

- Ambrosini, M. (2007). *Una persona in famiglia? Oltre la privatizzazione dei rapporti di lavoro*. www.qualificare.info, no. 8.
- Arlotti, M. (2009). Regionalism Italian style? Reflections on the financial dimension of regional social policy. *La Rivista delle Politiche Sociali*, 1, 259–268.
- Ascoli, U., & Paci, M. (2004). Il sistema di welfare italiano tra tradizione clientelare e prospettive di riforma. In U. Ascoli (Ed.), *Welfare State all'Italiana*. Bari: Laterza.
- Ascoli, U. (Ed.) (2011). *Il welfare in Italia*. Bologna: Il Mulino.
- Baltes, P. B., & Smith, J. (2003). New frontiers in the future of aging: From successful aging of the young old to the dilemmas of the fourth age. *Gerontology*, 49(2), 123–135.
- Bettio, F., & Plantenga, J. (2004). Comparing care regimes in Europe. *Feminist Economics*, 10(1), 85–113.
- Bettio, F., Simonazzi, A., & Villa, P. (2006). Change in care regimes and female migration: The ‘care drain’ in the Mediterranean. *Journal of European Social Policy*, 16(3), 271–285.
- Brosio, P. (2003). *Intergovernmental relations in Italy*. Retrieved from http://www.irefeurope.org/col_docs/doc_20_fr.pdf.
- Cembrani, F., Cogno, R., Gori, C., Pesaresi, F., & Ragaini, F. (2010). Le politiche nazionali. In C. Gori & Network Non Autosufficienza (Eds.), *L'assistenza agli anziani non autosufficienti in Italia. Secondo rapporto*. Santarcangelo di Romagna: Maggioli.

- Centre for Economic and International Studies [CEIS]. (2009). *VI Health Report*. Rome: Fondazione Economia Tor Vergata.
- Chiatti, C., Barbabella, F., Lamura, G., & Gori, C. (2010). La “bussola” di NNA: lo stato dell’arte basato sui dati. In C. Gori & Network Non Autosufficienza (Eds.), *L’assistenza agli anziani non autosufficienti in Italia. Secondo rapporto*. Santarcangelo di Romagna: Maggioli.
- Costa, G. (2007a). *Quando qualcuno dipende da te. Per una sociologia della cura*. Roma: Carocci.
- Costa, G. (2007b). La regolazione del lavoro privato di cura come sfida per il welfare locale. *Politiche Sociali e Servizi*, 2, 12–12.
- Costa, G. (2009). *Prove di welfare locale. La costruzione di livelli di assistenza in Provincia di Cremona*. Milano: Franco Angeli.
- Costa, G., Spadea, T., & Cardano, M. (2004). Disuguaglianze di salute in Italia. *Epidemiologia e Prevenzione*, 28(3), 1–161.
- Da Roit B. (2008). Gli anziani beneficiari dell’indennità di accompagnamento. Risultati di un’indagine esplorativa. In C. Gori (Ed.), *Le riforme regionali per i non autosufficienti*. Roma: Carocci.
- Da Roit, B. (2007) Changing intergenerational solidarities within families in a Mediterranean welfare state. *Current Sociology*, 55(2), 251–269.
- Eurofamcare Consortium. (2006). *Carers of older dependent people in Europe: Characteristics, coverage and usage*. Retrieved from <http://www.uke.uni-hamburg.de/extern/eurofamcare>.
- Ferlie, E., Lynn, L. E., & Pollitt, C. (Eds.). (2005). *The Oxford handbook of public management*. Oxford: Oxford University Press.
- Fujisawa, R., & Colombo, F. (2009). *The long-term care workforce: Overview and strategies to adapt supply to a growing demand* (OECD Health Working Paper No. 44). Paris: OECD Publishing.
- Gori, C. (2002). *Il welfare nascosto*. Roma: Carocci.
- Gori, C. (2008). Il dibattito sulla riforma nazionale. In C. Gori (Ed.), *Le riforme nazionali per i non autosufficienti: gli interventi realizzati e i rapporti con lo Stato*. Roma: Carocci.
- Gori, C. (2010). La corsa all’indennità di accompagnamento: cosa c’è dietro? *I luoghi della cura*, VIII(3), 5–10.
- Gori, C., & Lamura, G. (2009). *Lo scenario complessivo, in L’assistenza agli anziani non autosufficienti in Italia- rapporto 2009*. Santarcangelo di Romagna: Maggioli.
- Groppi, A. (2010). *Il welfare prima del welfare. Assistenza alla vecchiaia e solidarietà tra generazioni a Roma in età moderna*. Roma: Viella.
- INPS. (2010). *Statistiche sui beneficiari di indennità di accompagnamento*. Retrieved from www.inps.it.
- Istituto Nazionale di Statistica [ISTAT]. (2008). *Condizioni di salute e ricorso ai servizi sanitari—anno 2005*. Roma: Istituto Nazionale di Statistica. Retrieved from www.istat.it.
- Istituto Nazionale di Statistica [ISTAT]. (2009). *L’indagine censuaria sugli interventi e i servizi sociali dei Comuni—anno 2006*. Roma: Istituto Nazionale di Statistica.
- Istituto Nazionale di Statistica [ISTAT]. (2011). *Rapporto Annuale 2010*. Retrieved from www.istat.it.
- Jessoula, M., & Alti, T. (2010). *Italy: An uncompleted departure from Bismarck*. In B. Palier (Ed.), *A long goodbye to Bismarck*. Amsterdam: Amsterdam University Press.
- Kazepov, Y. (2008). The subsidiarization of social policies: Actors, processes and impacts. *European Societies*, 10(2), 247–273.
- Kingston, C., & Caballero, G. (2009). Comparing theories of institutional change. *Journal of Institutional Economics*, 5(2), 151–180.
- Knijn, T., & Kremer, M. (1997). Gender and the caring dimension of welfare states: Toward inclusive citizenship. *Social Politics*, 4(3), 328–361.
- Lafortune, G., & Balestat, G. (2007). *Trends in severe disability among elderly people: Assessing the evidence in 12 OECD countries and the future implications* (OECD Health Working Paper No. 26). Paris: OECD Publishing.

- Lamura, G., Chiatti, C., Di Rosa, M., Mechiorre, M. G., Barbabella, F., Greco, C., Principi, A., & Santini, S. (2010). Migrant workers in the long-term care sector: Lessons from Italy. *Health and Ageing Newsletter*, 2, 8–12.
- Leira, A. (1993). Concepts of care: Loving, thinking and doing. In J. Twigg (Ed.), *Informal care in Europe*. York: The University of York.
- Lewis, J. (1993). *Women and social policies in Europe. Work, family and the state*. London: Elgar.
- Mahoney, J., & Thelen, K. (2010). *Explaining institutional change: Ambiguity, agency and planning*. Cambridge: Cambridge University Press.
- Mesini, D., & Gambino, A. (2006). *La spesa per l'assistenza continuativa in Italia*. In C. Gori (Ed.), *La riforma dell'assistenza ai non autosufficienti. Ipotesi e proposte*. Bologna: Il Mulino.
- Millar, J., & Warman, A. (1996). *Family obligations in Europe*. London: Family Policy Studies Centre.
- Naldini, M., & Saraceno, C. (2008). Social and family policies in Italy: Not totally frozen but far from structural reforms. *Social Policy and Administration*, 42(7), 733–748
- OECD. (2003). *Policies for an ageing society: Recent measures and areas for further reform*. Paris: OECD.
- OECD. (2011). *Help wanted? Providing and paying for long term care*. Paris: OECD.
- Österle, A. (2001). *Equity choices and long-term policies in Europe*. Ashgate: Aldershot.
- Paci, M., & Ascoli, U. (1984). *Il sistema di welfare italiano tra tradizione clientelare e prospettive di riforma*. In U. Ascoli (Ed.), *Welfare state all'italiana*. Bari: Laterza.
- Pasquinnelli, S., & Rusmini, G. (2009). *I sostegni al lavoro privato di cura*. In C. Gori & Network Non Autosufficienza (Eds.), *L'assistenza agli anziani non autosufficienti in Italia* (Secondo rapporto). Santarcangelo di Romagna: Maggioli.
- Pasquinnelli, S., & Rusmini, G. (2010). *La regolarizzazione delle badanti*. In C. Gori & Network Non Autosufficienza (Eds.), *L'assistenza agli anziani non autosufficienti in Italia* (Terzo rapporto). Santarcangelo di Romagna: Maggioli.
- Pavolini, E. (2004). *Regioni e politiche sociali per gli anziani. Le sfide della non autosufficienza*. Roma: Carocci.
- Pavolini, E. (2011). *Welfare e dualizzazione dei diritti sociali*. In U. Ascoli (Ed.), *Il welfare in Italia*. Bologna: Il Mulino.
- Pesaresi, F. (2003). Regioni e livelli essenziali delle prestazioni sociali. *Prospettive sociali e sanitarie*, 15–17, 1–8.
- Pierson, P. (2001). *Coping with permanent austerity: welfare state restructuring in affluent democracies*. In P. Pierson (Ed.), *The new politics of the welfare state* (pp. 410–456). Oxford: Oxford University Press.
- Ranci, C. (2008). *Tutelare la non autosufficienza. Una proposta di riforma dell'indennità di accompagnamento*. Roma: Carocci.
- Ranci, C., & Migliavacca, M. (2011). Trasformazioni dei rischi sociali e persistenza del welfare. In U. Ascoli (Ed.), *Il welfare in Italia*. Bologna: Il Mulino.
- Ranci, C., & Pavolini, E. (2011). *A (weak) universalism by default? The inertial path towards the transformation of the Italian long-term care model and its consequences*. Mimeo.
- Ranci, C., Pavolini, E., & DaRoit, B. (2008). *Partire dall'esistente: le caratteristiche dell'Indennità di accompagnamento e alcune proposte di riforma*. Roma: Carocci.
- Sabatier, P. A., & Weible, C. M. (2007). The advocacy coalition framework: Innovations and clarifications. In P. Sabatier (Ed.), *Theories of the policy process*. Boulder: Westview Press.
- Sabatier, P. A., & Jenkins-Smith, H. C. (1993). *Policy change and learning: An advocacy coalition approach*. Boulder: Westview Press.
- Saraceno, C. (1994). The ambivalent familism of the Italian welfare state. *Social Politics*, 1(1), 60–82.
- Saraceno, C. (2002). Prefazione. In C. Ranci (Ed.), *Le nuove disuguaglianze sociali in Italia*. Bologna: Il Mulino.
- Saraceno, C. (2010). Social inequalities in facing old-age dependency: A bi-generational perspective. *Journal of European Social Policy*, 20(1), 32–44.

- Spanò, P.(2006). *Le convenienze nascoste. Il fenomeno badanti e le risposte di welfare*. Venezia: Nuova Dimensione.
- Streeck, W., & Thelen, A. K. (2005). *Institutional changes in advanced political economies*. Oxford: Oxford University Press.
- Titmuss, R. M. (1973). *The gift relationship. From human blood to social policy*. Harmondsworth: Penguin.
- Van Hooren, F. (2008). Welfare provision beyond national boundaries. The politics of migration and elderly care in Italy. *Rivista Italiana di Politiche Pubbliche*, 3, 87–113.

Chapter 12

Long-Term Care Reform in Central–Eastern Europe: The Case of the Czech Republic

Jana Barvíková and August Österle

12.1 Introduction

The central-eastern European (CEE) region has seen major social policy reforms over the past 2 decades (see Cerami and Vanhuysse 2009; Cook 2010; Inglot 2008; Kovács 2002). For example, health care systems have been transferred from a “Semashko” model orientation (named after Semashko who laid out the foundations of the USSR health system in the 1920s) toward Bismarckian social health insurance systems with varying degrees of emphasis on liberal or universalist elements (Marée and Groenewegen 1997; Nemeč and Kolisnichenko 2006). The privatization of pensions also became an important part of reform efforts from the mid 1990s, not least due to the strong influence of the World Bank (Orenstein 2009). Yet, in contrast with such major social policy reform areas, long-term care did not play any prominent role in social policy debates in CEE in the 1990s and into the 2000s (Österle 2011a). While long-term care became a major issue on the social policy agenda in many western European countries in the 1990s (see other chapters in this volume), it has not been addressed as a distinctive policy sphere in CEE. Policy debates and reform efforts toward a more comprehensive public response to long-term care needs only intensified in the new millennium. This chapter investigates the changes to long-care systems in CEE, with a particular focus on the situation in the Czech Republic, the first CEE country to see the establishment of a novel long-term care system in 2006. The analysis covers a time span of more than 2 decades, starting from the transition from communism to market-oriented democratic systems up until today. Apart from describing how the long-term care system has developed over that period, the particular focus of the analysis is on identifying the drivers of reform

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(or nonreform), in studying the importance of key actors involved in reform processes and in analyzing the impact of the reforms.

The following section provides an overview of long-term care policies in CEE. It outlines the context for long-term care reform in CEE and identifies commonalities and diversities in the development and the status quo of long-term care in this European region. The next section provides an in-depth analysis of the situation in the Czech Republic. This section starts with an outline of Czech long-term care policies, delineating the situation before the transformation, the gradual reforms from the 1990s, and in particular the 2006 reform. With this reform, a new foundation for long-term care was established in the Czech Republic. The section then proceeds with an analysis of the drivers of reform, the actors involved, and the mechanisms of institutional change. In addition, impacts of reform in terms of changes to long-term care expenditure, changes to needs coverage, or changes to the care labor market will be studied. A brief summary discussion concludes the chapter.

12.2 Long-Term Care Policies in Central–Eastern Europe: An Overview

12.2.1 The Context for Long-Term Care Reform in Central–Eastern Europe

Before the 1990s, long-term care in CEE countries was largely a family responsibility with rather limited public support for those in need of care and those who provided care informally within families or households (Österle 2011a). This is not very different from many other European countries (except for the Nordic countries or the Netherlands), where public long-term care policies remained rather limited into the 1980s (Österle and Rothgang 2010). However, coverage levels in terms of nursing home beds or financial support schemes were on even lower levels in CEE than in many western European countries.

With regard to the broader social and economic context for long-term care reform, CEE countries share many of the challenges and pressures western European countries are also faced with, even if their relative importance differs for specific regions and over time. CEE countries are no exception to major demographic trends: a further increase in life expectancy; a growing number and an increasing proportion of older people; as well as low fertility rates (Hoff 2011; Österle et al. 2011). According to Eurostat (2008) forecasts, in the EU27, the proportion of those 80+ will increase from 4.66 % in 2010 to 6.93 % in 2030 and to 10.99 % in 2050. In CEE countries, the proportion of the older population is currently lower, but will see more substantial increases. In the Czech Republic, e.g., the proportion of those 80+ will increase from 3.59 % in 2010 to 6.64 % in 2030 and to 9.32 % in 2050. The proportion of the population aged 65+ will even exceed the European average in most CEE countries in 2050. An increase in the older population can give some preliminary indication of growing long-term care needs, even if future changes in the prevalence of chronic illness and disability can either have moderating or expansionary

effects on the respective growth rates. At the same time, fertility rates are below the European average in CEE. In 2009, the average fertility rate in the EU27 was 1.59, but only 1.49 in the Czech Republic, 1.38 in Poland, and 1.25 in Hungary. Low fertility rates together with substantial outward migration of younger generations in some of the CEE countries leads to a double burden. It increases the pressure on funding social security systems when the proportion of those in employment as compared with those in older age decreases. And, it impacts on traditional modes of informal caregiving by family members.

Under state socialism, women have been largely integrated into the labor market as full-time employees in CEE countries. Well-developed systems of financial benefits, leave programs, and child care facilities allowed mothers to work outside the home (Auth 2010). However, in contrast with child care, long-term care services have not been developed to any substantial extent. Hence, long-term care was largely left to families and—as a consequence of the gender-based division of care labor—in particular women within families. In the transition process, cuts in social policies and ideologies referring to traditional patterns of family roles have even reinforced traditional gender divisions (Klenner and Leiber 2010; Pascall and Manning 2000). Relatively strong family orientation is also found in value studies. When asked about the preferred care arrangement if regular help and long-term care were needed, the option “care at home by a relative” is chosen by a larger proportion of the population in CEE countries than in most western European countries. According to a Eurobarometer survey, 54 % of Czech, 66 % of Hungarian, or 50 % of Slovakian respondents prefer care at home by a relative, as compared with 45 % in the EU27 average. When asked about the expected care arrangement in case regular help and long-term care are needed, 57 % of respondents in the Czech Republic and 68 % of respondents in Slovakia refer to care at home by a relative, compared with only 45 % of respondents in the EU27 average (European Commission 2007). Research on family care arrangements confirm the dominant role of women in long-term care giving in CEE. (For the Czech Republic, see Barvíková and Bartoňová 2005 or Holmerová 2007.). The dominance of women as caregivers is determined by a combination of factors, aforementioned cultural factors, legally defined family obligations, a lack of publicly cofunded provisions, often difficult labor market situations, but also allowances to family caregivers creating incentives for family care arrangements (Österle 2011a). For the future, however, it remains questionable whether family members will be in a position to provide the same amount of long-term care work. Factors such as low fertility rates, increases in labor market participation, or changes in cohabitation will make it increasingly difficult to provide long hours of informal care and, hence, will increase pressure to develop complementary or supplementary services to ensure the necessary care.

In a European comparative perspective, CEE countries form a group with relatively low levels of public long-term care expenditure. Availability and quality of comparative information on long-term care expenditure is largely limited. But even if different sources (for an overview, see Huber et al. 2009 and Österle 2011b) provide substantial variations in the level of expenditure, the overall picture remains stable. According to OECD figures, public long-term care expenditure (“services of

long-term nursing care”) amounts to 2.5 % of GDP in Denmark and in the Netherlands, to 1.3 % in France, 1.2 % in Austria, 1.0 % in Germany, or 0.6 % in Spain in 2009. In CEE countries, spending levels are significantly lower, only amounting to, e.g., 0.3 % in the Czech Republic or in Hungary (OECD 2011). With a view to future long-term care expenditure, a European Commission (2009) study indicates that long-term care expenditure as a percentage of GDP will double between 2007 and 2060. Underlying assumptions in this scenario only account for changes in the proportion of the older population. Taking changes in the prevalence of long-term care needs or changes in the modes of caregiving into consideration, it is possible that long-term care expenditure may not increase to the same extent or to an even larger extent. However, this does not change the overall conclusion that EU countries will have to substantially increase long-term care expenditure over the coming decades. In the aforementioned European Commission study, relatively moderate expenditure levels are forecasted for CEE countries. But this is only because the projections did not consider any major change in policies. Assuming that long-term care policies in CEE countries will, to some extent, converge with policies in western European countries, it is likely that there will be even more substantial increases in long-term care expenditure in this region. Following such an assumption, according to OECD projections (Oliveira and de la Maisonneuve 2006), public long-term care expenditure would increase from 0.4 % of GDP in the Czech Republic in 2005 to 2 % in 2050, or, in Slovakia, from 0.3 % in 2005 to 2.6 % in 2050.

12.2.2 From Incremental Changes to Major Reforms in Long-Term Care?

In the 1990s, long-term care was not a major issue on the social policy agenda in CEE, neither on national agendas nor in the programs of various international organizations advising countries in the transformation process. In fact, long-term care was not even addressed as a distinctive policy field, even into the early 2000s. Addressing the need of younger and older people in need of long-term care was characterized by fragmentation, with potential support from social assistance policies, disability policies, health policies, or pension policies. Developments from the early 1990s were characterized by a mix of continuity, considerable financial pressure on public budgets (limiting the scope of discretion), and various indirect effects. Such effects were either rooted in new principles applied to public policies (in particular decentralization and pluralization) or in reforms that took place in related policy fields, in particular in social assistance and in health care (Österle 2010).

Decentralization and pluralization were two major institutional orientations characterizing policy debates from the early 1990s, not least through recommendations of international organizations such as the World Bank, the OECD, or the European Union. Decentralization soon had an impact on social policies, in particular in social assistance schemes (Van Mechelen and De Maesschalck 2009). In the highly fragmented long-term care policy arena, social assistance—apart from the health

sector—was the major source for publicly cofunded long-term care provisions (see below). In Hungary, e.g., the Social Act 1993 was a first major step in defining county responsibilities for the residential care sector and local responsibilities in the community care sector. Reforms in 1999 and 2001 attempted to clarify and to strengthen the coordination between the health and the social sectors (Gulácsi et al. 2011). In Romania, it was only in 2000 that care for older people was explicitly addressed in a social assistance reform, also indicating a shift from the dominant medical approach (with service provisions organized in the health care sector) toward a social care approach (Popescu 2011). Similar developments have also taken place in other CEE countries. Overall, a stronger involvement of local governments in the funding and administration of social assistance was widely promoted, while a lack of experience in local social care governance and budgetary constraints have for many years constrained the modernization, coordination, and extension of services.

Similar to decentralization, pluralization was a key principle in the transformation process. But compared with decentralization, actual developments have been much slower in translating the pluralization idea into practice. Pluralization in social policies was aimed at broadening the welfare mix, involving state actors, the market, nonprofit organizations, civil society; as well as family and the individual in developing an adequate mix of public and private responsibilities in the funding, provision, and governance of social protection. In some CEE countries, from the early 1990s, nonprofit organizations became active in social welfare including care for older people. At that time, many church-related organizations began to reintroduce their earlier activities as service providers. Other organizations were built with financial and organizational assistance from international partners. But despite the pluralization rhetoric, social care legislation in many CEE governments still favored public providers over private ones. Applying different reimbursement principles created considerable hurdles for private providers entering social care provision. In addition, budgetary constraints left little room for expanding service provisions beyond already-existing traditional public provisions. But there were also measures to support nonprofit activities. For example, Hungary, Slovakia, and Romania introduced a system where tax-payers could dedicate a small proportion of the personal tax payment to a nonprofit organization (e.g., Jenei and Kuti 2009). Taken together, nonprofit providers are playing an increasingly important role in long-term care provision, while the role of for-profit providers remains relatively small in CEE. Nonprofit providers are particularly strong in community care. In Romania, the majority of community services are now provided by nonprofit organizations (Popescu 2011). In addition to the provider role, nonprofit organizations also have a strong role in pioneering novel service provisions and in lobbying for the interests of those in need of care and for family caregivers.

A major characteristic of long-term care systems across Europe is the different delimitations of responsibilities between the health and the social sector. In CEE, the health sector has long been the major provider of long-term care services, including inpatient provisions (in specific geriatric care, transitional care, or long-term care units, but also in general hospital units) and outpatient services (home nursing). The relative importance of the health sector was a result of lacking services in the social

sector, but also because of the economic incentives arising from relatively small private copayments in the health sector as compared with the social sector. Home nursing has often been the only community care service available across the entire country. Health care reforms aimed at cost-containment, however, have increased pressure to limit health sector provisions to medically needed acute care provisions and to shift long-term care provisions to the social care sector.

Provisions in the social sector in CEE countries generally include residential care, community care services, and cash-for-care programs. Similar to other European countries, residential care has a long tradition as a major policy approach where long-term care needs cannot be met within family networks, even if bed density in many CEE countries was traditionally below the European average. Only in the past decade have governments intensified their efforts to strengthen community care services as a key pillar of their social care policies. Community care services have been unavailable in most rural areas in CEE in the 1990s and have been very limited even in many urban areas. In recent years, measures have been intensified to start developing the community care infrastructure. Different from the health sector, funding of residential and community care provisions is usually based on social assistance principles involving substantial user contributions (Österle 2012). A third distinctive element of social care policies in CEE is cash-for-care programs. In the 1990s, many western European countries introduced new cash-for-care programs, directing payments mostly at those in need of care. Such a program was also introduced in the Czech Republic as a key element of the 2006 reform (see Barvíková 2011). The most common and often well-established cash-for-care approach in CEE countries, however, is allowances paid to informal carers. Many of these benefits were introduced in the 1990s. The main objective was to offer financial support to informal carers. Even if these benefits are usually means-tested and at relatively low levels, they can make up an important element of disposable income for poor households. Another approach in some CEE countries has been the provision of direct payments. Originally aimed at younger people with disabilities, programs have been extended to older people in general (as in Romania) or to older people if they have received the benefit when aged below 65 (as in Slovakia).

During the past decade, long-term care has slowly become recognized as a distinctive social policy concern in CEE. In the national context, growing concern about the implications of demographic changes, about the future of social care, and about the economic and social situation of older people in need of long-term care has driven this development. Beyond that, a process of cross-border exchange of ideas and developments has helped to build awareness. This happened through the EU Open Method of Coordination on social protection and social inclusion requiring Member States to report on the progress toward common goals in the field of long-term care (Österle 2011b; Theobald and Kern 2009). The need for reform is increasingly recognized in policy papers and reform debates. In many countries, reform proposals have been put forward. Several countries developed concepts for long-term care insurance, most advanced in Slovenia (Flaker et al. 2011). Objectives such as the development of community care infrastructure, the pluralization of service provision, or the improvement of access to services are widely shared. But most countries have

so far only seen smaller incremental changes toward these objectives. The Czech Republic is the first country in the CEE region where a major policy reform established the foundations for a new, comprehensive long-term care system. The context of long-term care reform in this country, the actors and mechanisms involved, and the outcomes of the reform are discussed in the following section.

12.3 Long-Term Care Reform in the Czech Republic

12.3.1 Long-Term Care Policies in the Czech Republic

The term “long-term care” is so far not used in Czech legislation and the provision of long-term care, as in the other countries of CEE, is not organized in a single system in the Czech Republic. While the Ministry of Labour and Social Affairs (MoLSA) takes the responsibility for the social services sector, health care for senior citizens forms part of the health care sector (Bryndová et al. 2009). Each of these systems has its own regulations, independent criteria for accessibility and quality, and a different method of financing. Health care is paid for by public health insurance (in addition to user copayments) while social care is paid for through state and local budgets and by contributions from users.

Developments in the Legislative Framework of Long-Term Care Long-term care (social care) is provided within the framework of social services. Legislation covering social care services valid until 31 December 2006 was based on laws passed in the late 1980s (particularly, the Act No. 100/1988 Coll., on Social Security). At that time, social policy and the social services sector were seen in a substantially different manner, particularly with regard to the individual’s freedom to make decisions and the democratic principles involved in the operation of public administration. The recipients of social services had a passive position; concerning the types of long-term care, the Act only recognized institutional care and in-home day care. After 1990, social services developed in quantitative as well as qualitative terms: Social services providers came to include not only the state, regions, and municipalities, but also churches, NGOs, and natural persons. A number of new facilities (operated primarily by municipalities and NGOs) were established. New methods were introduced into practice, the quality of care, accommodation, and equipment was improving. However, this development was not coordinated: Social services (e.g., personal care, early care, contact centers, respite services), which typically conform more to social integration principles than “traditional” services (institutional care or community care services), had no legislative support. There was no clear, equal system for financing social services and there were no quality inspection procedures. This basically put a brake on the required developments in social services and did not ensure that these services were provided to the required standard or that they were available at all to potential users in all regions (Ministry of Labour and Social Affairs [MoLSA] 2005a; Barvíková 2011).

The legislation evidently could not be changed in any fundamental way through amendments, which were only patchwork repairs. MoLSA made its first attempt to adjust the conditions governing the provision of social services in 1994 by submitting the proposed content of an Act on social assistance. The draft bill was subsequently changed and amended several times, yet no version was adopted as the coalition governments taking turns in taking power held opposing views on its key principles, which were also under critique of professionals.

Only since 1 January 2007 have there been deep systematic changes in social care brought about by the adoption and promulgation of Act No. 108/2006 Coll., on Social Services. Apart from other radical changes (equal conditions in financing social services from the state budget, registration duty and inspection of social services, providing social services on a contractual basis, establishment of standards for the quality of social services, redefining existing services, and legal grounding of some new services, etc.), a new instrument of direct payments to users of social care services was introduced. Under the terms of the Act, the level of care allowance is tailored to the extent of dependence (four levels) and enables people to pay for the required assistance and support, provided by family members or other informal carers or by professional social care service providers. The proportion that care receivers have to contribute from their own resources is regulated by the maximum limit that a provider can claim from clients. The concept of social services aims to ensure a wider supply of services provided primarily in households of clients to enable them to lead an independent life and to codecide the amount and type of services they receive. From a general perspective, developments in social services reflect the trend away from institutional care toward care in the community, in line with the idea of individualizing care and coming close to ordinary life in a domestic environment. This places an emphasis on an individual approach toward users and their human rights. With the introduction of care allowances directed at care users, the emphasis of individual autonomy was further strengthened (MoLSA 2005b).

The Act on Social Services covers a wide range of social care services and social prevention services. In the field of long-term care, these include residential social services facilities (week-day care centers, homes for older people and those with disabilities, and special regime homes for mentally ill or people with Alzheimer's/dementia, etc.), outpatient services (daily short-stay hospitals, day service centers, respite services, etc.), and home services (home help, personal assistance, emergency care, etc.) (MoLSA 2006a).

It should be noted that sufficiently reliable data on the funding, structure, and capacity of long-term care are not available in the Czech Republic, mainly because the data that would meet the definition of long-term care are not consistently monitored. In addition, after the adoption of the Act on Social Services (2006), some types of services were redefined or renamed. Many facilities changed their orientation in reaction to the new legislative conditions. As a consequence, continuity of some data groups was lost. Opportunities to compare data up until 2006 and also from 2007 are thus limited. However, Table 12.1 provides a basic overview of long-term care data in the Czech Republic between 1995 and 2005.

Table 12.1 Basic long-term care data, 1995–2005. (Adapted from Ministry of Labour and Social Affairs)

	1995	2000	2005	2006	2007	2008	2009	2010
Number of persons in long-term care ^a	147,977	184,368	190,592	184,279	170,020	184,082	187,867	188,492
Number of persons in residential care ^b	61,776	70,840	77,665	79,191	71,647	72,211	73,503	75,254
Number of persons in community care ^c	86,201	113,528	112,927	105,088	98,373	11,871	114,364	113,238
Total population 65+ ^d	1,356,232	1,423,003	1,456,391	1,482,437	1,512,834	1,556,152	1,598,883	1,635,826
Persons in residential care settings as a percentage of total population 65+	4.55	4.98	5.33	5.34	4.74	4.64	4.60	4.60
Recipients of community care services as a percentage of total population 65+	6.36	7.98	7.75	7.09	6.50	7.19	7.15	6.92
Total spending on LTC as percentage of GDP	–	0.51	0.53	0.52	0.55	0.57	0.63	0.65
Spending on LTC in € (million CZK)	–	442 (11,492)	641 (16,666)	674.15 (17,528)	772.58 (20,087)	850.77 (22,120)	911.12 (23,689)	943.12 (24,521)
On residential care (percentage of total)	–	92.08	90.44	90.66	92.08	92.57	91.97	91.91
On community care (percentage of total)	–	7.92	9.56	9.34	7.92	7.43	8.03	8.09

Comparability of data before 2006 and after that year is limited because of changes related to the Act on Social Services (2006).

^aEquals the sum of “persons in residential care” + “persons in community care”

^bTotal number of clients in all types of residential care; data for 31 December of the stated year (statistical statement MoLSA V1–01)

^cNumber of persons using community home care services inclusive meals on wheels (statistical statement MoLSA V10–01)

^dStatistická ročenka ČSÚ, situation to the year-end

^e1 € = 26 CZK

Residential Care From the early 1990s until 2006, the number of places in residential care rose continually, from 37,742 in 1990 to 51,049 in 2006 (MoLSA 2001, 2007). At the same time, there was a steep increase in the number of applicants on the waiting list, increasing from 17,307 in 1990 to 66,097 in 2006 (MoLSA 2001, 2007). It is believed that the very large demand for residential care is caused by an inadequate supply of community care and by care recipients' limited experience of community care services. Finally, residential care facilities still represent a certain level of safety for seniors. The feeling of being able to get help when in need is the main reason why many still self-sufficient people with no specific need of nursing care are on waiting lists. At the same time, before 2007, residential services were motivated to accept users with more moderate care needs (Horecký 2010). Current legislative and strategic documents, however, support the reassessment of the target groups for institutional and home care in order to ensure the financial sustainability of the system. The aim is to reserve residential care for persons with a greater need for assistance, in particular nursing care. In contrast, for people with a lower need for assistance, support should be provided in the private environment of the user in connection with family and local community resources (MoLSA 2006a).

Before 2006, residential care was organized in two types of facilities, the "pensioners' houses" or *domovy důchodců*, where comprehensive care was provided, and the "pensioners' lodging houses" or *domovy-pensiony pro důchodce*, where only some services were provided. Following the introduction of the 2006 Act on Social Services, these were replaced by so-called "homes for older people" (*domovy pro seniory*), "homes for persons with disabilities" (*domovy pro osoby se zdravotním postižením*) and "special regime homes" (*domovy se zvláštním určením*), the latter providing specialized care for mentally ill or people with Alzheimer's/dementia. Homes for older people correspond to "nursing homes" in international terminology. In homes for older people, in-patient services are provided to persons with reduced self-sufficiency, in particular, due to their age, whose situation requires the regular assistance of someone else. The services provided include the provision of accommodation, food, assistance with handling common self-care acts, assistance with personal hygiene or arranging for personal hygiene conditions, mediating contacts with the social environment, social therapeutic activities, activation activities, assistance with asserting rights, justified interests, and looking after personal matters.

Field Social Services The most widespread field social service available to older people living at home is community home care services. According to the 2006 Act on Social Services, the service package includes: (a) assistance with handling common self-care acts, (b) assistance with personal hygiene or arranging for personal hygiene conditions, (c) provision of food or assistance with arranging for food, (d) assistance with running a household, and (e) mediating contacts with the social environment. From 2007 till 2010, the number of users has increased from just below 100,000 to 113,000. As can be seen in Table 12.2, total expenditure for community care services increased in the same period from € 61 million to € 76 million. Another very popular service is the so-called houses with care services (*domovy s pečovatelskou službou*). To a great extent, these houses correspond to "sheltered accommodation." Residents

Table 12.2 Community care services, 1995–2010. (Adapted from MoLSA 2011b)

Year	Total spending in million CZK/€ ^a	Number of users	Average contribution of a user per year (CZK/€)
1995	2,526/97.15	86,201	483/18.58
2000	1,540/59.23	113,528	1,316/50.61
2005	1,593/61.27	112,927	2,028/78.00
2006	1,637/62.96	105,088	2,156/82.92
2007	1,591/61.19	98,373	4,263/163.96
2008	1,643/63.19	111,871	4,261/163.88
2009	1,903/73.19	114,364	5,063/194.73
2010	1,984/76.31	113,238	5,248/201.85

^a1 € = 26 CZK

live in well-equipped flats, have access to several social services and especially a feeling of getting help when in need. The main services available comprise the full or part-time presence of a caregiver and the supply of meals. However, because flats in these houses usually have a status of rental housing, houses with care services have not been adopted by the Act on Social Services. Since 2007, some of them have transformed into “homes for older people.”

While developments since the 1990s have brought about a number of positive changes in community care, in particular, with regard to extended options for providing care in the home of the user, the conditions under which this care is provided are not considered to be adequate. Basically, there is a lack of consultation services focusing on the needs of senior citizens, a lack of capacities for interim respite stays, and equipment loaning facilities. Community care services, which are felt to be most lacking include all-day supervision, night services, and other activities to secure the care primarily of the least independent senior citizens. In addition, there are huge interregional differences in the accessibility of community care. The situation is usually better in urban areas than in less populated or in mountainous regions (Průša 2011b).

Care Allowances Until 2006, two kinds of payments for care were provided. The first, an “Increase in Pension for Helplessness” (*zvýšení důchodu pro bezmocnost*), was delivered to pensioners whose health or age required care by another person. The aim of this allowance was to help secure the assistance provided to the recipient on the grounds of helplessness. The second one, a “Contribution for the Care of a Close Person or Another Person” (*příspěvek při péči o blízkou nebo jinou osobu*) aimed to ensure at least basic security in the form of a minimum income, pension, and health insurance to informal caregivers compelled to give up gainful employment. In 2006, the average monthly number of beneficiaries of the Contribution for the Care of a Close Person or Another Person was 49,740 people. Total expenditure was 3,186 million CZK (MoLSA 2007). Due to the adoption of the Act on Social Services and its promulgation as of 1 January 2007 and due to the introduction of a newly conceived “Care Allowance” (*příspěvek na péči*), both benefits were abolished.

The new care allowance is granted to citizens to secure the assistance required to deal with their difficult social situation. It is provided to persons more than 1 year

Table 12.3 Care allowance provision according to four levels of dependence, 2012. (Adapted from Zákon 2006)

Level of the benefit (CZK/€ ^a)		
Level of dependence	Persons up to 18 years of age	Persons more than 18 years of age
I—mild	3,000.00/115.38	800.00/30.77
II—medium	6,000.00/230.77	4,000.00/153.85
III—heavy	9,000.00/346.15	8,000.00/307.69
IV—complete	12,000.00/461.54	12,000.00/461.54

Average gross monthly wage in the Czech Republic was around 920 € in 2010, average old age pension was around 389 €
^a 1 € = 26 CZK

of age who are dependent on the assistance of another individual for care activities related to their own person and independence. The law distinguishes four levels of dependence, from mild to complete dependence. These levels thus also correspond to the level of the contribution (see Table 12.3).

The allowance aims to strengthen people's financial independence as users of social services and to give them the opportunity to decide on the method of securing assistance, as well as the opportunity to look for sources of assistance in their environment among close persons, or other individuals and among social service providers. Both forms of assistance can be combined. Assistance can also be provided at the same time by more than one close person or other individuals, although only one of them (the one who provides the greatest amount of care) may—on the basis of caring for a person from dependency level II to IV—be credited with care time as compensatory time for retirement pension purposes. The benefit is not means-tested and it is financed from the state budget through taxes.

Over the last 5 years, the care allowance was adjusted several times (the last adjustment was made on 1 January 2012). The growing number of recipients and increasing total expenditure (see Table 12.4) were the main reasons for the changes. In essence, the amount of the allowance was reduced for persons in dependency levels I and II aged 18+ (for details, see Sect. 12.3.4) and increased for persons under the age of 18. In addition, a dependent child or the parents of a dependent child may now apply for an increase by up to 2,000 CZK (77 €) on condition that their income and the income of jointly assessed persons do not reach twice the amount of the family subsistence level. In 2010, the total number of beneficiaries exceeded 300,000 people. Total spending on the care allowance approached 20,000 million CZK in that year (see Table 12.4). About 70 % of recipients are 65 years and older; about 27 % are aged 85+ (Daňková et al. 2011).

Social Care Assistants The concept of “social care assistants” was introduced at the beginning of 2012; the concept refers to individuals other than close persons (e.g., neighbors) providing dependent persons with care that is covered from the care allowance. Only individuals more than 18 years of age with a sound state of health can qualify to become social care assistants. A social care assistant must enter into a written contract on the provision of assistance with the care recipient that will stipulate the scope, place, and time of the assistance and the corresponding

Table 12.4 Care allowance beneficiaries according to four levels of dependence^a and total care allowance expenditure, 2007–2010. (Adapted from Průša 2011c and MoLSA 2011b)

Level of dependence	2007	2008	2009	2010
I—mild	109,825	118,233	114,558	115,926
II—medium	86,508	92,674	87,951	91,305
III—complete	39,714	47,617	58,362	59,801
IV—heavy	19,724	31,041	35,260	37,810
<i>Total</i>	<i>255,771</i>	<i>289,565</i>	<i>296,131</i>	<i>304,842</i>
Total expenditure in € (million CZK)	561.85 (14,608)	702 (18,252)	719.11 (18,697)	753.81 (19,599)

^aTill 31 December of the stated year

remuneration. If the provided care is adequate, the number of persons an assistant can serve is not limited. Social care assistants are under no obligation to register as social service providers or to acquire a trade's license. They are, however, obliged to pay income taxes if their monthly income exceeds 12,000 CZK (462 €).

12.3.2 *The Drivers of Reform: Opportunities and Constraints for Reform*

As already indicated, the lack and inadequacy of social services legislation was the main reason for the reform in 2006. Under these circumstances, deep systematic changes were inevitable. The essential reform bill proposal underwent numerous conceptual changes following the first draft of its principles in the mid-1990s. At the turn of the millennium, in order to make use of foreign experience and achieve a higher degree of accord with practices common in the EU, MoLSA established cooperation with the UK Department for International Development within a Czech–British twinning project “Support for the MoLSA in Reforming Social Services” (2000–2003). A major principle of the collaboration was a user-oriented approach to social services based on community planning, quality standards, and an efficient quality control system. The national program document, the White Paper on Social Services (MoLSA 2003) emerged from this cooperation brought up a significant progress in drafting a new legislation (adopted in 2006) in accordance with the key principles of social inclusion policies.

Although long-term care debates do not specifically focus on the older population, but also on the disabled, the direction of long-term care reforms has been strongly determined by demographic (see Sect. 12.2.1) and economic factors. The issue of financial sustainability in an ageing society and a reference to the general economic situation have produced very strong pressure to keep public expenditure under control. Since the early 1990s: (a) moving from an institutional care system (characterized by a relatively large institutional sector and a small community care sector) toward a system, which emphasizes the development of easily accessible social services at the local level and (b) providing incentives and support (in particular

cash benefits) for families to take care of their close ones were major responses to these pressures (MoLSA 2005a, 2006b). Besides concerns about cost-containment and efficiency, this strategy is in line with the emphasis on rights of disabled groups and with the familistic care culture, which is dominant in the Czech Republic. Most of the care is still provided by family members in the private home of the user (Sowa 2010). In addition, living in the own household (or in the household of adult children) with the support of family members is still expressed by Czech seniors and their grown-up offspring as the preferred way of care provision in case of dependency in old age (Veselá 2002; Možný et al. 2004). At the same time, public responsibility for ensuring adequate conditions of formal and informal long-term care is widely anticipated.

To sum up, the care allowance introduced in 2007 was expected to be the main lever for changing social services funding and other necessary, desirable, and long-awaited reform steps (see Sect. 12.3.3). However, compared with some other European countries, long-term care was and still is dealt with in professional circles without broader public debate or systematic media attention. Over the past 15 years, broader media coverage has mostly related to quality failure in residential care facilities, but without any more significant effect on long-term care reform. Although long-term care is reflected in the National Program of Preparation for Ageing 2008–2012 (MoLSA 2008) as well as in the Program Declaration of the current government and although a new bill on long-term care is under preparation (see Sect. 12.3.3), it has not become a major public policy concern and media topic yet.

12.3.3 The Actors Involved in Policy Change

Long-Term Care as a Policy Field As already mentioned above (see Sect. 12.3.1), the term “long-term care” has not yet been adopted by the Czech law. And, this has not changed with the 2006 reform. In practice, the terms care for older people with reduced self-sufficiency and care for disabled persons are widely used. Lacking a systematic approach, the organization and financing of long-term care is fragmented and ensured by the Ministry of Health (covering facilities for patients in long-term care, nursing care beds, psychiatric aftercare, and hospice care), MoLSA (covering residential and community care services, care allowances, and benefits provided to disabled persons), the pension system (disability pensions and old-age pensions), regional authorities, municipal authorities, and health insurance funds. Services provided by the Ministries are not coordinated. As a result, there are significant differences in terms of costs, quality, and availability between the health care sector and the social care sector. The financial contribution made by a citizen to cover residential care costs differs significantly depending on whether the care is provided by the health care sector or the social care sector. In the social sector, clients make a contribution to cover board and lodging up to the amount stipulated by law, i.e., a maximum of 330 CZK (12.70 €) per day for hotel services and an average of 150 CZK (5.80 €) per day for social care (to be paid from the care allowance).

A patient admitted to a health care institution only covers the regular copayment amounting to 100 CZK (3.80 €) per day. As a result of this discrepancy, and also due to the lack of capacity in the social sector, health care institutions often hospitalize patients who, de facto, are the target of long-term care. But this situation was increasingly seen as a burden to health insurance expenditure. However, health insurance companies refuse to make full compensation of the necessary health care provided in residential social service centers (MoLSA 2011a).

The lack of coordination in the approach of the two Ministries, MoLSA and the Ministry of Health, has constantly been subject of criticism. In 2009, in an attempt to improve the bond between social care and health care services provided to older people and the disabled, MoLSA established a Social and Health Care Expert Panel. It consists of the representatives of the Ministries, health insurance companies, and other experts, particularly NGOs. This expert working group was engaged to prepare a development concept that recognizes the mutual link between social care and health care and to propose a new way of financing these services. In 2009, MoLSA published a Discussion Paper concerning the foundations of long-term care in the Czech Republic (Válková et al. 2010) as a document open for comments and amendments. Over subsequent years, the document was updated to include new suggestions and options of system changes. The Paper was based on both domestic and international resources concerning long-term care in European countries, recommendations of the Government Council for the Elderly and Population Ageing and the National Program of Preparation for Ageing for 2008 through 2012 (MoLSA 2008). It served as a basis for a draft bill on long-term care prepared as a joint project of both the Ministries. In 2010, in its Program Declaration, the current government promised, inter alia, to adopt a chain of reforms that would lead to modernization and improved effectiveness of the health care system, to support the development of care for older people and the disabled in their domestic environment and, together with the relevant experts, to define long-term health and social care and to propose the implementation of a comprehensive health and social service system and the method of its financing. The draft bill entered the external and internal comment process in 2011. It is too early to foresee the final version of the act. Nevertheless, the draft bill proposed a long-term care system to be implemented in the Czech Republic from 2013. The system should be based on a combination of health care services and social services with a more effective financing system. With regard to financial sustainability, it should support care provided in the private home of the user.

Actors and Reform Coalitions As the outdated legislation from the late 1980s governing social services was far from ideal (see Sect. 12.3.1) and prevented further development of social services, professionals from MoLSA and other levels of the state administration and self-administration as well as social service providers and users perceived the need to implement new legislation. This legislation was intended to reflect the changes occurring more or less spontaneously from the beginning of the 1990s and lay down clear rules for the operation and financing of social services.

After several unsuccessful attempts of MoLSA to implement a reform, the pressure for change exerted by the above parties intensified after 2000. Although previous

reform draft legislation (Bill on Social Assistance) was stopped when a government formed by the Czech Social Democratic Party came to power (1998–2002), there have been no clear political and ideological positions with regard to long-term care and to social services more generally. In 2005, the final version of the reform law (Act on Social Services), supported by the then Minister of Labour and Social Affairs (Czech Social Democratic Party) was accepted by the Czech Government. In 2005–2006, it was passed by both Houses of Czech Parliament, from members across the political spectrum.

Similar to other European countries, there is a deficit in organization and direct representativeness of a main target group of long-term care policies, namely, older people in need of care. The representatives of people with disabilities (e.g., the Czech National Council of the Disabled), however, were most active among the groups protecting the interests of users during the preparation of the draft bill on social services. As a result, the adopted legislation particularly reflected the interests of this group of users, sometimes to the detriment of patients with internal or psychiatric disorders (including dementia) and sensory disorders. Other active and influential interest groups in the reform process were social services providers and their representatives (e.g., The Association of Social Service Providers of the Czech Republic, SKOK—The Association of Nongovernmental, Nonprofit Organizations Active in the Areas of Social Assistance, and Social Health Care). Especially, since 2000, the main domain of their cooperation with MoLSA was in standards and quality assurance in social services. Trade unions, employer organizations, as well as regional and municipal administrative bodies only played a minor role in designing the reform.

As already mentioned, learning from other countries' experience played a very important role in the Czech reform process. Since the early 1990s, many professionals have availed of the opportunity to learn from foreign experience and best practice. This has significantly contributed to the spontaneous development of social services, which, however, increasingly required an appropriate reform in the legal framework. As regards the care allowance, the scheme was inspired by Austrian and German cash-for-care models. The system of long-term care insurance, as in Germany, has been considered, but this scheme only had a few advocates among experts and lacked more general support. Other fundamental aspects of the reform were influenced by current European trends, including issues of standardizing social care, enhancing the role of users in social services systems, and in social inclusion policy (MoLSA 2003).

As discussed before, the reform process, which culminated in the adoption of the Act on Social Services in 2006, is still ongoing. In the past few years, in the context of the efforts to better integrate health and social care services, experts from the Czech Society of Gerontology and Geriatrics and the Czech Alzheimer Society have been very active in the process of preparing an Act on long-term care and in the work of the Social and Health Care Expert Panel.

Mechanisms and Forms of Institutional Change The changes implemented in 2007 by the Act on Social Services covered not only long-term social care, but the general

system of social services that serves as a framework for the provision of social services to older citizens with reduced self-sufficiency and to disabled citizens. Anticipated for more than 12 years, the new Act introduced in many respects a breakthrough change in the conditions of social service provision and financing. The care allowance was expected to become the key element of the new system that should, inter alia, support the position of social service users and their choices. Based on their needs, the users were to decide about the use of the care allowance to purchase the relevant services. In line with user demand, desirable, high-quality, and effective services were expected to develop while unsuitable services not meeting the above criteria were expected to fade away. However, due to the reasons described in detail in Sect. 12.3.4, the above key assumption has not been fulfilled so far and the development of social services through the purchase of services from the care allowance has not occurred. In this respect, the Czech Republic is among countries where the implementation of adopted measures governing long-term care has proved to be more complicated than the creators and supporters of the measures expected and, up until now, the reform has not had the desired effect.

12.3.4 Impacts of the Reforms

Despite the original expectations, the 2006–2007 social services system reform has not had the desired effect in terms of the development of long-term care services. Most of the current services were already in place in the period prior to the reform (Sowa 2010). On the national level, there have been no major changes in the structure, availability and scope of care in residential facilities, and field day care services since 1995 (Průša 2011a). The reasons include insufficient medium-term planning of services on regional and municipality levels (Bareš 2008), a limited use of care allowances to pay for formal services and, particularly, the inappropriateness of the social services financing system.

The social services system development is apparently limited by certain elements aimed at protecting the service users, i.e., by the fixed maximum amount of user contributions to board and lodging costs in residential care and out-patient care institutions and payments for separate field services. The contributions together with the allocated care allowances do not even cover the average costs of a given type of service at the national level, let alone reaching at least minimum profit. This is an obstacle to entrepreneurial entities entering the social care sector, which results in service providers being dependent on subsidies from the state budget or from regional and municipality funds (Průša 2011a; RILSA 2010). The proportion of funds allocated to social services from the state budget changes every year depending on the macroeconomic situation and political interests in the given period. In addition, the subsidy policy rules are regularly subject to changes adopted by the MoLSA (Horecký 2010). And, there is no entitlement to subsidies from the public budgets. All these aspects make the situation and financial position of social service providers very unstable. As a result, the entire system is stagnant and does not stimulate the

expected and desired changes in the structure of social services (Průša 2011a; RILSA 2010).

The social service providers' dependency on state subsidies, the price regulation of payments for provided services, and the absolutely insufficient coverage of indicated and provided nursing care and physiotherapy by the public health insurance lead to a situation in which residential social care providers prefer clients with higher care allowances. As a consequence, the providers recommend their service users to apply for higher-level care allowances or even participate in filing the application (Průša et al. 2009; Průša 2010). The actual number of care allowance recipients and thus the amount allocated to care allowances out of the state budget significantly exceeded the legislators' estimates. The 2005 estimates expected about 175,000 recipients and total expenditure amounting to about 8 billion CZK (MoLSA 2005b). In 2010, the average monthly number of beneficiaries was 310,006, total expenditure exceeded 19.5 billion CZK (MoLSA 2011a). However, to a much lesser extent than expected, recipients use their care allowances to purchase social services. Older people often seem to consider the care allowance as a simple supplement to their pension "due to age" or a compensation for worsening health conditions (Válková et al. 2010). Not least as a consequence to this development, since 2007, the amount of the care allowance has been reduced for persons more than 18 years of age for the two lower levels of dependency. Also, a combination of vouchers for social services and cash benefits was considered. But given the uneven geographical availability of social services and given that such a measure might be detrimental to informal home care, the alternative was abandoned.

Without doubt, the implementation of the care allowance and other reforms implemented in 2006–2007 contributed to the strengthening of the position and an increase in the choices of service users within the social services system. To a large extent, however, decision making was hindered by the lack of available field services, particularly social services, and by the insufficient self-confidence of current senior generations who spent most of their lives in another social system and, unaware of their rights, often find themselves in the role of sufferers and passive recipients of low-quality services rather than acting as service "consumers." The situation and the position of long-term care clients in the Czech Republic is probably going to change very quickly with the future generation of seniors—baby boomers who are likely to be much more capable of communicating their requirements (Válková et al. 2010).

Concerning the situation in the long-term care labor market, Sowa (2010) emphasizes the low wages of nurses, physiotherapists, and other qualified staff as well as a lack of qualified personnel, in particular nurses. Also linked to staff shortages, Válková et al. (2010) raise certain objections to the quality of nursing care in the social service sector. While long-term care services requiring lower qualification are often provided by nonqualified staff through a gray labor market in other countries, this is not yet the case in the Czech Republic. However, Válková et al. (2010) argue that after the successful use of immigrants in auxiliary building works and other nonqualified lines of work, the use of migrant labor might also extend to social care.

12.4 Conclusions

Developments in central–eastern European long-term care systems are characterized by similarities in important context variables and development paths. At the same time, there are significant differences in the processes of change and the pace of change, due to country-specific pressures, actor constellations, and institutional settings. In general, long-term care—a term used more frequently in this region only in recent years—is a rather fragmented policy issue, with responsibilities in the health sector and in the social sector, but also in the area of disability policies or pension policies. Until the 1990s, the provision of residential care settings was the major public policy toward people in need of long-term care. Services such as home care and hospice care have been widely underdeveloped and are even nonexistent in many regions. In the Czech Republic, it became increasingly obvious that legislation from the late 1980s was highly inadequate. A lack of services and the inadequacy of the social services legislation was the main reason for a major reform that in the end only took place in 2006–2007. The process toward this reform took more than 10 years with only incremental changes to the system and with various attempts to implement a more comprehensive social service legislation. The reform debate and the direction of the changes were determined by demographic and economic factors and were inspired by foreign concepts, in particular the care allowance scheme implemented with that reform. Major actors in the reform process were professionals from MoLSA and social service providers. A particular role was played by representatives of people with disabilities—which were most active toward a care allowance scheme—as well as the Czech Society of Gerontology and Geriatrics and the Czech Alzheimer Society, which have been very active in the recent process of preparing the new act on long-term care.

The care allowance scheme introduced in 2006–2007 extended the financial support for those in need of care, but it was also expected to work as a lever for changes in social services funding and for the development of a more adequate social service infrastructure. However, these developments remained rather limited while the costs of the entire system soon widely exceeded the expectations of policy makers. In this respect, the developments in the Czech Republic are similar to other countries where the implementation of new governance structures proved to be more complex than the creators and supporters expected. It became apparent that unless the basic principles of social services financing, organization, and planning are re-assessed, no significant changes can be expected. With a view to these systemic problems and growing demographic pressure (Průša 2011b), a draft bill on long-term care has recently entered the legislative process and—if adopted—should come into force in 2013 (MoLSA 2011a). If successful, this would mark a major transformation, helping to materialize many objectives already underlying the 2006–2007 reform.

References

- Auth, D. (2010). Welfare states and gender in central and eastern Europe: The current state of research and prospective research. In C. Klenner & S. Leiber (Eds.), *Welfare states and gender inequality in central and eastern Europe* (pp. 33–55). Brussels: etui.
- Bareš, P. (2008). *Cílové skupiny v krajských střednědobých plánech rozvoje sociálních služeb zpracovaných v období 2006–2007*. [Target groups in regional mid-term social services development plans compiled in the period 2006–2007]. Praha: Research Institute for Labour and Social Affairs.
- Barvíková, J. (2011). Long-term care in the Czech Republic: On the threshold of reform. In A. Österle (Ed.), *Long-term care in central and south eastern Europe* (pp. 81–103). Frankfurt a. M.: Lang.
- Barvíková, J., & Bartoňová, J. (2005). Příběhy pečujících rodin [The stories of caring families]. *Problematika—generace 50 plus. II. mezinárodní konference*, Třeboň 6-7 October 2005, Sborník přednášek, Třeboň.
- Bryndová, L., Pavloková, K., Roubal, T., Rokosová, M., & Gaskins, M. (2009). *Czech Republic: Health system review*. Copenhagen: World Health Organization.
- Cerami, A., & Vanhuysse, P. (2009). *Post-communist welfare pathways. Theorizing social policy transformations in central and eastern Europe*. Basingstoke: Macmillan.
- Cook, L. (2010). Eastern Europe and Russia. In F. G. Castles, S. Leibfried, J. Lewis, H. Obinger, & C. Pierson (Eds.), *The Oxford handbook of the welfare state* (pp. 671–686). Oxford: Oxford University Press.
- Daňková, Š., Hrkal, J., Hromádková, E., Roubal, T., & Žofka, J. (2011). *Analýza příjemců příspěvku na péči a potenciálních klientů dlouhodobé péče* [Analysis of the care allowance beneficiaries and potential long term care clients]. Praha: Ministry of Labour and Social Affairs. Retrieved from http://www.mpsv.cz/files/clanky/11991/Analýza_prijemcu_Prispevku_na_peci_a_potencialnich_klientu_dlouhodob_pecce.pdf. Accessed 25 Jan 2012.
- European Commission. (2007). *Health and long term care in the European Union* [Special Eurobarometer 283/Wave 67.3]. Brussels: European Commission.
- European Commission. (2009). *The 2009 ageing report: Economic and budgetary projections for the EU-27 Member States (2008–2060)* [Joint report prepared by European Commission (DG ECFIN) and the Economic Policy Committee (AWG)]. Brussels: European Commission.
- Eurostat. (2008). *Ageing characterises the demographic perspectives of the European societies (Statistics in Focus 72/2008)*. Brussels: European Communities.
- Flaker, V., Kresal, B., & Nagode, M. (2011). Needs and beads: The emerging long-term care system of Slovenia. In A. Österle (Ed.), *Long-term care in central and south eastern Europe* (pp. 189–212). Frankfurt a. M.: Lang.
- Gulácsi, L., Érsek, K., & Mészáros, K. (2011). Long-term care in Hungary: Between health and social care. In A. Österle (Ed.), *Long-term care in central and south eastern Europe* (pp. 105–122). Frankfurt a. M.: Lang.
- Hoff, A. (Ed). (2011). *Population ageing in central and eastern Europe. Societal and policy implications*. Aldershot: Ashgate
- Holmerová, I. (2007). *Supporting family carers of older people in Europe. The national background report for the Czech Republic*. Hamburg: LIT Verlag.
- Horecký, J. (2010). *Long term care in the Czech Republic*. Comment Paper for the peer review—Achieving quality long term care in residential facilities. Murnau, 18–19 October 2010.
- Huber, M., Rodrigues, R., Hoffmann, F., Gasior, K., & Marin, B. (2009). *Facts and figures on long-term care: Europe and North America*. Vienna: European Centre for Social Welfare Policy and Research.
- Inglot, T. (2008). *Welfare states in east central Europe, 1919–2004*. Cambridge: Cambridge University Press.
- Jenei, G., & Kutí, É. (2009). The third sector and civil society. In S. Osborne (Ed.), *The third sector in Europe: Prospects and challenges* (pp. 9–25). London: Routledge.

- Klenner, C., & Leiber, S. (Eds.). (2010). *Welfare states and gender inequality in central and eastern Europe*. Brussels: etui.
- Kovács, J. M. (2002). Approaching the EU and reaching the US? Rival narratives on transforming welfare regimes in east-central Europe. *West European Politics*, 25(2), 175–204.
- Marée, J., & Groenewegen P. P. (1997). *Back to Bismarck: Eastern European health care systems in transition*. Aldershot: Avebury.
- Ministry of Labour and Social Affairs [MoLSA]. (2001). *Základní ukazatele z oblasti práce a sociálního zabezpečení České republiky ve vývojových řadách a grafech 2000* [Basic indicators of labour and social protection in the Czech Republic – Time series and graphs 2000]. Praha: Ministry of Labour and Social Affairs.
- Ministry of Labour and Social Affairs [MoLSA]. (2003). *Bílá kniha v sociálních službách* [White Paper on social services]. Praha: Ministry of Labour and Social Affairs.
- Ministry of Labour and Social Affairs [MoLSA]. (2005a). *Důvodová zpráva k zákonu o sociálních službách* [Explanatory report on the Social Services Bill]. Praha: Ministry of Labour and Social Affairs.
- Ministry of Labour and Social Affairs [MoLSA]. (2005b). *Preliminary national report on health care and long term care in the Czech Republic*. Praha: Ministry of Labour and Social Affairs.
- Ministry of Labour and Social Affairs [MoLSA]. (2006a). *National report on strategies for social protection and social inclusion for years 2006–2008*. Praha: Ministry of Labour and Social Affairs.
- Ministry of Labour and Social Affairs [MoLSA]. (2006b). *Koncepce podpory transformace pobytových sociálních služeb v jiné typy sociálních služeb, poskytovaných v přirozené komunitě uživatele a podporujících sociální začlenění uživatele do společnosti* [Concept of supporting residential social services transformation into different social services types provided in the user's natural community and supporting user's social inclusion in the society]. Praha: Ministry of Labour and Social Affairs.
- Ministry of Labour and Social Affairs [MoLSA]. (2007). *Základní ukazatele z oblasti práce a sociálního zabezpečení v České republice ve vývojových řadách a grafech 2006* [Basic indicators of labour and social protection in the Czech Republic – Time series and graphs 2006]. Praha: Ministry of Labour and Social Affairs.
- Ministry of Labour and Social Affairs [MoLSA]. (2008). *Kvalita života ve stáří. Národní program přípravy na stárnutí na období let 2008–2012*. [Quality of life in old age. National programme of preparation for ageing for 2008–2012]. Praha: Ministry of Labour and Social Affairs. Retrieved from http://www.mpsv.cz/files/clanky/5045/starnuti_cz_web.pdf. Accessed 3 Jan 2012.
- Ministry of Labour and Social Affairs [MoLSA]. (2011a). *Věcný záměr zákona upravujícího řešení dlouhodobé péče* [The general principle of law regulating the long term care solution]. Praha: Ministry of Labour and Social Affairs.
- Ministry of Labour and Social Affairs [MoLSA]. (2011b). *Základní ukazatele z oblasti práce a sociálního zabezpečení v České republice ve vývojových řadách a grafech, 2010* [Basic indicators of labor and social protection in the Czech Republic—time series and graphs, 2010]. Praha: Ministry of Labour and Social Affairs.
- Možný, I., Přidalová, M., Bánovcová, L., & Pakosta, P. (2004). *Mezigenerační solidarita. Výzkumná zpráva z mezinárodního srovnávacího výzkumu—Hodnota dětí a mezigenerační solidarita* [Research information from international comparative research—value of children and intergenerational relationship]. Praha: RILSA.
- Nemec, J., & Kolisnichenko, N. (2006). Market-based health care reforms in central and eastern Europe: Lessons after ten years of change. *International Review of Administrative Sciences*, 72(1), 11–26.
- OECD. (2011). *OECD Health data: Health expenditure and financing. OECD Health Statistics (database)*. Retrieved from doi:10.1787/data-00349-en.
- Oliveira, M. J., & de la Maisonnette, C. (2006). *The drivers of public expenditure on health and long-term care: An integrated approach* (OECD Economic Studies No. 43, 2006/2). Paris: OECD.

- Orenstein, M. A. (2009). Transnational actors in central and east European pension reforms. In A. Cerami & P. Vanhuysse (Eds.), *Post-communist welfare pathways. Theorizing social policy transformations in central and eastern Europe* (pp. 129–147). Basingstoke: Macmillan.
- Österle, A. (2010). Long-term care in central and south eastern Europe: Challenges and perspectives in addressing a 'new' social risk. *Social Policy and Administration*, 44(4), 461–480.
- Österle, A. (Ed). (2011a). *Long-term care in central and south eastern Europe*. Frankfurt a. M.: Lang.
- Österle, A. (2011b). A comparative analysis of long-term care in central and south eastern Europe. In A. Österle (Ed.), *Long-term care in central and south eastern Europe* (pp. 213–242). Frankfurt a. M.: Lang.
- Österle, A. (2012). Long-term care financing in central eastern Europe. In J. Costa-Font & C. Courbage (Eds.), *Financing long-term care in Europe: Institutions, markets and models* (pp. 236–253). London: Macmillan.
- Österle, A., & Rothgang, H. (2010). Long-term care. In F. G. Castles, S. Leibfried, J. Lewis, H. Obinger, & C. Pierson (Eds.), *The Oxford handbook of the welfare state* (pp. 378–390). Oxford: Oxford University Press.
- Österle, A., Mittendrein, L., & Meichenitsch, K. (2011). Providing care for growing needs: The context for long-term care in central and south eastern Europe. In A. Österle (Ed.), *Long-term care in central and south eastern Europe* (pp. 17–39). Frankfurt a. M.: Lang.
- Pascall, G., & Manning, N. (2000). Gender and social policy: Comparing welfare states in central and eastern Europe and the Former Soviet Union. *Journal of European Social Policy*, 10(3), 240–266.
- Popescu, L. (2011). Long-term care policy in Romania: A hesitant response to a pressing need. In A. Österle (Ed.), *Long-term care in central and south eastern Europe* (pp. 123–149). Frankfurt a. M.: Lang.
- Průša, L. (2010). Změny ve struktuře příjemců příspěvku na péči v letech 2007 a 2009 [Changes in the structure of care allowance beneficiaries in 2007 and 2009]. *Fórum sociální politiky*, 4(5), 20–22.
- Průša, L. (2011a). Dotace ze státního rozpočtu jako klíčový důvod stagnace sociálních služeb [Subsidies from the state budget as a key reason for the stagnation of social services]. *Rezidenční péče*, 7(2), 8–10.
- Průša, L. (2011b). Vývoj vybavenosti regionů službami sociální péče pro seniory a osoby se zdravotním postižením [Regional development of services of social care for seniors and handicapped people]. *Kontakt*, 13(2), 157–165.
- Průša, L. (2011c). *Model efektivního financování sociálních služeb* [Model for the effective financing of social services]. Working paper, unpublished.
- Průša, L., Jeřábková, V., Bruthansová, D., Červenková, A., Galetová, Z., Kaplan, E., & Svět, L. (2009). *Poskytování ošetřovatelské a rehabilitační zdravotní péče uživatelům pobytových sociálních služeb v pobytových zařízeních sociálních služeb a v lůžkových zdravotnických zařízeních* [Provision of nursing and rehabilitation care provided to the users of social services in residential social-service facilities and inpatient health-care facilities]. Praha: Research Institute for Labour and Social Affairs.
- Research Institute of Labour and Social Affairs [RILSA] (2010). *Poskytování sociálních služeb pro seniory a osoby se zdravotním postižením* [Provision of social services for the elderly and persons with disabilities]. Praha: Research Institute for Labour and Social Affairs.
- Sowa, A. (2010). *The long term care system for the elderly in the Czech Republic* [ENEPRI Research Report No. 72]. Brussels: Centre for European Policy Studies.
- Theobald, H., & Kern, K. (2009). Elder care systems: Policy transfer and Europeanization. In A. Cerami & P. Vanhuysse (Eds.), *Post-communist welfare pathways. Theorizing social policy transformations in central and eastern Europe* (pp. 148–163). Basingstoke: Macmillan.
- Válková, M., Kojesová, M., & Holmerová, M. (2010). *Diskusní materiál k východiskům dlouhodobé péče v ČR* [Discussion paper on the foundations of long term care in the Czech Republic].

Praha: Ministry of Labour and Social Affairs and Faculty of Humanities, Charles University, Prague. Retrieved from http://www.mpsv.cz/files/clanky/9597/dlouhodobá_pece_CR.pdf. Accessed 3 Jan 2012.

Van Mechelen, N., & De Maesschalck, V. (2009). Devolution of social protection arrangements. In A. Cerami & P. Vanhuysse (Eds.), *Post-communist welfare pathways. Theorizing social policy transformations in central and eastern Europe* (pp. 181–198). Basingstoke: Macmillan.

Veselá, J. (2002). *Představy rodinných příslušníků o zabezpečení péče nesoběstačným rodičům* [Ideas of family members about safe care for non self-sufficient parents]. Praha: Research Institute for Labour and Social Affairs.

Zákon č. 2006/100 Sb., o sociálních službách. [Act No. 100/1988 Coll., on Social Services, as subsequently amended].

Part III

Conclusions

Chapter 13

Institutional Change in Long-Term Care: Actors, Mechanisms and Impacts

Costanzo Ranci and Emmanuele Pavolini

13.1 Introduction

As illustrated in the previous chapters of this book, long term care (LTC) has been one of the welfare policy fields in which the most significant institutional changes and policy innovation have taken place over the last two decades, both in Western and Central-Eastern Europe. The national case studies presented in this volume show that very different trends have taken place throughout Europe: from a general growth in public financing, an expansion of beneficiaries, and, more generally, an attempt to define larger social responsibilities and related social rights in some countries, to cuts in public expenditure, targeting of services and a general reduction in social rights in others. This final chapter aims to describe these general trends; identify the factors which explain them; summarize the main differences between European countries; and consider the most important consequences of the various developments. We also look at institutional conditions and the gaps between “problem pressures” and existing solutions which require policy innovation; at the political and institutional processes through which subsequent changes have taken place; and at the general impact of such changes on the structure of the care systems.

The chapter is organized in the following way. Section 13.2 describes the state of affairs in the individual countries at the beginning of the 1990s, just before major reforms were introduced in several different countries. Two fundamental care regimes will be identified which explain the developments which subsequently took place in the countries included in our analysis. Section 13.3 discusses the main drivers which led to reform and also the constraints which hindered it. The subsequent Sect. 13.4 is dedicated to identifying the problems requiring a change: how the gaps between problem pressures and available solutions were perceived in our countries, preparing

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the stage for innovation. Section 13.5 then outlines the main thrust of the reforms introduced in the last two decades in the countries considered.

If Sect. 13.6 is about the politics of LTC reform (who have been the main actors and coalitions who push for change or stability, which are their values, interests and resources), Sect. 13.7 outlines the institutional and political mechanisms through which change has taken place. Section 13.8 then considers the impacts of the reforms on potential beneficiaries and their families, as well as on workers and on the overall organization of the LTC delivery system. Finally, the conclusion (Sect. 13.9) draws a general overview and interpretation of the ongoing reform processes.

13.2 The LTC Policy Field before the Main Reforms

LTC regimes in Europe can be analyzed and classified around different criteria. We have chosen to focus here on two of the most salient: the first concerning the level of coverage to meet demand (measured first by the percentage of the population aged 65+ receiving home or residential care services and second by the relevance of cash programs); the second, the extent to which LTC care services are well-integrated and coordinated with other social and healthcare services. At the beginning of the 1990s, a wide spectrum of coherently different LTC care regimes co-existed, with a “universalistic” model and another “fragmented” model operating at the two extremes (see Table 13.1).

At the beginning of the 1990s, Denmark, Sweden and the Netherlands were already characterized by universalistic approaches, namely, providing very high coverage of LTC needs, completeness of care services and a strong integration among providers (Anttonen and Sipila 1996). In Denmark and Sweden, long-term care policies date back to the late 1950s and were subject to systematic expansion from the 1950s until at least the 1990s; the LTC policy arena was firmly embedded in the structures of central-local relations which are one of the cornerstones of the political system. In the Netherlands, the *Algemene Wet Bijzondere Ziektenkosten* (AWBZ) dates back to 1968 and it is considered one of the main institutions of the Dutch welfare state. If we look at the level of fragmentation—integration of the LTC as a policy field, these three countries presented a situation in LTC policies of “integration”, confirmed by the presence of a mature community, which has been established since the 1960s, and by the fact that LTC was a well-institutionalized policy arena firmly embedded in decades of central-local government relations (in Scandinavia) and public-private providers relations (in the Netherlands). The Netherlands is arguably the best example of a case of maximum integration, given the fact that health and social care are strongly coupled in the case of LTC needs: the main program, the AWBZ, has been historically framed as part of the health-care system. In these countries, therefore, an universalistic, service-led LTC system was already in place at the beginning of the 1990s as a consequence of the extension to the care system of the same approach to welfare that was dominant in the health, pension and education systems.

Table 13.1 LTC policies: the scenario at the beginning of the 1990s. (Source: Huber et al. (2009); for the Netherlands, Anttonen and Sipilä (1996) and for the Czech Republic (Barvíková and Oesterle, see Chap. 12); the data for the Czech Republic refers to coverage in terms of beds in residential care in relation to the elderly population)

Country	Coverage at the beginning of the 1990s			(Beginning of the 1990s)	Integration–Fragmentation
	Home care	Residential care	Relevance of cash programs		
Denmark	20	4.1	Low		
Sweden	12	8.4	Low	Universalistic	Integration
The Netherlands	8	10	Low		
Great Britain	14.2	3.9	Medium-Low	Semi-universalistic	Fragmentation
Germany	7.3	3.3	Low		
France	2.5	2.4	Low		
Austria	13.2	2.8	Low	Residual (partially based on residential care)	Fragmentation
Spain	1.1	2.8	Low		
Italy	1.8	2.2	Medium		
Czech Republic	n.g.	2.8	Low		

At the other extreme, continental and Southern Europe both had a residual LTC care regime at the beginning of the 1990s. Within this model, service coverage was relatively limited and was based more on cash programs and residential rather than home care. The LTC policy field appeared also quite fragmented: different institutions, often with different (and overlapping) geographical remits with high levels of discretion, were each responsible for different aspects of LTC and there were problems of coordination among these institutions. For instance, in Italy, cash-for-care programs were run separately from local authorities' social care services for LTC users and, in most of the countries, there were also problems of integration between social care and health care services at the local level. This situation meant that there were different actors operating in different arenas, each working according to partially different definitions of what LTC should be. Great Britain was a peculiar case in this scenario: the level of coverage at the beginning of the 1990s was something in between the prior two regimes, but the level of fragmentation remained high as in Continental and Southern Europe.

Central and Eastern European countries (CEE) found themselves in an even more complicated situation. Before the 1990s, long-term care was largely a family responsibility with rather limited public support. Coverage levels, in terms of residential care or financial support schemes, were lower than in many Continental and Southern European countries. In the early 1990s, with the transition process, cuts in social policies and ideologies referring to traditional patterns of family roles served to reinforce traditional family responsibility in LTC (Barvíková and Österle, cap 12). The Czech Republic showed a similar, if slightly better picture, than other CEE countries. Also here the LTC system was mainly based on residential facilities and was quite fragmented overall, consisting of a range of health and social care providers, as well as pensions' regulators and other institutions. To sum up, the weak development

of the LTC system in Central and Southern European countries is the result of a combination of familism and residualism in care policies. Moreover, the dominant Bismarckian approach to welfare in these countries, based on a combination of insurance and assistance principles, hampered the progress of universalistic principles in the care policy field.

13.3 The Drivers of Reform: Problem Pressures

All of the countries considered here have experimented with new “problem pressures” since the early 1990s. As we explained in Chap. 1, in our model, a problem pressure is a situation that is characterized by a growing gap between new social and institutional problems emerging in a specific policy field and the capacity of the existing repertoire of political measures to give an adequate answer to these problems (Ferrera 2005). In such cases, a policy crisis becomes increasingly evident and requires policy innovation. This was the case for all the countries analyzed here. Three types of pressures have been most evident: socio-demographic pressures; financial pressures; socio-cultural pressures.

Socio-demographic pressures In the field of LTC, the most relevant pressure came, first of all, from demographic changes taking place all over Europe due to the ageing of the population (see Chap. 2). As a consequence, not only the amount of dependent people in need for care increased, but also the capacity of informal and family ties to provide support was weakened (OECD 2011; Lafortune and Balestat 2007). At the same time, the increasing participation of women to the labor market lowered the supply of family care work, driving more and more dependent people to professional services (Sarasa and Mestres 2007; Saraceno 2008). Disability and dependence mainly concentrated in the elderly, as well as vulnerability related to heavy informal caregiving, emerged as ‘new social risks’ (Taylor-Gooby 2004): situations in which individuals experience welfare losses and which have arisen as a result of the socio-demographic transformations that have brought postindustrial societies into existence. As Bonoli (2005) states, if during the *trente glorieuses* care for frail elderly or disabled people was mostly provided by non-employed women on an unpaid, informal basis, with the change in women patterns of labour market participation, this task had to be externalised. The inability to do so (because of lack of services) therefore has resulted in a new relevant social risk. All ten countries experienced these trends, even though levels of pressure on the existing systems differed. Also, in the Southern, Germanic Continental and CEE countries, which could count on the very rooted family solidarity that favored the creation of new care arrangements within families, demand for residential and home care services increased exponentially (Lamura et al. 2008). Meanwhile, the individualistic culture that was dominant in the Nordic countries, in England and in France, channeled a new demand for care directly towards professional care services.

Financial pressures The rising demand for care also put pressure on welfare services which were not specifically tailored for long term care, but which were substantially

Table 13.2 Percentage variation in the public per-capita expenditure on healthcare in the 1990s and in the 2000s (constant prices at 2000 level). (Source: Eurostat, Espross database 2011)

LTC Care Regime (early 1990s)	1991–2000	2000–2008
<i>Universalistic</i>		
Sweden (from 1993)	+29.5	−0.2
Denmark	+28.6	+33.5
Netherlands	+11.3	+40.0
<i>Semi-Universalistic</i>		
United Kingdom	+54.9	+5.5
<i>Residual</i>		
Germany	+26.2	+4.6
Austria	+29.2	+13.2
France	+31.1	+20.6
Spain	−4.5	+37.6
Italy	−20	+18.7
Czech Republic	−	+88.5

affected by the growing number of dependent people asking for help and assistance. A second source of pressure was therefore financial, coming from the functioning and difficulties of other welfare institutions and programs. Of these institutions, health-care systems were and still remain in the front line: in most countries, increasing costs in the healthcare system, as a consequence of the aging population, were reported (see Table 13.2). According to the OECD (2011), between 40 and 50 % of the total costs of healthcare in Europe is currently used to provide services to older people, often with chronic and long-term needs. In the 1990s, the highest growth in healthcare expenditures occurred in the UK, France, Sweden, Austria, Denmark and Germany. Only Mediterranean countries saw strong cuts in healthcare, aimed at matching the Maastricht criteria in order to enter the Eurozone. In the UK, the pressure of costs was so high in the early 1990s that new solutions were sought in order to shift the responsibility for funding residential and nursing care away from the health care system.

The development of new LTC services was seen as a good strategy to shift costs from the health care sector, where services were provided on the basis of universalistic principles, to the social sector where rights and costs were not so highly and precisely defined (Morel 2007). The Ädel-reform (1992) in Sweden was also aimed to shift part of these costs to social care services in order to diminish the pressure on the health care sector. In Denmark, England and Germany, particular attention was paid to the length of stay in hospital of patients with disabilities. The search for new solutions allowing earlier discharges from hospitals had repercussions for the demand on long-term care. In Sweden, the rising costs of nursing homes managed by the health care sector were under scrutiny and paved the way for a shift in their financial management from the health sector to social care services managed by municipalities. In CEE, the health sector has long been the major provider of long-term care services. Throughout the region, home nursing has often been the only community care service available to those with chronic health problems across the entire country. Health care reforms aiming at cost-containment, however, increased pressure to limit health sector provisions to medically-needed acute care provisions and to shift long term care provisions to the social care sector.

These strategies seem to have worked out quite well in many countries as health-care expenditures slowed down throughout the following decade (with the exceptions of Denmark and partially of France, where expenditures dropped only in the second half of last decade). In other countries, however, expenditure in health care increased only in the last decade, as is the case for the Netherlands and Spain, resulting in increased pressure on LTC reforms more recently.

Other financial strains came from the social security or the social assistance systems. In some countries, such as France, Germany, Spain and England, large parts of care services for older people, including residential and home care, were financed by national or, more frequently, local programs of social assistance (Oesterle 2001). In England, reforms which took place in 1993 capped social assistance expenditure on long term care and shifted both the budget and allocation responsibilities to local authorities. In Germany, the growth of residential care provided at the local level within the framework of the Federal Law of Social Assistance put most of the local authorities under very strong financial pressure. In Spain, the 1985 Local Government Act assigned financial responsibility for providing social care to local authorities. In Italy this responsibility had been assumed by local authorities since 1977, with the national state only playing a residual and complementary role. The same happened in the Nordic countries, which were characterized by a long tradition of a locally based social welfare. In Sweden, the economic crisis of the early 1990s squeezed resources for care for older people in a time of increasing demand for social assistance benefits). These local infrastructures of social services, largely developed in the 1970s and the 1980s to meet the demand for care of particular social groups (older people with limited means or living on their own, people with disabilities and so on), began in the 1990s to be captured by a huge mass of dependent older people seeking care services. Local authorities and the social assistance administrations managing these services were under very tight financial and organizational constraints, and seemed to be unable to keep the social spending under control. In the Czech Republic, as in other CEE countries, the situation was only partially different: a lack of experience in local social care governance and budgetary constraints have for many years constrained modernization, coordination and extension of services at local level. Community care services were unavailable in most rural areas in the 1990s and were only very limited in many urban areas. Funding of residential and community care provisions was usually based on social assistance principles involving substantial user contributions.

Financial pressures also came from the overall economic conditions of the countries, which served both as constraints for LTC reforms and as catalysts of institutional innovation. This contextual factor has been particularly relevant in certain countries and in particular years. Table 13.3 illustrates the financial situation of each country in terms of debt and deficit/surplus in relation to the National GDP. LTC radical reforms were introduced in years that were characterized by relatively low levels of financial debt in all of the countries. Germany introduced the new LTC system in 1995, when the deficit/surplus ratio was under 2.0. Similarly, France introduced the APA reform in 2002, a year in which the financial strain was lower than either previously or afterwards. Spain also introduced a reform in 2007 in the context of a relatively favorable financial situation.

Table 13.3 Fiscal constraints on welfare reforms in Europe: gross debt and deficits in the last two decades. (Source: Eurostat 2011)

LTC Care Regime (early 90s)	General government gross debt (% GDP)	General government deficit/surplus (% GDP)		
	Average 1995–2007	Average 1995–2000	Average 2001–2007	Average 2008–2010
<i>Universalistic</i>				
Sweden	57.7	– 1.2	1.1	0.6
Denmark	51.4	– 0.3	2.8	– 0.7
Netherlands	57.6	– 0.3	– 1.0	– 3.4
<i>Semi-Universal:</i>				
United Kingdom	43.8	– 1.3	– 2.5	– 8.9
<i>Residual:</i>				
Germany	61.9	– 1.7	– 2.7	– 2.5
Austria	65.6	– 3.0	– 1.6	– 3.1
France	60.5	– 3.1	– 2.9	– 6.0
Spain	54.2	– 3.4	0.5	– 8.3
Italy	110.5	– 3.7	– 3.2	– 4.2
Czech Republic	22.3	– 5.5	– 4.1	– 4.3
EU 27	61.8	– 1.2	– 2.1	– 5.3

However, more serious fiscal problems appear to have hindered the possibility of strengthening reforms after their introduction, as in the case of France, Spain, the UK and the Czech Republic. For instance, in Spain, the financial crisis, which started right after the LTC reform in 2007 was adopted, was detrimental to the reform's implementation phase, as shown in Chap. 10. In the UK, after years of discussion and “White Papers”, the most recent Labour government in England was not able to finalize a proposal of reform in LTC at the end of its term in office: partially because the deficit had risen from around 2 % to around 9 % between 2008 and 2010. An even bigger problem affected Italy: any expansive and explicit reform proposal in LTC had to first overcome its permanent huge public gross debt.

Socio-cultural pressures Together with socio-demographic and institutional pressures, the 1990s were characterized by a strong change in the political and cultural attitudes towards care provision. These changes concerned the predominant ideas both in the political arena about how to run public services and in the social arena about the role of users in care provision. While the '70s and the '80s were dominated by a demand for professional, highly qualified care services and for a progressive extension of long term care to minorities (such as specific categories of disabled people), a new orientation towards efficiency and flexibility became predominant in the 1990s (Daly and Lewis 1998). On the one hand, the ideology of New Public Management (NPM) largely penetrated the public administration and the political class claiming for a standardization and marketization of service provision. On the other hand, social groups representing the interests of dependent people started to elaborate a new vision of care, based on the principles of self-determination and autonomy.

The influence of NPM has been very significant throughout each of the ten countries' analysis. After three decades in which the expansion of social services was considered a still far-reaching but considerable goal of social policy, high public social expenditures have been seen as a problem since the 1990s. Even in a social-democratic country like Denmark, "concerns for containing expenditure, value for money and responding to individual needs become predominant" (Burau and Dahl, Chap. 4). Therefore new forms of accountability and budget control; novel regulation, splitting the responsibility for financing from provision; new market mechanisms; and new forms of standardization of quality and costs, were introduced into the care systems in all the countries (Ascoli and Ranci 2002). As discussed in following sections, cost-containment has become a dominant principle even in countries where radical reforms and new principles of universalism were introduced. It would be fair to say that, since the early 1990s, the policy field of long-term care in all ten countries has been strongly influenced by concerns about cost-containment and efficiency. The NPM ideas were largely introduced in order to guarantee cost-efficiency, effectiveness and strict budget control on both expenditures and service provision. This "recipe" was also provided in an even more explicit form to CEE countries over the last two decades: international organizations, such as the World Bank and the OECD, promoted reforms based on NPM ideology.

This attention to efficiency has been paradoxically matched by a deep change in the care culture in many countries. Until the 1990s, the most common claim by both groups representing people with disabilities and trade unions was to extend care service provision, to de-institutionalize the care system allowing people to stay at home as long as possible and to guarantee high professional and quality standards. In the 1990s, this idea of the professionalization of care was challenged. Groups representing people with disabilities were strongly influenced by ideas of self-determination and independence, and professionalization of care started to be considered as a synonym of bureaucratization and managerial control on the life strategies of the disabled. Part of this change had to do with the individualization of social life and the consequent refusal of bureaucracy and standardization. But this was also due to the great improvements in the health treatment of chronic diseases and to technological innovations, which did not only lengthen the life expectancy of people with disabilities, but also improved their everyday conditions, thus reducing their dependence on other people and increasing the chances of social and economic integration. Therefore the empowerment of the disabled became not just an appeal as a real opportunity to be taken.

As a consequence of these changes, groups representing people with disabilities started to call for a new public regulation of care giving beneficiaries more autonomy and freedom to organize care according to their wills and needs. User-led care and flexibility became new principles to use against the professional definition of the contents of care. New regulation proposing freedom of choice, welfare pluralism, cash for care measures, was strongly supported by these groups in order to empower users and alter the definition of care provided either by the public administration or by professional providers (Da Roit and Le Bihan 2010). Therefore, calls for free choice and empowerment on the one hand, and the NPM claim for flexibility and

marketization of care on the other, matched together to foster a new cultural definition of care, paving the way for new regulatory principles to be introduced in the care system.

13.4 Diagnosis: How the Policy Crisis has been Defined

Although the pressures for change were almost the same throughout the ten countries analyzed in this volume, these pressures have been perceived and cognitively framed quite differently due to the different LTC care regime traditions.

In the countries that had already adopted before the 90s a universalistic care regime (Sweden, Denmark and the Netherlands), a conflict emerged between universalism and pressures for cost-containment. According to universalistic principles, the provision of care services had to be as complete as possible. Moreover, high quality professional standards had to be guaranteed. However, completeness and high quality of care services significantly increased the costs of service provision. In the Nordic countries, this original, full version of universalism had already proved to be unsustainable in the late 1980s, requiring a number of organizational adaptations in order to cut public expenditure. Shifting public investments from residential services to home care provision was not only a strategy aimed at improving the life conditions of the care recipient, but also implied the involvement of family networks in the provision of care in order to reduce public costs. Since the early 1990s, the strategy of deficit reduction has become dominant, but, in comparison with other countries, the fiscal constraints were less tight (the level of debt and deficit was relatively more limited). As a large part of the financial responsibility for care provision was held by local authorities, new legislation was introduced in Denmark and Sweden to cut the state financing of local governments and to limit taxation and social spending at the local level. A re-centralization strategy was therefore adopted in order to curb social expenditures. As we will see later, innovation was also introduced in the public regulation of the care system in line with the NPM doctrine both by social-democratic and neo-liberal or conservative parties.

In addition, given to the fact that the fiscal constraints were loose, the gap between problems and available solutions was mainly understood in these countries as an organizational and a management problem. Cost-containment was never considered a radical challenge to the mainstream principles of universalism and service completeness. The high public consensus on universalism was untouched and there were no serious attempts to fight against the strong welfare constituencies defending it. Innovation put in place was not explicitly questioning the institutional setting or the normative principles of the care system, but was focused on technical and organizational aspects related to financing and providing services. But even in these technical discussions, entitlements to social care were neither disputed nor formally reduced, even though cutbacks in expenditures and service provision were actually introduced in Sweden and the Netherlands. Only Denmark resisted against cost containment by adopting new regulation which has so far not affected spending and coverage levels.

In Denmark and the Netherlands, the tension between universalism and cost containment was therefore at play. But the policy crisis was not recognized as a problem requiring a radical change in the general orientation and institutional setting of the care system: universalism *per se* was not considered as part of the problem. Only Sweden experienced a stronger tension between rising costs and an equivalent increase in demand for care. In this country, in contrast with what happened in Denmark and the Netherlands, cost containment was perceived and explicitly discussed as a challenge to the universalistic foundation of the care system. It was not only a matter of targeting and focusing care services. The ideological basis of the welfare system was under strong attack from the NPM approach which deeply influenced the public discourse and was also strongly penetrating the social-democratic culture. A new epistemic community of economists, managers and welfare experts advocated the NPM approach and succeeded in permeating the public arena with these arguments. The strong cultural influence of NPM, as shown by Meagher and Szebehely, can explain the peculiarity of the Swedish case compared with the other Nordic countries, and the fact that, starting from the 1990s, policy makers, including the same traditional constituency groups of the Swedish welfare state, were searching for new solutions outside of the universalistic public care system. Sweden therefore experienced a real policy crisis that paved the way for more radical changes. But even in Sweden, as we will show below, the way out of universalism was achieved through incremental changes which did not explicitly change entitlements and social rights.

In England, the only country defined as a “Semi-Universalistic” LTC care regime at the beginning of the 1990s, local authorities were both the funders and the providers of social care services. The growth of the demand for LTC raised costs in the early 1990s, resulting in an attempt to put the local budgets under the control of the national government, as actually happened with the Community Care and NHS Act enacted in 1993. The new budgetary system failed to prevent cost increases as the responsibility for funding residential care passed from local and health authorities to the national social assistance budget; local and health administrations were also asked to split commissioning from providing, delegating the latter to private care providers. The consequence was a financial disaster as local authorities and hospitals shifted responsibilities for funding residential and nursing care to the social assistance budget and a private market in residential and nursing homes quickly developed in response to this new funding opportunity, as Glendinning showed in Chap. 9.

Over the following years, a labour-led government introduced more financial constraints and did not seem able to reform the LTC system, although older peoples’ organizations, regulatory bodies and Parliamentary committees called for increasing resources to be allocated to long term care. As a consequence of this political inertia, proposals for funding reform tended to focus on accessing some of the income and/or wealth held by older people, complemented by very limited additional contributions from general taxation. Over the same period, there was extensive marketization in the provision of care services (both residential and domiciliary). These have been almost entirely transferred from the public sector to third-sector charities and for-profit organizations, with individual service users increasingly expected to exercise consumer choices over the purchase of their own support. The lack of basic changes to

the entitlement structure of the long term care system has therefore been exacerbated by organizational measures aimed at cost-containment and more efficiency in care provision.

In the countries characterized by a residual LTC care regime at the beginning of the 90s, the most important pressure came from the huge rise in demand for care, associated with the increase of the costs of social assistance programs funding the delivery of residential and home care services. In comparison to the universalistic care regimes, the entitlement structure of the care system in these countries was much more challenged as the degree of development of care services was much lower than in the former countries' care regimes. The increase in the demand for care was initially matched by social services managed at the local level. This happened in Germany, where the increasing high costs for residential care provided at local level was the main incentive for introducing a radical reform in 1995. Spain, Italy and Austria experienced the same situation, as the responsibility concerning care services provision and funding had been entirely delegated to local authorities since the 1970s or the 1980s. However, the residual nature of social care programs, mainly provided on the basis of means-tests and highly restricted to specific kinds of patients, contributed to increasing the health costs as hospitals and health territorial services were increasingly seeing dependent people asking for assistance.

In Austria and Germany in the 1990s, and in France, Spain and the Czech Republic in the last decade, local administrations faced financial difficulties, which, coupled with an inability to extend the provision of care services, stimulated the search for new policy solutions that involved a national or regional financial responsibility. The shift from local to regional or national responsibility was perceived as a necessary precondition for any possible change in this policy field. Neither accommodation of the existing programs was seen as possible (as it happened in the Nordic countries), nor alternative cash-based measures were already in place to temper the lack of care provision (as it was the case in Italy). The policy crisis therefore came to a crucial breakpoint, paving the way for a general, radical reform.

In this situation the main problem for all these care regimes was to find a way to finance a new national long-term care program, large enough to respond to the care needs of the dependent, without exploding the public finances or raising taxes. The reluctance to increase taxes played an important role in the delay of any political decision in many countries, such as France, Spain, Italy and the Czech Republic, in spite of the huge public discussions taking place about the need for reform in this policy field. From this point of view, the timing of reforms in different countries is important: Austria, and Germany introduced reforms during a period when fiscal constraints were less strict, both in terms of debt and deficit. France, the Czech Republic and Spain started respectively to discuss or to implement new programs in the second part of the last decade when their financial situation got worse: with deficits between 2008 and 2010 respectively of 6, 4.3 and 8.3 %, reforms and their implementation became a more complicated task, as illustrated in the chapters on these countries.

Specific conditions, moreover, paved the way for reform. In Germany and Austria, the strong family solidarity that is a particular trait of these countries allowed a

reorganization of the care system, under a new nation-wide program, that included the family care provision within a broader public care system, therefore lightening the financial burden for the public budget. In Spain, the strong activism of some regional governments in the previous decades was a good resource in the creation of a new LTC system strongly based on the decentralization of financing and responsibility, with the state assuming only a complementary financial role. Furthermore, in France, the APA reform was based on a mixed funding system, to which both departments (local authorities) and the State contribute.

Italy is the only residual LTC care regime characterized by institutional inertia in terms of reforms. What happened in LTC mirrors a more general landscape of the Italian welfare state as almost “frozen” (Naldini and Saraceno 2008). A pertinent reason for this situation is the fiscal constraint: the huge public debt has forced Italy to be cautious in proposing new expansive LTC policies. Moreover the existence from the 1980s of a cash-based program, the “Indennità di Accompagnamento”, providing a limited amount of resources to LTC beneficiaries but universalistic in nature, functioned as a buffer, especially because, thanks to its automatic institutional mechanisms, it was progressively extended to slightly meet the increasing demand for care. In the last decade, more than one million Italian dependent people were in receipt of this cash-based benefit, which substitutes the lack of service provision and is mainly used to support family-based care arrangements.

13.5 The Contents of Reform over the Last 20 Years

Almost all the countries studied went and continue to go through transformations in their LTC systems thanks to either changes in their institutional arrangements or changes in other policy fields, which have an impact on the sector. Table 13.4 tries to synthesize the various reforms. In doing so, it frames the more recent reforms in a longer time span in order to understand what happened, on one hand, taking into consideration what has been written in previous sections on the period before the 1990s, on the other, in more recent years during the implementation of the main reforms where they have taken place. The idea of looking not just on the main reforms but also to frame them within a longer time span is useful in order to better comprehend the transformations in LTC policies. Let us look first at LTC universalistic countries.

As outlined by Meagher and Szebehely, since the beginning of the 1990s, Sweden has gone through significant changes not directly related to the institutions of LTC, but in more general settings: from the Adel reform and the Disability Act at the beginning of the 1990s to tax deductions on household services and personal care in more recent years. Such changes, coupled with the introduction of market practices and rationalization of elderly care provision over the last two decades, have resulted in a retrenchment in overall LTC coverage for older people. Something similar was attempted in the Netherlands through different reforms (from the one concerning health-care to the Social Support Act, and also through different forms of cost-containments in relation to co-payments and limiting access to AWBZ). However,

Table 13.4 LTC reforms in Europe, 1970–2012

Country	Situation in 1970–1980	Main reform since the 1990s	Other reforms following the main one (if present)
Sweden	Universalist regime	None	Disability Act (1994) Rationalizing elderly care: falling coverage (since 1990s) Adel reform (1992) Municipal Act (1992) Introduction of market practices (1991–2010) Tax deduction on household services and personal care (2007) Re-centralization (1990s) Restructuring (e.g. “Common Language” (1998); “Free choice” in home-care (2002)) Health-care reform (2005) Restructuring and retrenchment reforms (since 1990) (e.g. cost-containment; de-institutionalization; co-payments; limiting access)
Denmark	Universalist regime	None	
The Netherlands	Universalist regime	None	
England	Semi-universalistic regime	None	Personal budget (1995) Marketization of service delivery (since 1990) Social Support Act (2007) Community care reforms (1990s)
Austria	Residual regime	The Cash-for-Care Reform (1993)	Consumerist initiatives (direct payments and personal budgets; 2000s) Cost-containment policies (since 2000s) Support for informal care (since 1998) Regularization of migrant care (2007)
Germany	Residual regime	The Care Insurance Reform (1994)	Cost-containment policies (since 2000s) with an increase in benefits in 2008 Complementary Nursing Act (2002)
France	Residual regime	APA (2002) with previous experiments (PSD—1997)	Ongoing discussion on the role of private LTC insurances vs. a ‘fifth’ pillar
Italy	Residual regime	None	Piecemeal regularization of migrant care work (since 1990s)
Spain	Residual regime	Dependency law (2006)	Slow and fragmented implementation of the new care system
Czech Republic	Residual regime	Act on Social Services (2006)	Several adjustments (soon after the reform)

the results were closer to restructuring and real retrenchment failed (see Da Roit, Chap. 5). Denmark seems the case where minor reforms were undertaken at the national and at the local level in order to improve and restructure the LTC system, rather than to shrink or to expand it. Experiences such as “Common Language” (1998) and “Free choice”, which were aimed at introducing standardization and rationalization in home care, seem to have had more of an impact on how services are provided than on the level of public coverage and funding (see Burau and Dahl, Chap. 4).

Despite numerous official reports, England has failed to introduce major explicit changes to its long term care funding arrangements. The community care reform of the 1990s (with the introduction of quasi-markets) and the consumerist initiatives of the last decade (the introduction of programs such as Direct Payments and Personal Budgets) seem to have played a bigger role in the intellectual debates about the regulation of LTC than promoting higher needs’ coverage: the overall result has been, in any case, a retrenchment in coverage (see Glendinning, Chap. 9).

Among the countries characterized by a residual care regime, five introduced major LTC reforms and programs in the last two decades: these are three continental countries (Austria, Germany and France), Czech Republic and Spain, all of them (old or new) Bismarkian welfare states. All these reforms were aimed at expanding LTC coverage.

As indicated by Oesterle (Chap. 8), 1993 represented a major turning point for the Austrian long-term care system: a Federal Long-term Care Allowance Act and nine Provincial Long-term Care Allowance Acts introduced a cash-for-care system. In addition, the agreement confirmed provincial responsibility for social service developments. Finally, the central level took responsibility for developing a system of social insurance coverage for family carers. The care allowance system aims to enable chronically ill people to stay in their own homes, at promoting autonomy and free choice of care arrangements, at supporting informal care provided in the family and at creating incentives for consumer-driven community care development. On average, in recent years, recipients of the care allowance account for about 19 % of the total population 61+, and for about half of the total population 81+.

With the introduction of the Long term Care Insurance in 1995/1996, Germany established a universally oriented, long term care scheme at a central level to provide support in situations of care dependency valid throughout the whole country. The introduction of the Long-term Care Insurance resulted in a considerable expansion of the available funds—with € 15.94 Billion within the framework of the social Long-term Care Insurance and € 2.10 Billion within the framework of the private Long-term Care Insurance in 1997 (see Theobald and Hampel, Chap. 6). Since the end of the 1990s, the French LTC system has been mainly organized around a specific allowance. Thus, after a period of local experimentations (1995–1996), it consisted of a “cash for care” scheme, initially targeted to the more dependent and economically disadvantaged, and opened to all frail elderly people in 2002. The 2002 reform, which created the ‘Allocation personnalisée à l’autonomie’ (APA—‘personal allowance for autonomy’), represents the main turning point in the policy framing process. The number of recipients rose drastically from 150,000 in 2001 to 1,185 million in 2010 (see Le Bihan and Martin, Chap. 7).

As indicated by Cabrero and Gallego (see Chap. 10), Spain introduced a law for the Promotion of Personal Autonomy and Care for Dependent Persons (otherwise known as the Dependency Act), which came into force in January 2007. It is a system of universal social protection which is financially limited and subject to strict rules of cooperation, as well as some degree of institutional rationalization and coordination. The new system of social protection has had many effects: the extension of public coverage; the creation of social services employment; the broadening of the combined public network of social services; advances and tensions in cooperation between regions; innovative uses of social services; and attempts to develop cooperation between social and health services. The Czech Republic was the first CEE country to establish a new long-term care system in 2006 with the promulgation of an Act on Social Services. Apart from other relevant changes (social services on a contractual basis, establishment of standards for their quality, redefinition of existing services and legal grounding of some new services etc.), a new care allowance was introduced. The level of this care allowance is tailored to the extent of dependence (four levels) and enables people to pay for the required assistance and support, provided by family members or other informal carers or by professional care providers. It is given to individuals over one year of age who are dependent on the assistance of another individual for activities related to their own person and independence (see Barvíková and Oesterle, Chap. 12). The benefit is not means-tested and it is financed from the state budget through taxes.

The fact that there were ‘major’ reforms in only some countries does not mean either that in the other countries with a residual care regime nothing happened or that, once reforms took place, nothing happened afterwards. In Italy, an extensive cash-based program (*Indennità di Accompagnamento*) was introduced in 1980, followed in the 1990s by a relatively strong debate about the need of a comprehensive LTC reform in order to expand public service provision and funding. However, Italy proved unable to radically reform the system, notwithstanding many attempts and broad and intense public discussion. Since the end of 1990s, the only intervention has been the regularization of migrant care work. Even if some other minor reforms were introduced (in 2007 for instance a “National Fund for LTC” was created but its financial assets were quite limited and down to 400 million Euros per year), the system seems to be shaped more and more around informal and migrant care work (see Costa, Chap. 11).

If minor changes were to be expected in Italy, it is noticeable that minor changes happened also in the residual countries that had recently introduced major reforms. These minor changes appear to contrast with the previous (expanding) reforms and, even if not of the same magnitude, they represent some sort of retrenchment: in general, different forms of implicit cost containment policies have been implemented.

In Austria there have been some cuts and changes in the definition of benefit levels and the tightening of eligibility criteria for some benefit levels. Moreover benefit levels have not been adjusted to inflation for many years: as a consequence, the “no changes” policy has significantly decreased the purchasing power of the benefit by almost 20 % over a 15 year timespan. In Germany, a similar process happened, at least until 2008, when an increase in the level of benefits was decided:

before 2008 the non-adaptation of the benefits to the increasing service costs led to a loss in purchasing power of 18.8 % and to an increase of beneficiaries resorting on social assistance benefits.

In France and Spain, given the fact that the reforms were quite recent, there has been no room for minor transformations afterwards. The debate taking place in France is complex to detect. Since the Presidential election in spring 2007, a new reform was announced as imminent, but in fact was systematically postponed during the five subsequent years. The last government reports published in June 2011, after a vast consultation of the different main actors, present three main scenarios without supporting any of them officially: to consolidate the current APA system (in order to reduce the private costs for the users); to define a new branch of the social security system (option of universality); or to introduce a new system based on a compulsory private insurance. In Spain the implementation of the 2007 reform has been very slow because of the difficulty of involving regional governments in the financing and in supporting the development of new home care and residential services at the local level; as a consequence, care services are still very poor while cash-based benefits spread over, paving the way for the growth of an extensive provision of care by migrant care workers. The implementation of the LTC law was also territorially “unequal” distributed because only some regional governments have invested with intensity following the spirit of the law, while others have not.

In the Czech Republic, the care allowance program was adjusted several times in the years following the reform of 2006–07. In essence, the amount of the allowance was reduced for individuals in dependency levels I and II aged 18+ and increased for persons under the age of 18. Therefore it went in a direction that lowered the coverage for older people, especially for those who were not particularly frail.

13.6 The Politics of LTC Reform: Actors and Coalitions

13.6.1 Social, Economic and Political Actors

As with other complex policy arenas, the LTC policy arena is characterized by a multiplicity of social, political-institutional and economic actors. Among the social actors, the associations representing frail older people and individuals with disabilities are the key ones. Trade unions, entrepreneurs’ associations and care providers associations are the main economic actors. Political parties with different ideological orientations, local and national governments, are central amongst the political-institutional actors.

In comparison with other policy fields, LTC suffers from a deficit in organization and direct representativeness of its main stakeholder: the older population (Taylor Gooby 2004; Bonoli 2005). In most of the countries analyzed in this book, the users’ organizations represented the interests of adults with disabilities, while dependent older people were commonly represented, not necessarily with specific attention,

by trade unions or political parties. In some countries, like Italy, trade unions organized specific branches of their organizations devoted to aggregate and represent the retirees. But the political influence of such sub-organizations has been very weak and was subordinated to the mainstream interests of workers, still the “core stakeholders” of trade unions. The only exception is Denmark, where a specific interest organization of older people—DaneAge (*Ældresagen*)—mobilized to safeguard and expand the user rights of its membership.

If this field is characterized by a political weakness of the main recipients, other actors have played a central role in the innovation process. On the demand side, a major role was played by the organizations of adults with disabilities. These groups have been quite influential, especially in universalistic care regimes, where they had long supported the progressive evolution of welfare services. In the 1990s, they started to mobilize in order to obtain more services and a clearer recognition of social rights for those whom they represented. The capacity of these groups to aggregate the demand of a higher educated population was striking in respect of the latency of trade unions and traditional welfare advocates. In many countries all over Europe, disability rights groups were able to open up public discussions about their needs and rights through demonstrations, strikes, public events, circulation of information about the impact of disability and the aspiration of disabled people to welfare and independence.

In Sweden, the 90s saw the emergence of a strong disability rights movement, which played a critical role in promoting the prioritization of support for people with learning disabilities. Other groups advocated for adults with extensive physical disabilities. The active political role played by these groups helps to explain why the priority in long-term care policies in Sweden shifted from care for older people to services addressing the needs of adults with disabilities. In the Netherlands, the increasing visibility of users’ organization represented one of the most important developments in the structure of organized interests in the field of care in the last 20 years. Similar groups also activated in England, in Austria and in France. In the Czech Republic, along with the clear deficit in organization and direct representativeness of the older population, the representatives of people with disabilities were very active during the preparation of the draft bill on social services. As a result, the adopted legislation particularly reflected the interests of this group of users, sometimes to the detriment of patients with internal or psychiatric disorders (including dementia) and sensory disorders.

Other active and influential interest groups in the reform process were social services providers and their representatives. In many countries, social partners were also quite influential actors: trade unions in particular campaigned in order to introduce reforms expanding social rights in the field of LTC policies or tried to resist retrenchment policies. In addition, enterprise representatives in many countries, also did not oppose reforms. On the supply side, innovation was supported by care service providers, which played a relevant role in countries with a residual care regime like Austria, Germany and Spain. In the Nordic countries, the predominance of public-managed services prevented providers from organizing independently, while care and social workers were aggregated in specific unions advocating their interests. In

England, care professionals and the associations of private (for profit and charitable) care providers were relevant players in the 1993 reform, while groups representing people with disabilities lead efforts to introduce the new cash-for care programs. In Austria and in Spain, finally, private and nonprofit providers were involved, together with disability groups and local governments, in national bodies designed to set the stage of the long-term care reforms introduced in these countries.

Generally speaking, the role played by service providers in the reform process was based on a twofold interest: if on the one hand they supported new public programs draining more financial resources to the field, on the other hand they resisted the introduction of competition and free choice, considered as a way to shift responsibility and control from care suppliers to recipients. Only private providers, as new entries in the field, supported the introduction of quasi-markets in order to lessen the monopoly and the privileged positions of traditional care providers (usually public or nonprofit organizations).

In many countries, therefore, care recipients and care providers were on two opposite sides, claiming for regulatory settings that contrasted with the interests of the others. It is, however, unquestionable that the leading role was played by disability groups in the last two decades. As we already explained, their ideological orientation to independence and free choice at the same time mirrored the NPM claims for more efficiency and accountability, favoring the introduction of market mechanisms and welfare pluralism in the care delivery system, promoting flexibility and user-led innovation rather than professionalization and higher quality standards. In spite of their juxtaposed cultural and political orientations, NPM supporters inside political parties and governments and disability groups converged together in demanding a shift of responsibility from care professionals and service providers to individual users. The creation of quasi-markets and the recognition of the users' freedom to choose were the two main regulatory instruments introduced in order to achieve these results. In countries with a strong familistic culture, such as continental Germanic and south European countries, this new vision of care was considered as a good way to recognize the relevance of family solidarity and to support family-based care arrangements. If disability groups were therefore the winners in this process, traditional service providers resisting against welfare pluralism in the name of their high quality standards and care workers arguing for a better recognition of their profession, were the losers, with a few exceptions.

As far as what concerns political actors political parties did not usually play a major role in fostering reforms. As a matter of fact, reforms in many countries were promoted jointly by left-wing and conservative governments or the switch from a government with a specific orientation to another with a different one did not hinder the pace of transformation. This happened both in countries where a LTC expansion took place (e.g. Germany, Austria and the Czech Republic) as well as in countries where restructuring or retrenchment have been at work (e.g. Denmark, Sweden, England). In Germany, for instance, the Reform of 1994–1995 was passed by the Christian-Democratic and Liberal Government, with the Social-Democratic party also in agreement. On the contrary, in Sweden, the NPM-orientation of many Social-Democrats in the 1980s paved the way to retrenchment reforms of centre-right

governments over the last two decades. In England, the marketization approach by the Tories during a good part of the 1990s was not reversed by subsequent Labour governments. In the Czech Republic, there were no clear political and ideological positions with regard to LTC: in 2006 the final version of the Act on Social Services was passed by MPs across the political spectrum.

If political parties did not differentiate among each other in the majority of cases, other aspects of the State functioning played a relevant role. The innovations often occurred within a specific multilevel governance structure of the care systems. We have already described the relevance of local authorities in the provision of care in most of the countries analyzed in this volume. Local authorities and regional or provincial governments have played an important role even in the reform process. As the primary accountable bodies for care provision, these institutions had been experiencing a heavy financial burden for many years until the 1990s. In the early 1990s, a broad re-centralization process started up in many countries, limiting the financial autonomy of local governments, fixing budget ceilings, and stopping the State funding of local programs. The interest in innovation by local authorities retaining responsibility in LTC was therefore clear, and explains why local authorities and provincial/regional governments were very often actively involved in the reform process. Reforming LTC programs was a strategic means to rescale welfare responsibilities and more generally to renegotiate the State-local authorities. Innovative reform was introduced exactly in the interplay between state and local governments and was favored by the multilevel structure of LTC provision (Kazepov 2010).

The main interest of local and regional governments in this process was to retain responsibility in the service delivery and regulatory autonomy, and to shift part of the financial burden to central levels at the same time. National states, for their part, were trying to increase their central control by introducing a more restrictive regulation about care provision and funding. Negotiations between these two different positions were in place in almost all the countries analyzed here. In all the countries, nevertheless, the State had to take greater responsibility in LTC than it had before the 1990s. In the last two decades, all the relevant reforms or incremental innovations here considered were introduced at the national level, fixing specific national thresholds for entitlements and provisions, setting particular regulations, or introducing financial responsibility on the part of the state. Local authorities and regional governments still take an important part in regulating and delivering services in the renovated LTC systems. But national states play today a stronger role than before, taking more financial responsibility and restricting the autonomy of local governments. If the previous LTC systems were characterized by the central states playing a subsidiarity role while the local authorities took the core responsibility for funding and delivering care services, now this vertical subsidiarity system has been overcome by stricter budget controls applied by national governments, new steering regulation by central governments, or direct provision of benefits by central states. In exchange for their greater financial investments in LTC, central states have assumed a stronger control on the care delivery system. Welfare rescaling in this field has meant re-centralization of responsibility at the national level, with local authorities and regional/provincial governments in a complementary position. From a subsidiarity role of the state, we have moved to a new form of state centralism and regulatory power.

13.6.2 Residual and Universalistic Care Regimes: Different Coalitions at Work?

Innovation was the result of interactions between the variety of actors involved, and their main orientation and interests. Reforms or incremental transformations were carried out by specific coalitions and were opposed by other actors (Sabatier 1988). The roles played by the various actors and their relationship in these innovation processes have been quite different according to the care regime. In two of the three universalistic care regimes, Denmark and the Netherlands, the constellation of interests supporting the status quo was very strong. Service providers, social workers and users' organizations were strongly organized as a welfare advocacy coalition. The high level of integration of the LTC policy community resisted against any attempt to frontally attack universalism and social citizenship. Political consensus was also grounded on the diffusion of a solid knowledge of social rights among citizens. In this situation, characterized by impracticality of radical changes, cost-containment concerns were focused on the regulation of the social care system. In these countries, innovation was focused indeed on introducing or strengthening market mechanisms, recognizing freedom of choice, standardizing social care provision, limiting public funding, and focusing social care services on their core functions. The actors leading this process were the new epistemic community organized around the values of NPM and the organizations representing adults with disabilities advocating for flexibility in social care and the empowerment of citizens.

In Denmark, the most relevant action for change came from State attempts to obtain a stronger steering capacity in respect of local authorities. Innovation was focused on regulation and implementation rather than on the redefinition of social entitlements. The NPM ideas were introduced without an open public discussion about the general meaning of free choice and its implication in terms of social rights and redistributive impact, but only on its practical implications (the number of social care providers, the definition of quality standards, the fixing of prices for service delivery, and so on). Managerial and accountability questions predominated in the policy field, in a context still characterized by high consensus about the benefits of universalism and the principles of NPM. Social democrats as well neo-liberal and conservative parties shared this perception of absence of conflicts between these two visions. Trade unions and employers organizations—the traditional constituencies of the Scandinavian welfare state—played a minor role in this policy field. In the Netherlands, the organizations representing people with disabilities became the most important allies of the national government in the attempts to restructure the LTC system and reduce its costs, via de-professionalization, enhancement of informal care and the introduction of customer-driven interventions. Even in this country, however, universalistic principles were not opposed and innovation was more focused on introducing a new public regulation. Cost containment strategies were strongly driven by the national governments together with the establishment of new measures—such as the Personal Budget—granting users some autonomy in the definition of the services to be provided. Local-national relationships were also restructured in this process.

In Denmark, the steering role of the State was strengthened while the financial autonomy of local authorities was placed under stricter central control. New regulatory mechanisms were enforced by the State in order to limit expenditure and restrict service delivery. A stricter standardization of care services was also established in order to focus the supply of care to its core functions and to limit decision-making at the local level.

In comparison with the two former countries, Sweden followed a slightly different path. Three types of actors were particularly relevant in this case: political parties, associations for people with disabilities, and entrepreneurs' associations. Moreover these three actors were able to build a strong and coherent coalition for reform. The role played by Social Democrats was important in facilitating this coalition, especially under the influence of economists inside the ranks of the party; as Meager and Szebehely show in Chap. 3, the process of legislating for market reform began in the mid-1980s under a Social Democratic government, which established initiatives to promote competition in the public sector, with the goals of increasing efficiency and quality. In the same years, the Social Democratic party started viewing the public sector as a part of the problem, not the solution. Once Social Democratic parties positively embraced NPM reforms, it became harder for them to criticize strong marketization reforms by Conservative governments. The different ideological and political approaches to NPM seem to be the main differences between the Danish and the Swedish Social Democrats: the latter were more intent than the Danes on reforming the LTC system through marketization (Green-Pedersen 2002). Furthermore, more so than in Denmark, Swedish Social Democrats and Conservatives agreed on the necessity to restrict the public budget for social care and to limit the supply of care services. Associations advocating on behalf of both children and adults with disabilities also played a major role, especially thanks to their strong ties with Liberal and Conservative parties: they reinforced a "freedom of choice" anti-professional service orientation which helped to raise doubts about the traditional approach to welfare service provision. Also, the main employers' organization, the SAF (Swedish Employers' Confederation), began a strong neo-liberal attack on the welfare state in the 1980s, arguing for market mechanisms and privatization of public services. The SAF's propaganda efforts included sponsoring market-oriented think tanks.

To sum up, in universalistic care regimes, the traditional welfare coalitions were still very strong and did not allow an open discussion of the failures and weaknesses of such care regimes. Under the pressure of cost containment, national governments acted in order to limit social expenditures at the local level by re-centralizing the organization of the care system. This orientation was shared by both right- and left-wing parties with only marginal distinctions. Innovation was focused on regulation and did not explicitly address the issue of social rights and inequalities. Thus, central governments found an unexpected ally in the organizations representing people with disabilities, which became strong and active advocates of a new, flexible and user-driven care system.

In the semi-universalistic LTC care regime of England, the role of organizations representing young and adults with disabilities was almost as relevant as in the universalistic regimes. Over the last thirty years, and particularly since the early 1990s,

these organizations advocated for more freedom of choice, control and flexibility: a good part of the discussion in the LTC arena has been centered on these types of issues. This approach was reflected in successive governments' attempts to tackle long term care pressures mainly through regulatory innovation (Direct Payments, Personal Budget, etc.), while serious prospects for reforms in the levels and distribution of resources for long term care were avoided. Moreover, advocacy organizations' preferences for cash programs already in place prevented them from supporting any serious reform proposal. However, these actors also strongly opposed any attempt to introduce reforms aimed at including the traditional cash programs in a broader, renewed LTC program. The interests of the insiders were therefore used to build a new care system providing adequate care for the older people. The strong fragmentation of the policy field also hampered any attempt to create agreements among the parties. In a care system characterized by a multiplicity of LTC programs, captured by different users with specific interests, coalition building proved to be very unlikely. Moreover, the absent neo-corporatist tradition hindered political effort from moving in this direction, with a bigger role played by social partners.

In residual care regimes, the coalitions leading the innovation process were very different. The role of the associations for people with disabilities was less relevant in these countries, with the exception of Austria, the Czech Republic and Italy, and was to some extent the reverse of that of their equivalents in the Nordic countries. Much of the public discussion about LTC developed at the national level and required a stronger, more direct intervention from the national governments. Local authorities were broadly supporting this centralism in the reform as they wanted to discharge part of the financial burden that had been part of their remit until the 1990s. In Spain, the LTC reform enacted in 2007 assigned a shared responsibility in financing to both the State and the regions, leaving responsibility for delivery at the regional and local levels. In Germany as well as in France, the previous locally-based care delivery systems were largely substituted by new national measures for financing and regulation at the national level.

The active role played by national governments in residual care regimes is the product of a strong aggregation of multiple interests around a specific reform project. This happened in Germany, in Austria, in France, in Spain and in the Czech Republic, though not in Italy. In the former countries, with the exception of the Czech Republic, the reforms were strongly favored by a tradition of neo-corporatist agreements, involving not only the main political parties, but also traditional social forces as trade unions and employers' organizations. The final reforms gained a strong and broad consensus from opposite sides as they were the results of a protracted intermediation between the principal actors. The capacity to coordinate such intermediation was one of the main drivers of the institutional change taking place in LTC in these countries.

In Germany, the national LTC insurance scheme was established in 1995 by a coalition government held by the Christian Democratic Party and the Liberal Party (lead by Helmut Kohl), with the final agreement of the Social Democratic Party and of trade unions. The social insurance solution was adopted by both the main parties against other options carried out by minor actors. But the most disputed issue was related to the funding mechanism, namely, on which different options, ranging

from State taxation to a new contributory plan, were on the table. Trade unions and employers' organizations were deeply involved in the decision making process. After long negotiations, the abolishment of a bank holiday was accepted as a compromise between the unions and the Social Democratic Party on one hand, and the federal government and employers' organizations on the other.

In Austria, the policy formulation of the reform to be introduced in 1993 was delegated to several working groups involving disability organizations, trade unions, the main parties and local/provincial authorities. The strong corporatist structure of the representativeness system favored such an approach, which in turn made it possible to find a general agreement around a new national cash for care measure. This approach was supported not only by the Conservative Party and some provinces, but also by disability groups strongly advocating for the cash option. As Oesterle states in Chap. 8, political actors across the political spectrum have been in favor of a cash-for-care schemes even if for very different reasons, including support for family care, support for autonomy, for user-driven market developments or cost-containment. Lately, in 2007, most of the parties, with the exception of the right wing party, again supported the legalization of 24 h care workers. In Spain, finally, the reform was the result of a very complex negotiation involving institutional actors (regions, national government), political parties, nonprofit organizations, trade unions and employers' organizations, professional organizations. There is no evidence that users' associations played a relevant role in this reform process. While nonprofit providers and the trade unions proposed a finance system based on social security (following the German pattern), employers' organizations and autonomous regions advocated financing through taxes. The final compromise saw a dual system, by which the state finances part of the system and regional governments fund the rest (at least two-thirds) of the resources.

This capacity to build a general political agreement around a specific reform project seems to be crucial to distinguish between the situation of residual care regimes in which a reform took place in the last two decades from the only country where no change has been achieved: Italy. In Italy, the strong fragmentation of the policy field, as in England, hampered any attempt to create agreement between the various stakeholders. Moreover the landscape of the local governments was more complicated than in other countries: the contrast between the poorest regions of the South, requiring more financial intervention by the State, and the richer regions in the Northern part of the country, claiming for more regulatory autonomy, was one of the obstacles to the reform process. Also, the weaker neo-corporatist tradition hindered any political effort into this direction. The preference for cash programs already in place dissuaded many stakeholders, including trade unions and the disabled organizations, from supporting any serious reform proposal.

Overall, the composition of the reform coalitions playing a relevant role in residual care regimes was very different from the similar coalitions in the universalistic care regimes. In the former, the most important actors were nationally-organized neo-corporatist actors, supporting general interests including those of the traditional stakeholders of the welfare state. Trade unions and employers' organizations played a key role not only in the general support to reforms, but also in the discussions about

financing and delivering. The horizontal co-ordination of national neo-corporatist actors was also complemented by the vertical co-ordination of local, regional and national institutions. The multilevel structure of LTC favored a mutual adjustment process by which the re-centralization process was easily supported by both local and national actors. A distinction in the responsibility between funding, commissioning and providing was also introduced in such systems and eased the general agreements of all parties.

Finally, in the universalistic care regimes, and even in the residual ones, LTC reforms were not considered a partisan issue. Reforms were introduced by conservative as well as social democratic parties. Political turnovers did not endanger the previous reforms. Extension of entitlements and service provision on the one hand, and cost containment on the other, were goals shared among the different stakeholders. When conflicts emerged about the financing model to be introduced, the assumption of more State financial responsibility offered a good basis for compromise. That is why, with the relevant exception of Germany, all the LTC reforms were financed through taxation instead of social security. The coalition at work in the Czech Republic was partially different to the other ones seen in the traditionally residual LTC systems: experts from the Ministry of Labour and Social Affairs and other levels of the state administration as well as social service providers and users' organizations perceived the need to implement new legislation. Trade unions, employer organizations as well as regional and municipal administrative bodies only played a minor role in designing the reform.

13.7 Mechanisms and Forms of Institutional Change

Innovation taking place in the LTC policy field assumed different shapes in the countries here analyzed. In order to understand the mechanisms and forms taken by institutional change, we adopt the typology discussed in the first chapter proposed by Streeck and Thelen (2005) in their approach to evolutionary transformation based on incremental but cumulatively transformative changes. In particular we found three models of institutional change:

- a. Gradual transformation;
- b. Reproduction by adaptation;
- c. Breakdown and replacement.

In order to understand the complexity of such process, in the first chapter we proposed a basic distinction between institutional changes affecting welfare entitlements, and institutional changes that are related to the provision of benefits and the organization of care services (Dahrendorf 1988)—Social entitlements are directly related to encompassing policy goals (such as equity, social citizenship) or paradigmatic tensions (such as universalism vs. residualism, centrality of the market vs. centrality of the State, etc.): changes in the definition of entitlements can be understood, following the well-known typology of policy changes proposed by Hall (1993), as “third order

policy changes” affecting overarching policy goals. Provisions must comply with entitlements, but they also depend on specific regulations and the organization of the care delivery system; changes affecting provisions can be understood as “first” or “second order policy changes” according to Hall (1993), namely, changes related to specific policy instruments and their setting. First order changes are related, for example, to measures increasing/decreasing contributions, or lowering/increasing benefit levels. Second order changes can be considered as new rules for calculation of benefits or to control the access to specific welfare benefits, and policy instruments aimed at introducing new forms of care delivery.

Thus, it can be seen that LTC policy changes in the countries analyzed here can basically affect two aspects of LTC systems: first, they may change the existing balance/stability between policy goals (entitlements) and policy means (provisions) through either the introduction of new entitlements (third order policy change) or recalibration of provision indirectly affecting entitlements (second order policy change); second, it has introduced innovation in the policy instruments, through replacement of old instruments with new ones (second order change) or a re-shaping and recalibration of the previous ones (first order change).

In order to understand the relevance of these changes, we look at two aspects of policy innovation: first, we consider the forms of institutional transformation and the process that has been in place; second, we assess the impact of these processes in terms of continuity/discontinuity in respect of the previous situation. This section is devoted to the analysis of the institutional process, while the next section will discuss the main impacts.

Institutional changes took different shapes and produced different outcomes according to the care regime existing in the early 1990s. This differentiation in care regimes has proved to be very useful in understanding the direction and the shape of policy change. Universalist or semi-universalist care regimes have been characterized by either adaptive (Denmark and Netherlands) or incremental (Sweden and England) transformations, which were focused on policy instruments and regulation affecting the level and organization of provisions (first and second order changes), without altering basically the explicit goals of the care system. Only in Sweden and England has incremental change been able to implicitly reverse the (semi-)universalist orientation of the care system.

In universalistic care regimes, the pressure for cost containment was matched by adopting new administrative procedures and new regulation aimed at restraining the use of care services without explicitly challenging universalism of social entitlements. Denmark and the Netherlands have been characterized by “reproduction by adaptation” institutional change, where relevant transformations have not turned into third order policy change. This outcome is the result of different dynamics in each of the two countries. Denmark shows signs of first and second order policy changes from “below” (non-legislative change) and from “above” (legislative change). NPM regulation instituting the partial marketization of care provision was attached to existing institutions and free choice principles were softly introduced by establishing a new “users-centered-stage approach” giving individual users the right to express their preferences about care services. Even if market mechanisms and

Table 13.5 LTC regimes and types of institutional change in the last two decades

LTC Care Regime (early 90s)	Type of institutional change	First or Second order policy change (provision)	Third order policy change (entitlements)
<i>Universalist</i>			
Denmark	Reproduction by adaptation	Quasi-markets and Consumerism	–
Sweden	Gradual transformation	Quasi-markets and Consumerism	(Hidden) attack to Universalism
The Netherlands	Reproduction by adaptation	Quasi-markets and Consumerism	–
<i>Semi-universalist</i>			
England	Gradual transformation	Quasi-markets and Consumerism	(Hidden) attack to (Semi)-universalism
<i>Residual</i>			
Germany	Breakdown and Replacement	Tightening regulation on provision	LTC as a “universal” right
France	Breakdown and Replacement	Tightening regulation on provision	LTC as a “universal” right
Austria	Breakdown and Replacement	Tightening regulation on provision and migrant care worker regulation	LTC as a “universal” right
Spain	Breakdown and Replacement	–	LTC as a “universal” right
Italy	Gradual transformation	Migrant Workers regulation	–
Czech Republic	Breakdown and Replacement	Partially tightening regulation on provision	LTC as a (partial) “universal” right

consumerist approaches were introduced, rationing did not come into the picture: regulation was concerned with both ‘securing’ and ‘extending’ the welfare rights of citizens and, as a consequence, encompassed both measures of control and measures of choice/flexibility.

The Dutch LTC system has been undergoing a continuous process of reform in the past 20 years, which reflects an incremental approach to policy changes. Cost containment policies have been central and they have been pushed forward through a mix of first and second order policy changes: a series of tools have been introduced restricting the eligibility criteria in order to access public LTC, rising co-payments, switching from more to less costly forms of care, providing incentives to access informal and privately paid care as well as less costly alternatives to formal care. Cost containment was also pursued by adding new market-oriented measures (like the Personal Budget) in an attempt to replace more expensive in-kind service provision with cash for care. These attempts mainly failed thanks to appeals to the judiciary system: for instance an important court decision in 1999 clarified that Dutch residents had a “right to care,” based on the social insurance legislation and the government was held responsible for upholding this right, also against budgetary considerations. Some “seeds” of possible third order policy change in the future have been planted anyway. Da Roit (Chap. 5) suggests that potentially disruptive transformations can be produced by shifting non-core activities (home care) presently covered by the AWBZ to other fields of social protections (e.g. social assistance). Moreover, specific care needs of particular disabled categories (such as the patients with dementia) were also moved out from AWBZ to specialized health care services. This trend represents a qualitatively different development with respect to all previous reforms in the field, as it involves the redefinition of the boundaries of LTC.

England and Sweden share common features of a gradual transformation process through first and second order policy changes: in both countries, new rules on access to care services and new policy instruments were introduced in order to restrict public expenditures. These policies have turned out to have significantly changed, even though by an implicit process, the previous universalistic structure of entitlements and opened the way to a hidden marketization of the care system. It is valuable to notice that these policies were adopted not only for reducing the traditional public sector provision system, but also to shift the attention and the focus of the discussion in the public arena from (cuts in) public financial resources for LTC (through rationing) to the tools used to provide care (quasi-markets, choice, etc.). In both countries, left-wing parties participated in this transformation of their LTC systems, being either unable to reverse previous Conservative parties choices (as in England) or partly the promoters of market reforms (as in Sweden).

In England, a series of marketization policies has been pursued very consistently over two decades by different governments (Glendinning, see Chap. 9). In 1993, quasi-markets were introduced and a funding system boosting the number of private agencies providing residential and domiciliary care was established. In subsequent years, numerous attempts were made to control costs. However, all these efforts broke against the lack of interest of dependent people for cash-for care measures, and the strong opposition of specific constituencies to any reform aimed at replacing

old measures into a broader LTC program. The institutional fragmentation of the care system was a result of opposing specific interests and cultural orientations to a general change. Veto points and indifference therefore resulted in the care system remaining substantially untouched after more than two decades of discussions and experimentations. Meanwhile rationing became, since the mid-1990s, one of the main leitmotiv in LTC policies (e.g. the increase in the levels of needs required to qualify for local authority-funded social care; the lack of investment in services for people with lower level needs for help).

In Sweden, incremental change has been able so far to significantly alter the existing LTC system through first and second order policy changes aimed at rationing LTC expenditures and at introducing marketization of care. In this country the “gradual transformation” can be explained in terms of “layering” and “displacement” mechanisms and effects (Meagher and Szebehely, Chap. 3). Layering took place in the last 20 years, firstly, through a policy of rationalizing care for older people, actuated by a series of first and second level policy changes (e.g. a related shift from a more person-centered organizational model, under which each care worker was responsible for a small number of clients, towards a Taylorized ‘assembly-line’ model; the tax-freeze of the early 1990s for local governments; the deregulation of the fees municipalities charged older people for services; and the Ädel-reform which shifted responsibility for nursing homes from the health care sector to the social care sector). Secondly, thanks to the Disability Act of 1993, which separated provision for specific groups of younger disabled people only, creating a new ‘layer’ (and distinct constituency) in the social care system: because services under the Act are aimed explicitly at people under 65, this approach enabled the government to contain demand for costly services among another group with arguably similar needs (people with significant disabilities acquired after the age of 65). Displacement of the public sector came in through the marketization of the LTC provision system. Displacement and layering seem to have merged together in more recent years: the pace of marketization increased with the change of government in 2006, when new behavioral logics and new system dynamics were introduced through a sort of ‘Freedom-of-choice revolution’, encouraging municipalities to introduce customer choice models, with quasi-voucher system. Although the new private provision-based system has not replaced the old public provision-based one, a primary goal of the act is to promote the type of ‘differential growth’ that Streeck and Thelen (2005) argue is central to the system-changing dynamics established by institutional layering.

In brief, universalistic and semi-universalistic care regimes adopted mechanisms of institutional change that were based on incrementalism and mutual adjustment. The strategy of cost containment was pursued by altering the existing regulation and adding new measures to the old ones, without any explicit restructuring of universalistic entitlements to care (third order change). This approach was possible thanks to the fact that no potential conflicts were perceived, either by social democrats or by conservatives, between the need for cost containment and universalistic principles. Tensions and trade-offs were managed by introducing new regulatory instruments into the existing system and, especially in Sweden and England, through the incremental addition of new care measures, driving people to a more focused and targeted use of public care services.

Most of the countries adopting a residual care regime were characterized by a “breakdown and replacement” institutional change. Reforms were introduced at different times in each country, and explicitly affected the entitlement structure of the LTC system, therefore constituting a third order change in Hall’s terms. However, this radical transformation was immediately followed by incremental or adaptive changes (first and second order) aimed at recalibrating the new care system to emerging fiscal and cost-containment constraints. All these reforms were facilitated by a large debate at the national level, involving all the relevant political actors and social partners, in line with an interpretation based on an incremental social learning process, as described by Hall (1993).

In Austria, initiatives and debates about LTC started in the 1980s and finally led to a major reform in 1993. Three phases led to this reform. The period prior to 1985 can be defined as a period of problem definition. The second phase was the agenda setting period lasting from the mid 1980s till 1990. The third phase started after the federal election in October 1990. The new government defined the objective to develop a comprehensive nationwide system of social protection towards the risk of long-term care. Policy formulation was delegated to several working groups and was repeatedly pushed by manifestations of disability organizations, including a hunger strike. In 1991 and 1992, draft acts were sent out for opinions from experts, local governments and social partners.

In Germany the path to reform followed a similar process: the path that led to the 1994–1995 reform was a result of a long lasting discussion among a series of public and social actors. The LTC insurance scheme was an extraordinary innovation not only for Germany but also for all European countries, stimulating public discussions in many other countries. Nevertheless, it should not be forgotten that, in Germany as well as in Austria, the new design of the care system, with its focus on cash for care, was in perfect continuity with the traditional, familistic care culture that was dominant in these countries.

France followed a slower and more hesitant process. Since the mid-1990s, a series of steps can be identified in the creation of a specific public LTC scheme and the gradual broadening of the number of recipients. Initially, in 1994-1995, a group of local authorities were invited by the government to test a pilot program. In 1997, the government and the Senate decided to scale down the initial ambition of the experimentation and to adopt and implement a temporary national assistance scheme throughout the French territory—the ‘Specific dependency allowance’. Due to the many criticisms related to the PSD scheme, after a prolonged phase of “non-decision” in 2001, a new reform was introduced, promoting (a sort of) universalism. The new allowance, called ‘Personal allowance for autonomy’ (APA), is allocated to older people with high and middle dependency levels. This phase anticipated the big reform, established in 2001, through which the previous experimentation was extended and partially redefined. Even in France, the new measure introduced in 2001 recognized the social right of the dependent to be provided with care services. The same reform fixed specific national criteria for the needs assessment and the amount of benefits given in accordance to the level of disability.

Spain’s 2006 LTC reform was the accumulation and convergence of political and socio-demographic changes as well as consciousness-raising among the professional

classes, experts, and social actors. In 2001, the Policy for the Dependent fully entered the Social Dialogue Agenda between government, trade unions and employer organizations, paving the way for the introduction of a national program. The final reform in 2006 entailed a radical change through the breakdown of the old assistance-based system and its replacement with a universalistic system recognizing care as subjective rights for all citizens with dependency. Fundamentally the reform was the consequence of the accumulation of national and regional programmers, many being experimental and sporadic.

In the Czech Republic, the process towards the reform of 2006–2007 took more than ten years with only incremental changes to the system and with various attempts to implement more comprehensive social service legislation. The path that led to the reform was similar to the Spanish one. The reform debate and the direction of the changes were determined by demographic and economic factors and were inspired by concepts brought in by other EU countries LTC experiences: in particular, the care allowance scheme implemented with the reform was influenced by Austrian and German programs.

All of these countries therefore experienced a profound transformation in the care system, through which new responsibilities for funding and providing care, new regulatory settings, new forms of financing, and especially new entitlements were introduced. All these reforms appeared to create a discontinuity with the previous order, and therefore they were long discussed and prepared through a number of studies and local or national experimentations. A large political and social consensus was searched and found in order to establish these reforms, and to implement them. They were the result of national agreements among the most important national parties and LTC constituencies.

However, the implementation of these reforms after their official approval, or their maintenance in the following years, were not so clearly disruptive as the reforms first appeared to be. In Germany, right after the insurance fund was introduced in 1995, a large discussion started up about its financial sustainability. The financing of the reform through social contributions and an abolished one-day holiday put the new LTC system under cost pressure very soon, driving an open discussion about its reproducibility in the medium and long run. The amount of the social contribution had to be raised in order to keep the system in balance. But, over the last few years, cost concerns have brought the government to delay the adjustment of the benefits to inflation, so lowering the real value of care benefits. In Austria as well, cost-containment considerations have driven decisions not to adjust benefit levels by the inflation rate as Oesterle shows in Chap. 8. Opposition by disability groups and social service providers was not widely considered. In these two countries, nevertheless, entitlements have not been changed after the reform and only first order changes were introduced in order to guarantee the financial sustainability of the care system.

In France, Spain and the Czech Republic, difficulties and delays characterizing the reform process also followed the implementation phase. In France, the APA reform of 2001 has been placed under discussion and new public schemes supporting private LTC insurances could be introduced in the next years. In Spain, implementation of the 2006 reform proved to be very difficult as regional governments had different

propensities to develop a new care system. A similar situation took place in the Czech Republic. Consequently cash-based measures have been actually introduced rather than in-kind services in both these two countries, opposing the original goals of the reform and strongly depressing its potentially disruptive impact. The recent financial crisis seems to have left the implementation of the new LTC scheme out of the political agenda, seriously endangering its actual accomplishment.

Overall, in these countries, innovation occurred by means of a disruptive change, completely restructuring the previous care system on the basis of a new public scheme. New rights, more public money and new forms of service provision were indubitably introduced. The social and political consent was very high at the time when these reforms were accepted. However, the maintenance and implementation of such reforms have been much more difficult and less disruptive than expected. Cost containment concerns have driven governments either to moderate the amount of benefits (as happened in Austria and Germany) or to alter the reform implementation (as happened in Spain and the Czech Republic), or to change the system again (as seems to be happening in France). In the long run, reforms brought about sharp discontinuities in the institutional path of LTC systems, which have been followed by incremental decisions restricting part of the benefits, or delaying further planned developments. However, these further steps cannot be considered as the restoration of the previous situation, as an incremental process of adaptation has recalibrated the original reforms, resulting in changing financial and institutional situations.

Italy is a different case in respect of all the other residual care regimes as no reform in the care system has been introduced since the 1980s. There have been significant discussions and proposals concerning LTC, but no serious attempts to reform the previous system. Two facts have mitigated against any chance for change: first, the *Indennità d'accompagnamento* (IdA), a cash-based measure designed for the disabled according to universalistic principles, was extended to large part of dependent older people, therefore guaranteeing them a limited, but effective benefit. Second, the organizations representing disabled which were constituencies of such measure opposed any attempt to reform it. Notwithstanding the absence of an abrupt reform, a process of institutional change has taken place in Italy anyway, that can be explained as a “drift mechanism”, by which, according to Streeck and Thelen (2005), the neglect of institutional maintenance in spite of external change results in actual slippage in institutional practice: the missing recalibration of IdA has actually made this program the broadest LTC service used by an increasing number of severely dependent older people. It is interesting to notice that, in this case, contrary to how the concept has been used so far in the policy literature, the gradual transformation brought about through a policy drift went in the direction not of retrenchment but of an expansion of coverage. In the absence of national reform, attempts to reform LTC were taken at the local and regional level, through the introduction of quasi markets and complementary cash measures addressed to the most deprived dependent people. But the lack of funding and the high geographical heterogeneity of such policies have not significantly changed the situation. Lately, the development of a huge private and grey (migrant) care market has allowed Italian families to respond to their care needs, without any substantial public specific regulatory or financial intervention.

The legalization of such migrant care workers, established many times by the Italian government in the last years, confirms the profound political inaction in this policy field once again (as shown by Costa in Chap. 11).

Thus, it can be seen that Italy is the only residual country unable to introduce reforms in the LTC system. This substantive institutional inertia was complemented by high emphasis given to aspects of care regulation that were not effective in the absence of additional financial resources to be allocated in this policy field. The lack of public money and the reluctance of national governments to invest in this policy field, together with the absence of constituencies advocating for the needs of older dependent people, explain why in Italy the same problems which led to profound reforms in other similar countries, have not had any political solution so far.

13.8 The Impacts of the Reforms

One important aspect in considering LTC reforms in the last 20 years in Europe is their impact. However, the concept of impact or effect is quite complicated and needs to be clearly specified. According to Clasen and Siegel (2007) change in welfare state needs to be evaluated through a multiplicity of dependent variables: not only social expenditures but also measures that are related to social rights (Kangas and Palme 2007) and to the levels of generosity or conditionality of welfare programs. As LTC policies are characterized by a large gap between entitlements and provisions in all countries, both measures of expenditures and coverage on the one hand, and measures about the organization of the care delivery system (considering the impact both on professional services and on individual care workers) will be considered. Furthermore, as the needs of the dependent are still mainly met through informal caregivers, also the impact on the family care capacity has been reviewed. Therefore, our framework of analysis, together with the findings from the individual country case studies, allows us to differentiate between four different types of impacts:

- a. the impact in terms of *public expenditure and needs' coverage* (relative number of recipients, etc.),
- b. the impact on the structure and characteristics of the *LTC labor market*,
- c. the impact on the *regulation* and the *forms taken by provision in the field*,
- d. *the impact on the family care activity*.

13.8.1 Impact on Needs Coverage

Figure 13.1 summarizes the results of the cross-country analysis. As it can be seen from the graph, the results of the transformations and reforms are not unidirectional. As already outlined in Sect. 13.5, Germany, Austria, Spain, the Czech Republic and France experienced an expansion of coverage and public funding. Since the 1990s (or in more recent years in France and Spain), the total amount of beneficiaries has

*Retrenchment**Restructuring**Expansion*

 Sweden England Netherlands Denmark Italy France Czech R. Spain Austria Germany

Fig. 13.1 The impact of LTC reforms on coverage and public expenditure: retrenchment, restructuring and expansion

increased strongly and nowadays many more frail people do receive public help. In the Czech Republic, the increase in the total amount of beneficiaries has been mostly related to care allowances and not to formal service provision (residential and home care). The number of care allowance recipients significantly exceeded the legislators' estimates: 2005 estimates expected about 175,000 recipients, whereas in 2010 the average monthly number of beneficiaries was 310,006. However, to a much lesser extent than expected, recipients use their care allowances to purchase social services: older people often seem to consider the care allowance as a simple supplement to their pension compensating for worsening health conditions (see Barvíková and Österle, Chap. 12).

However, after a first wave of expansion, Germany and Austria introduced mechanisms slowing down the pace of growth in their LTC programs. As already underlined, cost-containment issues in relation to sustainability of the reforms continuously worked as a limiting factor: a set of tools were introduced in order to limit costs. In Spain, the policy making in the implementation phase has been not only adaptive but has introduced a gradual transformation of the original goals, substantially reducing the universalist orientation of the reformed system. In France, a public discussion has opened up in order to introduce a second LTC pillar based on private contributions, so challenging the original universalist orientation. In the Czech Republic, provision levels have been partially reduced for less in need beneficiaries.

Italy can be seen as a case of "expansion as a perverse effect of institutional inertia". Even if no reforms were introduced and the changes to the institutional arrangements of the system were very limited (apart from the regularization of migrant care work), there has been a strong increase in coverage, mainly thanks to the growth in the amount of beneficiaries of the principal cash-for-care program (the "Indennità di accompagnamento"): in just a few years the percentage of older people receiving the IdA increased significantly, from around 6 % in 2000 to around 11 % in 2011. This expansion was partial and related only to a cash program and not to services and also because the amount of benefits is very poor and was not related to dependency levels (see Costa, Chap. 11).

Denmark is arguably a case of welfare restructuring aimed at rationalizing the system. Since the 1990s, LTC policies have included elements of both control/standardization and flexibility/choice. This has led to substantial changes in terms of the organization of long-term care, through the introduction of market mechanisms and the tailoring of services to meet individual needs (through consumerism), in order to respond to the complex needs of a more individualized society (see Burau and Dahl, Chap. 8). However, levels of coverage and public expenditures were left untouched.

The Netherlands present a mixed picture. Several incremental reforms have been introduced: a set of different measures explicitly aimed at containing or reducing

the costs of the LTC system, increasing the power of the users and redistributing the responsibility for LTC between the public and private sector and also across the public sector more broadly. As previously shown, despite all the attempts of limiting the access to the AWBZ benefits, formal care provided through the national insurance system remains the pillar of Dutch LTC system. There is no evidence of a reduced accessibility to the system and of the substantial substitution of formal care with informal and market care. Possibly the most disruptive transformation introduced in the system is the shift of part of the risks covered by the AWBZ to other fields of social protection. Since the early 2000s the idea has become dominant that, in order to be sustainable, the AWBZ should go back to its “core business” and leave the coverage of complementary interventions to other policy domains. This trend represents a qualitatively different development with respect to all previous reforms in the field, as it involves the redefinition of the boundaries of LTC, outside of which the logics themselves of social protection differ significantly (see Da Roit, Chap. 5).

England and Sweden, to a larger extent, represent two cases of LTC policy retrenchment. In England, the coverage of publicly-funded adult social care, including for older people, has contracted significantly in the last 20 years (see Glendinning, Chap. 9). Intensive home care services are provided only to those with the highest levels of need: many people are excluded altogether from publicly funded residential or domiciliary care because of modest levels of assets and/or income. With the introduction of quasi-markets, care services have become more fragmented and personal budgets shift responsibilities for managing resources and risks onto individual older people and their families. At the heart of this failure is the challenge of finding a politically acceptable way of driving more money into the social care system. Over the past 20 years, the publicly-funded long term care system with a semi-universalistic orientation has shifted closer to a residual, safety-net only for the poorest older people with the very highest levels of need (and without families to provide essential daily care). The Swedish LTC system has also changed significantly during recent decades. There has been some *retrenchment* in eldercare, evident in reduced public spending, falling coverage and stronger targeting on people with higher levels of need. This development has led to the *informalization* of care for some groups of older people, as services, that for a previous generation would have been available as public services, must now be provided by family members, as well as to the de-commodification of care as a private care market is emerging to fill the gaps of public and family-based care provision (see Meagher and Szebehely, Chap. 3).

13.8.2 Impact on LTC Labor Market

Usually analysis of social policies focus on how reforms and changes affect citizens, (potential) beneficiaries and their families, and public financing. However, LTC, as with other social care and social policy fields (health care, education, child care, etc.), also plays an important role in terms of occupation. As care is basically a personal service delivered by individual workers, it is useful to understand to what extent

reforms have affected the care industry. As illustrated by the OECD (2011), there are millions of LTC workers in Europe: their incidence on the overall employment shift from around 2 % in countries like Germany, the Netherlands and Spain to almost 5 % in some Scandinavian states (Sweden for example). Moreover the just quoted OECD publication underlines that the number of LTC workers has grown by 3.2 % per year in the last decade, when, instead, the general occupational growth has been quite more limited (+0.4 %). In countries such as Germany, the yearly growth rate was even stronger (+4 % vs. +0.6 % in the general labour market).

The results of our analysis (see Table 13.6) show a double-faced impact: on one hand, there has been a strong growth in overall employment levels in this field over the last 20 years, on the other, there has been also a deterioration of working conditions. The ageing of the population with its consequent growth in terms of social demand and, where they took place, the increasing amount of financial resources available to beneficiaries thanks to the reforms, played a major role in fostering labor developments in the field. The conditions in which these workers are employed have often deteriorated in comparison with the past. Two different phenomena seem to explain this change. On one side, a “Taylorist-like” approach to LTC service delivery has been introduced. On the other, there has been a push toward a more consumerist approach.

A Taylorist-like approach means that in many countries there is a tighter definition of the tasks that have to be performed by care professionals when delivering services. For instance, under the influence of ideas from New Public Management, there was in Sweden a related shift from a more person-centered organizational model, under which each care worker was responsible for a small number of clients, towards a Taylorized ‘assembly-line’ model, under which a number of care workers jointly provided specific tasks to a larger number of clients. The Danish experience of “Common Language” shows a process of standardization of services provided, which reduces the autonomy of the homecare worker and therefore also changes her status. More specifically, her flexibility is limited as she is not able to respond to emergent and unassessed needs. Further, the time available for hands-on care is being limited as more time is being used for assessing needs and documenting the care delivered. This is an unintended effect which changes the ideal of care from providing care responsive to the immediate needs of the user to providing care based on standardized packages, and from a focus on delivering care to a focus on documenting care. In Germany, similar processes of standardization of care tasks (and the timing related to provide them) can also be found.

13.8.3 Impact on the Care Delivery Regulation

Institutional changes have affected not only the level of benefits and the amount of care work in the field, but also the public regulation of care services. Two main changes are evident: the recognition of more autonomy and freedom of choice to recipients and their families, and the increase of competition in care delivery. Both

Table 13.6 LTC reforms: the effects on public financing, beneficiaries, the labor market and regulation

LTC Care Regime (early 1990s)	Effects on funding and coverage	Effects on care workers	Other effects on the LTC regulation and provision
<i>Universalist</i>			
Sweden	Retrenchment (and partial re-familization) the risk is the loss of the middle class as a constituency for, and user of, public services Restructuring	Increase in occupation in the field but Taylorization of care tasks Strengthening of a cash-based (voucher-based) option Ambivalence between: Mix of control/standardization and choice/flexibility Taylorization of care work; De-professionalization of care work; substitution of formal with informal care	Rise of large, corporate for-profit providers; privatization of provision (and financing) Rise of private provision (with public funding)
Denmark			
The Netherlands	No retrenchment (even if attempts were made) but possibly most disruptive transformation introduced in the system is the shift of part of the risks covered by the AWBZ to other fields of social protections (redefinition of boundaries)		
<i>Semi-universalist</i>			
England	Retrenchment Risks/Responsibilities shifting from LAs to individual older people and their families	Increase in occupation in the field but risk of de-qualification of work (partially migrant care work)	Higher fragmentation in the management of LTC public provision Privatization of provision
<i>Residual</i>			
Austria	Expansion in the 90s with some retrenchment in the 2000s (cost-containment considerations have continuously worked as a limiting factor)	Increase in occupation in the field but risk of de-qualification of work (migrant care work)	

Table 13.6 (continued)

LTC Care Regime (early 1990s)	Effects on funding and coverage	Effects on care workers	Other effects on the LTC regulation and provision
Germany	Expansion (in the 90s) with some retrenchment in the 2000s (cost-containment considerations have continuously worked as a limiting factor)	Increase in occupation but also Taylorization, deterioration of employment conditions, substitution of formal with informal care (and rise of a semi-formal, grey care market)	Weakening of non-profit providers and rise of for-profit providers
France	Expansion and now attempts/discussion to support the development also of private insurance	Strong increase in occupation; APA scheme has significantly increased the number of qualified workers, even though they remain insufficient with precarious working conditions	
Italy	Unplanned (partial) expansion	Expansion of the care labor market but dequalification of work (migrant work)	
Spain	Expansion	Expansion of the care labor market but dequalification of work (migrant work)	
Czech Rep.	Expansion	Limited expansion of the care labor market but risks of dequalification of work (possible migrant work in the near future)	Limited increase in private provision (also nonprofit)

Italy	Austria	Spain	Germany	Netherlands	England	France	Sweden	Denmark
				Czech Republic				
Cash-for-care programs				More freedom of choice in care arrangements				

Fig. 13.2 The drivers of beneficiaries increasing autonomy

of these regulatory changes have been driven by the idea that both marketization and more flexibility of care provision reduce costs, increase efficiency and effectiveness, without basically altering the existing entitlement setting. In most of the countries analyzed here, an increasing amount of public resources dedicated to LTC are provided in a way that, in comparison with the past, offer more autonomy to beneficiaries. This process has taken mainly different inter-related forms: the rise of cash-for-care programs (alternative to service provision) and more freedom of choice given to users in deciding care arrangements even when services are provided (see Fig. 13.2).

Countries like Italy and Austria, and to a lesser extent Spain and Germany, have introduced or strengthened cash-for-care programs that transfer allowances to beneficiaries with high discretion in the way they can be used. The Italian *IdA* is a classical example, whereas the German LTC insurance offers beneficiaries the choice between services or cash, with the result that the vast majority of users opts for the latter.

Conversely, Scandinavian countries have chosen not to allow too much discretion to users within cash programs but they have strengthened the freedom and autonomy of beneficiaries in organizing the services they receive. For instance, the Danish “freedom of choice” program allows users to some extent the possibility to choose precisely which services they would like to receive. However, choice is conditional: the choice of individual users has to be approved by a care worker, and practical help cannot be exchanged for personal care tasks, if these are not included in the initial needs assessment.

France, England and the Netherlands have tried to mix cash programs and choice with some forms of professional supervision. The Personal Budget in the Netherlands, the direct payments in England and the way the *APA* works in France all share a common approach: the resources given directly to beneficiaries have to be spent appropriately and approved by social workers. A second relevant change deals with the regulation of the care delivery system. A main trend is common to most of the countries: a rise in private provision through for-profit enterprises. This outcome is clearly not only in countries traditionally characterized by public provision (as the Scandinavian ones), but also in those countries where there was a tradition of subsidiarity through non-profit provision (such as Germany).

In Sweden, private service providers nowadays play a significant role inside the publicly funded LTC system. In 1993, only 2 % of publicly funded homecare hours for older people were privately provided, whereas by 2010, this proportion had increased to 19 %. In 2010, a similar proportion of older people in residential care lived in privately run facilities. The entire increase in private provision has been among *for-profit* providers. Large corporate providers are dominant among for-profit private providers. The two largest players, Carema and Attendo, both owned by international private equity companies, held half the eldercare market in 2008. In Denmark, the

market for long-term care services has become more attractive for private providers and in 2010 every third recipient of home help chooses a private provider, although this applies exclusively to practical help such as cleaning, whereas only 4 % of older people receiving personal care choose private providers. In England, the reforms on social care which took place in the early 1990s have been the driver for a skyrocketing increase in private provision in home-care: in 1992, the year before the reforms, the private sector was supplying only two per cent of all home care contact hours; by 2001 this had already increased to 60 %. By 2001, 85 % of all residential care places for adults were also in the private sector.

In Germany, the funding from the LTC insurance has opened up a market for for-profit providers, in a country traditionally characterized by non-profit provision. Since the introduction of the LTC insurance scheme, the proportion of private for-profit home-based and residential care providers has steadily increased. In 2009, 61.5 % of home-based service providers were private for-profit organization, whereas within residential care 39.9 % of the care providers were private for-profit organizations.

13.8.4 Impact on the Family Care Activity

Institutional changes in LTC policies have had influence also over the level of familisation–defamilisation of care (Esping-Andersen 1999). In a previous study we already showed that in the early 1990s, a distinct dualism between a (formal) service-led model and an informal care-led model characterized LTC systems over Europe (Pavolini and Ranci 2008). At that time an extension in social rights in LTC was assumed as necessary as a development in state-funded services and a corresponding decrease in family care responsibility. In the course of the following two decades, however, tensions between formal and informal care (Pfau-Effinger and Rostgaard 2011) have been rising as reforms did not bring about a clear advance towards defamilisation of care as it was assumed. The boundaries between formal and informal care have been shifting and blurring, paving the way for intermediate, semi-formal care arrangements (Pfau-Effinger et al. 2009).

In general, most of LTC reforms considered in this study (in Germany, Austria, France, the Netherlands) have carried out some forms of inclusion of family care within the public care system. A relevant part of public responsibility for care has been recognized, either implicitly or explicitly, as a proper task also of informal caregivers.

The most widespread approach in most of the European countries has been to increase home care in order to reduce the amount of people who have to be institutionalized or hospitalized (or to shorten the time of their institutionalization). But home care is an activity requiring the presence of a social network supporting the dependent for many hours. Responsibility for everyday life activities has to be necessarily shared among many persons, including care workers, private suppliers of care, nurses, family relatives or friends, private family assistants, and so on. The uncertain status of care—an activity mixing professional and relational tasks—has

made it easy for governments to cover only a part of the needed care. Therefore a relevant part, implicitly, has been left to the responsibility of the informal networks, including relatives, friends, neighborhoods.

In parallel, renewed attention has been paid to cash and cash for care programs. While the receipt of cash benefits had used to be free of any obligations on the beneficiaries, the new tendency has been to increase the volume and to extend these measures by specifying clearer requirements for access and imposing better accountability for the use of these resources. It is in this context that measures have been introduced to regularize informal care workers and to pay benefits to family caregivers. The new forms of cash or cash-for-care benefits are not only a low-cost way to pay for care services provided by family members but they also constitute strong institutional recognition of the care work performed by women, previously considered as an implicit and ‘natural’ duty. Informal care, as a consequence, has been recognized as an integrated part of the public provision system. Informal caregivers have been financially sustained, providing them also with social rights, contributory schemes, respite services, income support. Part of the responsibility for the actual provision of care has been therefore delegated to private citizens, opening the door to the inclusion of family provision of care within the “public” care system. The expansion of LTC policies throughout Europe, therefore, has gone together with the introduction of new forms of regulation aimed at sharing the burden of costs and the responsibility for care provision between the public sector and individual citizens. The restructuring process that has been taking place in the last two decades has involved not only the creation of new responsibilities for the welfare state, but also the recasting of the relationship between State and the family.

13.9 Conclusions

The general debate on welfare policies in the last 20 years has turned around concepts such as (hidden and explicit) retrenchment, status quo and restructuring (Pierson 2001). According to Pierson, perspective restructuring has been merely considered as a “mitigated” form of retrenchment due to the “stickiness” of welfare institutions and to the high public opinion support towards the welfare state. In many policy fields we have witnessed cuts in social provision (pensions and healthcare reforms, etc.) directly implemented by governments, or indirectly promoted through different “policy drifts” mechanisms, as indicated by Hacker (2004) and Streeck and Thelen (2005).

Policy change occurring in LTC does not fit this classical model of policy change. LTC is indeed one of a few welfare policy fields where not only retrenchment but also expansion of coverage and expenditures has taken place. Restructuring in this policy field, therefore, is located in a broader area running from retrenchment to expansion. The pressures for change in LTC policy are related not only to cost-containment and financial constraints (like in Pierson 2001), but also to the need to address a new social risk (Armingeon and Bonoli 2006; Taylor Gooby 2004) emerging in contemporary

society that is related to demographic (ageing of population), social (higher women activity rate) and cultural (new vision of care) transformations. Change occurs in different ways in each of the various EU countries analyzed here in their attempts to deal with emerging trade-offs between cost-containment pressures and rising demand for care. Policy change in LTC is caused by new social risks which result in new demands for welfare in a time of permanent austerity.

From our analysis, policy change in LTC is not only the result of particular actions or reforms, but it is the product of a long-lasting process of institutional restructuring. It is a protracted institutional dynamic in which change and continuity are inextricably linked (Mahoney and Thelen 2009). In this long-standing transformative process, different forms of institutional transformation may occur simultaneously. The overall institutional transformation is the result of variable combinations of reproduction by adaptation, gradual transformation, and breakdown and replacement changes (Streeck and Thelen 2005). This interpretation is coherent with Palier's (2010) description of the "Long good-bye to Bismarck," characterizing continental welfare regimes, where the overall change in these regimes is the result of "evolutionary transformation based on incremental but cumulatively transformative incremental changes". Complementing Palier's interpretation, moreover, our analysis found a broader range of connections between institutional changes: not only an accumulation of reforms that created the conditions for radical transformation to occur, but also sudden innovations followed by adaptive/gradual transformation mechanisms reducing their original social and financial impact, combinations of layering and displacement giving way to gradual transformations, and expansion as a perverse effect of a policy drift mechanism. What is relevant is that in a situation of permanent trade-off between rising demand for care and financial constraints, institutional change becomes a continuous institutional activity, permanently restructuring and recalibrating policy instruments and their settings, and also indirectly affecting social entitlements and the extension of benefits.

In the early 1990s, institutional changes took different shapes and produced different outcomes according to the care regime in operation. This differentiation in care regimes has proved to be very useful in providing an insight into the direction and the shape of policy change. Universalistic care regimes were characterized by a large extension of care provision and a full recognition of the social right of dependent citizens to be provided with care services and/or cash benefits. The UK was somewhat closer to these systems. Residual care systems differentiated so that they had not developed social entitlements and, accordingly, adequate provision for the dependent people. In all care regimes, therefore, there was a substantial coherence between entitlements and provisions, to use the famous conceptual definition of Dahrendorf (1988). The policy crisis in the early 1990s was caused precisely because of new gaps emerging between entitlements and provisions. Innovation basically represented a way to restructure entitlements and/or provisions in order to recalibrate the care systems and fill this emerging gap.

In universalistic care regimes, social entitlements were not challenged. Social rights of people with disabilities were already established and were not really questioned in the process. Innovation was focused on the provision system, as first or

second order policy changes affecting the public regulation, the relationship between providers and funders, and the position of users in respect of care professionals. Cost containment and users' autonomy were the two most relevant drivers of such trend. Restructuring, rather than retrenchment, was the main effect of such changes. In the absence of a comprehensive reform of the whole care system, innovation focused on provisions was incremental and adaptive, adding new regulation and provisions to the existing ones, without any relevant attempt to reconfigure the whole system. Only in Sweden and partially in England, as has been shown, the regulatory change implicitly affected the care structure, bringing about a progressive decommodification of the LTC system.

In residual care regimes, reforms introduced new entitlements and established new social rights, understood as third order policy change. In these countries, dependent people finally obtained a right to care. The provision system was hugely expanded accordingly, on the basis of additional financial resources that were mobilized for the reform. However, cost containment pressures were soon at work, and conditioned the regulatory setting of the reform as well as its further implementation and maintenance. Cash for care measures were introduced not only in order to meet the demand for free choice, but also to contain public costs by supporting informal care provided by families. In some countries, such as Austria and Spain, the pre-existing locally based service systems were incorporated in the reform, which was limited to specific national measures or functions. Moreover, further limitation in provision was established in the implementation process, largely due to a lack of adjustment of benefits to inflation; the legalization of individual social workers offering care at very low costs; and a general deterioration in the quality and professionalism of the care work. After the reform had redefined the entitlements to LTC and the care provision system, an incremental innovation of first or second order occurred in the attempt to recalibrate the new provision system to fiscal and cost-containment constraints.

How can we explain these different processes? The most important factors are the following:

- a. *problem pressures*: financial pressures were weaker in universalistic regimes in the 1990s and required only light adjustments of the existing LTC policy (already well established), while they were stronger in residual regimes calling for a major shift of costs from local assistance and health care programs to new LTC programs; where fiscal constraints were too high (such as in Italy), there was simply no way for further change. On the demand side, the previous family-based care arrangements typical of many continental countries were put under strong pressure because of the increase in women's participation in the labor market; in universalistic regimes, a strong individualism in care obligations and higher provision of public care services and re-conciliation services did not impede these trends.
- b. *diagnoses*: in universalistic regimes, cost-containment was perceived as a functional problem unable to challenge the universalistic paradigm; changes were introduced in order to adapt the system to new constraints; in residual regimes, a State direct intervention was perceived as the only possible solution to the failure

of social assistance to provide an adequate answer, paving the way for a radical reform.

- c. *politics*: in universalistic regimes, the high consensus for already established welfare programs prevented a paradigmatic debate about the existing system; moreover, the actual alliance between NPM advocates and very strong disability movements allowed changes in the regulation of the system (marketization, freedom of choice, accountability, standardization, etc.); in residual regimes, stable neo-corporatist coalitions joined with state officials, care providers, local authorities and trade unions to claim for a general reform of LTC.
- d. *path-dependency*: in universalistic regimes, social care programs had been already installed since the 1970s or 1980s, creating a broad popular support and strong constituencies; in residual regimes, the existing locally-based care system collapsed because of rising costs and too weak development of their service infrastructures; the same constituencies of LTC favored a direct responsibility of the state; where nation-wide care programs were already setup, as in Italy, they functioned as relevant buffers that delayed or avoided a general reform of LTC.
- e. *rescaling*: in universalistic regimes, the bulk of care provision was local, and cost-containment pressures have brought to a re-centralization of spending responsibility and introduction of accountability under the auspices of NPM concepts; but responsibility for care provision was kept at the local level without basically altering the institutional architecture of the care system; in residual regimes, responsibilities for provision were also locally based, but the level of development of local assistance was much poorer; a new system was based on new responsibilities held by the State and regional governments. Both regimes faced a rescaling, centralizing process, but in residual regimes the poor development of local programs required a massive and substituting intervention of the state.

To sum up, LTC systems have been under a period of strong revision and adaptation in the last two decades. The trade-off between extending entitlements and constraining provisions has made innovation a very narrow path. Reforms in entitlements have been followed by incremental innovation focused on provisions that partially modified the impact of the former. When disruptive reforms proved impossible, innovation in care provision was achieved through incremental transformation in public regulation. As a result, it seems that radical reforms can take place inside a long run process of incremental innovation aimed at restructuring the provision system within the framework given by the entitlement system.

The main impacts of such changes are twofold. First, the original care regimes have developed in different directions, contributing to increased complexity today. The universalistic care regime seems to leave room for increased internal differentiation. Denmark adapted its care system without relevant changes in the coverage and funding, basically preserving the original model. Sweden introduced innovations in the system through a layering process, by which a partial privatization of care is now taking place. The Netherlands have followed a middle ground, alternating continuity with its universalistic path with some discontinuities. Great dynamism has moreover characterized the innovation taking place in residual care regimes, where expansion

and further adaptation of the care system have characterized Germany, France, Austria, Spain and the Czech Republic. The organization of such care systems differs from country to country, ranging from the cash-based delivery system dominant in Germany and Austria to the more decentralized and service-based system developing in France and Spain. Finally, two countries are outliers in respect of the others: Italy and England basically retained the old care systems, characterized by high level of fragmentation and separation between national cash measures and locally-based service systems, and by a general inadequacy of the public care system, in Italy supplemented by a strong family solidarity and lately by the diffusion of a large private market of migrant in-house care workers.

The overall result of these trends is, however, a partial convergence in LTC systems over Europe. While the universalist regimes have reduced the extension and generosity of their care systems, most of the residual care regimes have expanded entitlements and public expenditures. Moreover, the regulation of care provision is today more complex, but at the same combines in different national configurations, flexibility and autonomy of beneficiaries with market mechanisms and cost-containment measures.

The second outcome is related to the progressive dualization of the care systems all over Europe. In the last 20 years, there has been a first phase of progressive convergence of European care systems towards a care model characterized by a limited universalism: while universalistic care regimes retrenched their provision systems, most of the residual care regimes expanded the existing provision by introducing new national LTC schemes. This process has lasted until 2006, when Spain and the Czech Republic established their national LTC program. In the last decade, however, with only these two partial exceptions, all the countries converged towards retrenchment and cost containment. No radical reforms have been introduced in this direction so far, but incremental innovation has been always driving the care systems towards further restrictions in the public supply of care and in the quality of professional services. Shortage in the care supply and low quality of care services could well push more and more dependent people out of the public care system. The trend towards a partial re-familisation of LTC is also shifting responsibility from state to individuals and their kinship networks. If this trend towards retrenchment is confirmed in the future, then the risk of polarization between insiders and outsiders will be dramatically heightened.

References

- Anttonen, A., & Sipilä, J. (1996). European social care services: Is it possible to identify models? *Journal of European Social Policy*, 6(2), 87–100.
- Armingeon, K., & Bonoli, B. (Eds.). (2006). *The politics of post-industrial welfare states*. London: Routledge.
- Ascoli, U., & Ranci, C. (Eds.). (2002). *Dilemmas of the welfare mix. The new structure of welfare in an era of privatization*. New York: Kluwer.
- Bonoli, G. (2005). The politics of the new social policies: Providing coverage against new social risks in mature welfare states. *Policy & Politics*, 33(3), 431–449

- Clasen, J., & Siegel, N. A. (Eds.). (2007). *Investigating welfare state change. The 'dependent variable problem' in comparative analysis*. Cheltenham: Edward Elgar.
- Da Roit, B., & Le Bihan, B. (2010). Similar and yet so different: Cash-for-care in six European countries' long-term care policies. *Milbank Quarterly*, 88(3), 286–309.
- Dahrendorf, R. (1988). *The modern social conflict. An essay on the politics of liberty*. Berkeley: University of California Press.
- Daly, M., & Lewis, J. (1998). 'Introduction: Conceptualising social care in the context of welfare state restructuring'. In J. Lewis (Ed.), *Gender, social care and welfare state restructuring in Europe* (pp. 1–24). Aldershot: Ashgate.
- Esping-Andersen, G. (1999). *Social foundations of postindustrial economies*. Oxford: Oxford University Press.
- Ferrera, M. (2005). *The boundaries of welfare. European integration and the new spatial politics of social protection*. Oxford: Oxford University Press.
- Green-Pedersen, C. (2002). New public management reforms of the Danish and Swedish welfare states: The role of different social democratic responses. *Governance*, 15(2), 271–294.
- Hacker, J. (2004). Privatizing risk without privatizing the welfare state. *American Political Science Review*, 98(2), 243–260.
- Hall, P. (1993). Policy paradigms, social learning, and the state: The case of economic policy-making in Britain. *Comparative Politics*, 25(3), 275–296.
- Huber, M., Rodrigues, R., Hoffmann, F., Gasior, K., Marin, B. (2009). *Facts and figures on long-term care*. Wien: European Centre.
- Kangas, O., & Palme, J. (2007). Social rights, structural needs and social expenditures: A comparative study of 18 OECD countries 1960–2000. In J. Clasen & N. A. Siegel (Eds.). (2007). *Investigating welfare state change. The 'dependent variable problem' in comparative analysis* (pp. 106–129). Cheltenham: Edward Elgar.
- Kazepov, Y. (2010). *Rescaling social policies towards multilevel governance in Europe. Social assistance, activation and care for older people*. New York: Ashgate.
- Lafortune, G., & Balestat, G. (2007). *Trends in severe disability among elderly people: Assessing the evidence in 12 OECD countries and the future implications*, OECD health working paper, No 26, Paris: Organisation for Economic Co-operation and Development.
- Lamura, G., Döhner, H., Kofahl, C. on behalf of the EUROFAMCARE Consortium (2008). *Services for supporting family carers of older people in Europe: Characteristics, coverage and usage. A six-country comparative study*. Hamburg: Lit Verlag.
- Mahoney, J., & Thelen, K. (Eds.). (2009). *Explaining institutional change*. Cambridge: Cambridge University Press.
- Morel, N. (2007). From subsidiarity to 'free choice': Child- and elder-care policy reforms in France, Belgium, Germany and the Netherlands. *Social Policy & Administration*, 41(6), 618–637.
- Naldini, M., & Saraceno, C. (2008). Social and family policies in Italy: Not totally frozen. *Social Policy & Administration*, 42, 733–748.
- OECD (2011). *Help wanted? Providing and paying for long term care*. Paris: OECD.
- Oesterle, A. (2001). *Equity choices and long-term-care policies in Europe*. London: Ashgate.
- Palier, B. (Ed.). (2010). *A long good-bye to Bismarck. The politics of welfare reform in continental Europe*. Amsterdam: Amsterdam Univ. Press.
- Pavolini, E., & Ranci, C. (2008). Restructuring the welfare state: Reforms in long-term care in Western European countries. *Journal of European Social Policy*, 18, 246
- Pfau-Effinger, B., & Rostgaard, T. (Eds.). (2011). *Care between work and welfare in European societies*. New York: Palgrave.
- Pfau-Effinger, B., Flaquer, L., & Jensen, P. H. (2009). *The hidden work regime: Informal work in Europe*. London: Routledge.
- Pierson, P. (2001). *The new politics of the welfare state*. Oxford: Oxford University Press.
- Sabatier, P. (1988). An advocacy coalition framework of policy change and the role of policy-oriented choice. *Policy Sciences*, 21(1), 56–71.
- Saraceno, C. (Ed.) (2008). *Families, ageing and social policy. Intergenerational solidarity in European welfare states*. Cheltenham: Edward Elgar.

- Sarasa, S., & Mestres, J. (2007). Women's employment and the adult caring burden. In J. Esping-Andersen (Ed.), *Family formation and family dilemmas in contemporary Europe* (pp. 185–222). Bilbao: Fundacion BVA.
- Streeck, W., & Thelen, K., (Eds.). (2005). *Beyond continuity: Institutional change in advanced political economies*. Oxford: Oxford University Press.
- Taylor-Gooby, P. (2004). *New Risks, new welfare*. Oxford: Oxford University Press.

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