1 Introduction

Long-term care is a relative newcomer to social policy in most welfare states. Historically, this has been a task for families or has been done within the healthcare system. In the first edition of this handbook (Greve, 2013), long-term care could not even be found in the index. Long-term care is seen as a new social risk (see Taylor-Gooby, 2004) that welfare states have to address in the wake of the fact that people, or at least some people, are living for longer. Welfare states have therefore gradually taken on a higher responsibility for the elderly in need of support. However, despite acknowledging the impact upon family life if one is obliged to take care of a frail elderly person, long-term care is not even mentioned in the index in Taylor-Gooby (2004). The change in welfare mix thus also prevails in the field of long-term care, especially with a possible growing burden on women in order to care for a spouse and/or parents. This is not a new understanding however; see Norton (2000), who has already pointed to this possible impact.

In recent years increased focus on long-term care has come about as a consequence of changing family forms, the increase in the number of women in the labour market and demographic changes that imply a relative increase in the number of elderly compared to the rest of the population as a combination of low fertility and increase in life-expectancy. Increased participation of women in the labour market also reflects the possibility of fewer being able to do informal care (Saraceno, 2008). Furthermore, the increase in the number of elderly people with dementia has increased the pressure on long-term care.

This chapter is structured so that the next section provides a presentation and discussion of what long-term care actually is and how this might be defined, including whether one can measure quality in long-term care. It will then proceed with a short description of the official extent of long-term care in selected EU member states representing different welfare regimes (see also Chapter 11). This includes Nordic, Liberal, Conservative and also Southern and Eastern European welfare states. It will go on to discuss recent trends in long-term care – ranging from marketisation and the use of different types that can be interpreted as social investment, focusing on welfare technology, rehabilitation and re-enablement. The concluding section will sum up the chapter.
Long-term care systems in Europe are extremely fragmented and very diverse (Ranci and Pavolini, 2012) (see also the next section for varieties and differences of long-term care systems). This fragmentation implies a difficulty in presenting and systematising the variation in long-term care systems.

What is long-term care?

Long-term care (LTC) refers to policies that help with or try to facilitate the life of a person who is not able to take care of him- or herself. Thus, as examples of definitions, the following may be given:

a “The range of medical and/or social services designed to help people who have disabilities or chronic care needs” (US Department of Health and Human Services, 2009).

b “A range of medical and social services for persons who are dependent on help with basic activities of daily living, caused by chronic conditions of physical or mental disability” (European Commission, 2009).¹

Thus, long-term care focuses on how to help people who are not able to take care of themselves. In this sense this is not dependent on age, but on physical or mental abilities. It could also include the dependency related to an individual’s economic and social abilities.² However, due to ageing of populations, the elderly will be in special need of long-term care. Access to long-term care will often be dependent on a needs assessment looking into whether the individual is able to take care of him-/herself and often also whether there are family/friends who are able to help the individual with daily tasks. Measurement of needs is outside the scope of this chapter; however, it is used very differently and with various types in different welfare states in Europe (see Greve, 2017). Besides evaluation of needs, there may also be means-testing attached to receiving long-term care, and, further, user charges may be part of what the individual will have to pay in order to gain access to care or at least to some care.

In contrast to healthcare it is not always possible within long-term care to return to the position before there was a deterioration in the situation for the person in need. Definition of quality is thus difficult. A definition of quality is “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (Dandi, 2012 p. 3). Another way of defining quality is based on the WHO’s definition of quality of life: “individuals’ perception of their position in life in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns” (in Beerens et al., 2013, p. 1260). There are several ways of measuring and evaluating quality in long-term care (Rodrigues, 2017). It may therefore be argued that focus should be on how different services affect daily life (Forder and Caiels, 2011).

Quantifying the quality of the intervention is more difficult to measure in LTC than it is in healthcare. A classic description of elements of quality that can also be a starting point for long-term care is by Donabedian, which includes structure, process and outcome (Donabedian, 1980). An example of the classification of quality assurance inspired by Donabedian’s framework is one along three dimensions: organisation type (formal, informal institution at home), quality dimensions and systems dimensions (inputs, processes and outcomes) (Dandi and Casanova, 2012). Further, even when having defined quality, there is a need for quality assurance, which can, although it was with reference to healthcare, be defined as “all actions taken to establish, protect, promote, and improve the quality of health care” (Donabedian, 2003, p. xxiv).
Due to the often interrelated issue of personal relations with delivery of services to frail persons, this also implies that quality seen from the user’s perspective can be different from how it is seen from the deliverer’s point of view.

Users’ perspective elements of quality may include the following:

- Effectiveness and care safety
- Patient-centredness and responsiveness
- Care coordination.

The many varied, interrelated ways to measuring quality in long-term care have the consequence that there is no common agreement on the concept. For some recent discussion, see OECD (2013), Mot et al. (2012) and Greve (2017). This lack of a common understanding of what quality is also implies difficulties in measuring the impact of changes in the way long-term care is financed and delivered. How to evaluate different types of long-term care and new elements in the field is thus also very difficult (Rodrigues, 2017). Systems with a high degree of universalism and a high level of public sector spending quality for the workers within the sector can also be part of what and how quality can be evaluated.

Given that it is difficult to measure outcome in long-term care, interventions may not have an impact upon health, but may at the same time improve or restore “dignity, freedom of movement, and, control, outcomes that transcend health” (Makai et al., 2014, p. 84). Therefore, long-term care can still be very important for frail persons, who are often elderly.

The intersection of long-term care policies and analysis with other fields, such as labour economics, industrial organisation, insurance, life-cycle behaviour and demography (Norton, 2000), may be one reason why the field has received limited attention up until now.

One could add that the extent of long-term care (see below) also helps in explaining that the focus has been less strong than in other welfare state areas. The expected economic pressure in the years to come due to the increase in the number of elderly, despite the elderly being healthier than in the past, can help explain the increased focus on long-term care. The absolute increase in the number of elderly also implies more voters with an interest in the field.

Different systems of long-term care exist. To exemplify, according to a recent report from the European Commission (EU Commission, 2016, p. 173), there are five different long-term care systems in Europe:

A Formal care-oriented provision which is generous, accessible and affordable.
B Medium accessibility, some informal care orientation in provision.
C Formal care of medium to low accessibility, medium informal care orientation in the LTC approach.
D Low formal care accessibility, strong informal care orientation in the LTC approach.
E Relatively low formal care accessibility, almost exclusive informal care orientation in the LTC approach.

In addition, in the rest of the world’s welfare states the approach to and ways of financing and delivering long-term care is very diverse, but in many countries one of the five approaches listed above will presumably fit well with the understanding of how long-term care is structured and ways of delivering LTC.

Overall, one could argue that analysis of policy change within long-term care revolves around the why, who, how and what:
Long-term care

Why: old vs. new solutions and factors influencing change.
Who: the actors and who builds coalitions and is mobilised in order to change.
How: the mechanism – from incremental, adaptation, reforms.
What: outcomes, impact of change.

(Based on Ranci and Pavolini, 2012, p. 5)

Thus there may be different drivers for change (see also Chapter 26) in the field of LTC, and the variety of actors can be a strong force in the direction of change. Besides that, and despite being a newcomer to social policy, there will also be path-dependent change. Using these elements for analysis of change in long-term care it is argued that LTC has developed towards restricted universalism, “characterized by universal entitlements to LTC benefits constrained by limitations in provision due to financial constraints” (Ranci and Pavolini, 2015, p. 270).

Size and types of long-term care in Europe

As in most fields within social policy, there may be a variety of ways of delivering support. There may also be a variety related to whether it is universal or selective, in-cash or in-kind support. Especially in the field of long-term care there is a variation between having formal or informal care, and then there can be varieties in whether or not there is support to informal care. Thus, for example, in Europe, in 7 countries there is no support to informal care, whereas in 14 countries there is some kind of financial support to informal care (Riedel and Kraus, 2016). There may further be a difference related to whether the long-term care is for the elderly or for people with disabilities, as it is less frequent with economic support to care in relation to the elderly. Monetary benefits for carers can further be either a supplement to existing income or a substitute for income; for example, if one person is giving up his or her job in order to look after a person in need of care.

Therefore support to the elderly in need of long-term care is more frequently delivered as in-kind, often based on a needs assessment but not means-tested. The in-kind support is either support in the private home or in homes especially able to help people in need of care. Furthermore, support in the healthcare sector (especially hospitals) can be a kind of substitute for what is delivered in the long-term care sector.

Expenditure data within the field are scarce and not always very precise, especially due to the fact that long-term care sometimes does not really exist or, as mentioned above, is taken care of within the healthcare system. The following tries to present some data to inform on differences in approaches to long-term care. Countries used for the presentation follow the classical welfare regime approach combined with Southern and Eastern European countries. Furthermore, the countries presented represent different care regimes. Finally, more detailed information on the long-term care systems and their development in the relevant countries may be found in Greve (2017).

Despite the fact that there is a data problem, in the sense that data are not always comparable across countries, Table 43.1 is a reminder of the differences among different types of welfare states, with the universal Nordic welfare states spending more and the continental following close behind. The level of spending is also relatively high in the UK, but less so in Eastern and Southern Europe. A core reason for the lack of comparability is that part of the cost for long-term care may be measured within the healthcare system (see also Chapter 35), and the boundaries to other types of social spending are not always clear. A higher level of pension provision, for example, could imply that users may be better able to buy the service available in the market.

However, long-term care is a good example of economic reasons for collective action, since if “the premium is based on the risk of an event occurring and the size of the resulting loss” (Barr, 2010, p. 360), then only by pooling resources together will it be economically possible...
for individuals to be covered in case of need, the problem being that no one knows whether or not they will need long-term care. Furthermore, private insurance seems not to have been used by citizens, with the central reasons for this being excessive cost, social assistance, trust in family solidarity, unattractive rules of reimbursement, ignorance and denial of heavy dependence (Pestiaux and Ponthiere, 2011). Overall, the insurance market for long-term care has not been developing (Costa-Font and Courbage, 2015).

There is a difference between spending related to whether the individual is living in an institution or at home. The recent trend has been to focus more on patients being able to continue to live in their own homes instead of in an institution (see also the following section). This also implies that looking at the size of a population actually in residential care may give a very inaccurate picture of the long-term care system, since even a decline in the proportion may not imply quality deterioration. Thus, if there has been an increase in home care and support in private homes this may reflect better quality and not weaker quality of care. The same may be argued to be the case if initiatives to prevent the need for care have been successful, a decline in coverage rate and/or spending will not be informative on the development of a long-term care system. For more on prevention see Chapter 5.

Besides direct cost, there may also be indirect costs for those in need (higher expenditure, for example, for medicines) and for informal carers, as they may need to reduce their labour market participation.

### Table 43.1 Development in spending on long-term care as percentages of GDP

<table>
<thead>
<tr>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nordic Europe:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denmark</td>
<td>1.89</td>
<td>2.20</td>
<td>2.55</td>
<td>2.50</td>
<td>2.53</td>
</tr>
<tr>
<td>Finland</td>
<td>1.70</td>
<td>2.01</td>
<td>2.44</td>
<td>1.72</td>
<td>1.68</td>
</tr>
<tr>
<td><strong>Continental Europe:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Belgium</td>
<td>–</td>
<td>1.71</td>
<td>2.14</td>
<td>2.29</td>
<td></td>
</tr>
<tr>
<td>Germany</td>
<td>1.30</td>
<td>1.43</td>
<td>1.53</td>
<td>1.52</td>
<td>1.52</td>
</tr>
<tr>
<td><strong>Liberal:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>United Kingdom</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>1.20</td>
<td>1.19</td>
</tr>
<tr>
<td><strong>Southern Europe:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Greece</td>
<td>–</td>
<td>–</td>
<td>0.06</td>
<td>0.11</td>
<td>0.14</td>
</tr>
<tr>
<td>Italy</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>0.84</td>
<td>0.85</td>
</tr>
<tr>
<td>Portugal</td>
<td>0.09</td>
<td>0.09</td>
<td>0.15</td>
<td>0.21</td>
<td>0.21</td>
</tr>
<tr>
<td><strong>Eastern Europe:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hungary</td>
<td>0.14</td>
<td>0.31</td>
<td>0.64</td>
<td>0.29</td>
<td>0.31</td>
</tr>
<tr>
<td>Lithuania</td>
<td>–</td>
<td>0.64</td>
<td>1.13</td>
<td>0.47</td>
<td>0.54</td>
</tr>
<tr>
<td>Poland</td>
<td>–</td>
<td>0.43</td>
<td>0.43</td>
<td>0.45</td>
<td>0.43</td>
</tr>
</tbody>
</table>


Note
Data in the field vary and are not always comparable, especially over time.
Recent trends in long-term care

For some time, and in many countries, long-term care has mainly been the responsibility of civil society, and, in fact, civil society still seems to be the main provider when looking into state spending (as shown in Table 43.1). That there was some indicator of gradual higher state involvement can be implicitly interpreted by the fact that it has been argued that there has been a tendency towards refamiliasation of care to reduce fiscal burden and welfare programmes through cash support (Ranci and Pavolini, 2008). Ranci and Pavolini also argue that the UK was among the first to use marketisation in the field of long-term care. The trend towards refamiliasation is despite the pressure on those delivering long-term care (Verbakel, 2014). With the development of more institutional care, new actors are also becoming involved in the sector, so that today central actors in long-term care are civil society (users as well as family/friends as providers), user organisations, the public sector (national as well as local, depending on the specific structure of the system) and care workers (formal as well as informal employed).

Precisely one difficulty in discussing trends in long-term care is that the systems are very different in their emphases on formal and informal care, but also that the steering mechanisms are relatively diverse with very different uses of central or decentral responsibility for regulating long-term care (Riedel et al., 2016). Between 1990 and 2010, the overall picture of the development of long-term care reforms in Europe may be argued to be expansionist (e.g. higher coverage due to acceptance of the new risk as argued in the introduction to this chapter, but also related to cost containment in some countries and, since expansion, also retrenchment in some countries (Ranci and Pavolini, 2015).

In relation to the welfare mix there seems to have been a gradual movement towards a higher degree of using the market in the delivery of long-term care – also in the classical universal Nordic welfare states (Meagher and Szebehely, 2013). Thus, the use of market mechanisms seems to be a central tenet of the delivery of long-term care in many welfare states.

Prevention and rehabilitation in order to enable the elderly to stay as long as possible in their own home seems also to have been a trend for some years (Kümpers et al., 2010). Part of the explanation for this may be that care at home appears to be cheaper for the welfare state, while at the same time this may make it possible for the elderly to continue to live a life as close as possible to what they have been used to. Most Western countries appear to have a strong focus on home-based elderly care (Tinker et al., 2013).

Prevention (see principles in Chapter 5) has also been a central issue as a measure to help in the longer run to improve quality of life and reduce pressure on long-term care (Horstmann, 2012). This has further been argued within EU to be central: “a proactive response is to preventing to become dependent” (European Commission and the Social Protection Committee, 2014, p. 6.). Part of the approach to prevention is often outside the direct scope of long-term care (e.g. the use of and attempts to make people live a healthier life do not count as long-term care or long-term care spending, but may have an impact upon the long-term development of cost to the sector). However, the effect of influencing classic risk factors such as smoking, drinking, eating healthily and being physically active is an important aspect in reducing pressure on long-term care spending in the future (and healthcare costs). There are, at the same time, other types of preventive elements that are within the long-term care system which may influence cost and quality of life. This is the case, for example, when making changes in the private home to avoid falls, and making preventive home visits, which are seen as good practice (Kümpers et al., 2010, p. 11).

Marketisation seems to be a central trend in relation to the development of long-term care in several countries (Burau et al., 2016; Meagher and Szebehely, 2013). The trend is a consequence
of the weakened informal care, but is also influenced by ideological viewpoints on how best and under what conditions to deliver long-term care. The possible consequence for the users will depend on the way marketisation is done. One possible impact seems to be de-institutionalisation of long-term care and a trend towards re-familiarisation (Deusda, Pace and Anttonen, 2016). This trend towards re-familiarisation is in contrast to the possible weakening of the size of informal care.

Delivery of services by private actors may not necessarily have a negative impact upon users, on the condition that financing and criteria for receiving care are decided by the state. However, if access to a service is dependent on the ability to buy that service then there is a strong possibility that only a more limited number of elderly will receive the service, as there are still many elderly at risk of living in poverty.

Also in the field of long-term care, welfare technology and rehabilitation have been central issues in development in many countries over recent years, especially in the more mature welfare states, whereas this is less pronounced in Eastern and Southern Europe. Part of the reason for this may be that the overall level of spending in the field (see Table 43.1) is relatively limited and the responsibility lies with civil society to reduce the scope for investing in and implementing the use of new technologies in Eastern and Southern European countries. However, new welfare technology may in the future be part of the development, as this can increase quality of life for the elderly, improve working environments and relieve economic pressure on welfare states – at least in the longer term (for a Danish evaluation see Andersen et al. (2016), and for the challenge see Östlund et al. (2014)). Part of what looks to be important in order to implement and use new technologies is “trust, communication, commitment and the ability to take the other’s perspective [and] are key to partnership success” (Berge, 2016, p. 5).

Overall, to indicate the diversity in the development related to marketisation, the role of civil society, austerity measures and rehabilitation, Table 43.2 shows the developments in a number of European countries.

Even though the trends depicted in Table 43.2 may not be sufficient to argue for the same trends in all – at least European – countries, they do point to a stronger pressure on long-term care systems in all types of welfare state to maintain a continuously high level of impact and need for civil society in the delivery of long-term care, and that there have been trends towards marketisation. Furthermore, there has been a growing focus on rehabilitation and the use of welfare technology as central aspects of quality of care, but also in reducing pressure on spending and labour in the sector.

Some concluding remarks

Long-term care is of growing importance for welfare states as a consequence of people living longer and the informal care sector is also under pressure as a consequence of more people in the labour market.

Organising, financing and delivering long-term care is thus of central importance to welfare states around the world. There are many and very varied approaches to this social policy field – ranging from encompassing universal types of systems to fragmented systems relying largely on informal care within civil society. The diversity is so strong that it can sometimes be difficult to present and show the varieties in approaches to long-term care. The mix between state, market and civil society is also very different and is constantly changing. There is at the same time growing marketisation as a way to support the role of the market, and an expectation of that civil society to take on an even stronger role than it does today.

However, there is also awareness of new ways to support those in need of care by focusing on prevention and welfare technology.
Table 43.2 Development in marketisation, austerity, role of civil society, rehabilitation, etc.

<table>
<thead>
<tr>
<th>Country</th>
<th>Trends in marketisation of long-term care</th>
<th>Role of civil society</th>
<th>Austerity measures/change in financing</th>
<th>Rehabilitation/re-enablement – and other investments in the field</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denmark</td>
<td>Yes, especially for practical home help</td>
<td>Important</td>
<td>Limited, but can vary locally as long-term care services is within limits decided in the municipalities</td>
<td>Yes, stronger focus on rehabilitation and use of welfare technology</td>
</tr>
<tr>
<td>Finland</td>
<td>Yes, in part of the care system</td>
<td>Important</td>
<td>Limited as there has been increase in spending</td>
<td>Yes, strong emphasis in quality recommendations to use this</td>
</tr>
<tr>
<td>Germany</td>
<td>Limited</td>
<td>Important</td>
<td>Limited</td>
<td>Some increase in recent years</td>
</tr>
<tr>
<td>Greece</td>
<td>Limited</td>
<td>Very important</td>
<td>Limited</td>
<td>Limited</td>
</tr>
<tr>
<td>Hungary</td>
<td>Limited</td>
<td>Very important</td>
<td>Some and with a negative development in spending</td>
<td>Only more limited in this field</td>
</tr>
<tr>
<td>Italy</td>
<td>Limited, albeit a ‘grey’ market is important</td>
<td>Very important, including also NGOs and not-for-profit institutions’ involvement</td>
<td>Some</td>
<td>Limited, with some regional variation in the approach to and use of this</td>
</tr>
<tr>
<td>Lithuania</td>
<td>Limited, especially due to low involvement</td>
<td>Strong, and expectation that elderly will stay as long as possible in their own home</td>
<td>Limited, due to low public sector involvement</td>
<td>No, this has so far not really been on the agenda</td>
</tr>
<tr>
<td>Poland</td>
<td>Limited, for historical reasons and overlap to healthcare</td>
<td>Very important, especially family, but also migrant workers</td>
<td>Some</td>
<td>Limited and still in infancy</td>
</tr>
<tr>
<td>Portugal</td>
<td>Limited</td>
<td>Very important</td>
<td>No, there has been a large increase in spending</td>
<td>Limited</td>
</tr>
<tr>
<td>UK</td>
<td>Marketisation has been a clear policy objective since major reforms implemented in 1993</td>
<td>The prevalence of informal caregiving has grown during the period of austerity</td>
<td>Yes, especially since 2010</td>
<td>Yes, considerable investments in the area</td>
</tr>
</tbody>
</table>

*Source: Greve (2017, pp. 189–190).*
Notes

1 Both quotes are from Fernandez et al. (2011, p. 578).
2 This is based on Missoc’s introduction to long-term care (www.missoc.org/MISSOC/INFORMATIONBASE/COMPARATIVETABLES/CROSSCUTTINGINTRO/Introduction_Table_12.pdf) (accessed 10 December 2016). Missoc is a mutual information system on social security in Europe.
3 All the countries are included in a project (SPRINT) financed as part of Horizon2020 by the European Commission.
4 Some are born with a need for long-term care or will be in need of long-term care for other reasons even before they reach the age where they have a chance to be on the labour market, but they will never be able to be insured to save for the costs of long-term care, and, in these cases this will be the task of the welfare state.

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