



# Challenges in long-term care in Europe

A study of national policies  
2018

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**European Social Policy Network (ESPN)**

**Challenges in long-term care in  
Europe**

**A study of national policies  
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The European Social Policy Network (ESPN) was established in July 2014 on the initiative of the European Commission to provide high-quality and timely independent information, advice, analysis and expertise on social policy issues in the European Union and neighbouring countries.

The ESPN brings together into a single network the work that used to be carried out by the European Network of Independent Experts on Social Inclusion, the Network for the Analytical Support on the Socio-Economic Impact of Social Protection Reforms (ASISP) and the MISSOC (Mutual Information Systems on Social Protection) secretariat.

The ESPN is managed by the Luxembourg Institute of Socio-Economic Research (LISER) and APPLICA, together with the European Social Observatory (OSE).

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## Contents

PREFACE .....	4
SUMMARY, CONCLUSIONS AND RECOMMENDATIONS .....	6
Summary .....	6
Conclusions .....	9
Recommendations .....	10
1. DESCRIPTION OF THE MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S) .....	12
1.1 Governance and financing .....	12
1.2 Formal care services .....	13
1.3 Cash benefits for the care-dependent person .....	16
1.4 The role of informal carers .....	17
1.5 Marketisation of Long-term care .....	18
2 ANALYSIS OF THE MAIN LONG-TERM CARE CHALLENGES IN THE COUNTRY .....	20
2.1 Assessment of the main challenges in LTC .....	20
2.1.1 The challenges of access and adequacy .....	20
2.1.2 The quality challenge .....	28
2.1.3 The employment challenge .....	30
2.1.4 The financial sustainability challenge .....	34
2.2 Reforms and ongoing policy debates in long-term care .....	37
3 ANALYSIS OF THE INDICATORS AVAILABLE FOR MEASURING LONG-TERM CARE .....	40
ANNEX 1: FIGURES .....	43
ANNEX 2: DEFINITIONS .....	46
ANNEX 3: COUNTRIES' OFFICIAL ABBREVIATIONS .....	48
ANNEX 4: REFERENCES .....	49
ANNEX 5: PRESENTATION OF THE EUROPEAN SOCIAL POLICY NETWORK (ESPN), JUNE 2018 .....	50

## PREFACE

The solemnly proclaimed European Pillar of Social Rights (henceforth called “the Pillar”) lists access to affordable and good quality long-term care (LTC) services<sup>1</sup> as one its core principles. Formal care services<sup>2</sup> should be affordable since they can involve significant financial costs, leaving many persons who are reliant on care with unmet needs. The Pillar prioritises home care (provided at the home of a person in need of care) and community-based services (the range of non-institutional care services), including for persons with disabilities<sup>3</sup>. At the same time, having a well-developed and qualitatively good residential care<sup>4</sup> (including semi-residential care)<sup>5</sup> sector is important in order to provide support in all those cases where home care is not viable: absence of an informal support network, complexity of the LTC needs, lack of respite care, etc.

Population ageing is a key common challenge for Member States in the medium- to longer-term perspective. The European Union (EU) is facing significant demographic changes, with people living longer and healthier lives and with lower birth rates – over the next five decades, the number of Europeans aged 80+ is set to rise from 4.9% in 2016 to 13% in 2070. The old-age dependency ratio (people aged 65 or above relative to those aged 15-64) is projected to grow by 21.6 percentage points, from 29.6% in 2016 to 51.2% in 2070. For the EU, public expenditure on LTC is projected to increase from 1.6% to 2.7% of GDP between 2016 and 2070<sup>6</sup>. Increasing costs are an important challenge for the fiscal sustainability of LTC.

LTC is labour-intensive, relying heavily on informal care<sup>7</sup>. However, in future, the demand for formal care is likely to further increase as a result of a) the reduced availability of informal carers resulting from changing family patterns (notably the increase in the number of single households), b) the growing participation of women in the labour market, c) increased workforce mobility and d) expected further increases in the retirement age. At the same time, the skill-set that the care workforce is required to have is increasingly diverse: from “traditional” care-related competences and soft skills to technological expertise related to advancements in health technologies. In parallel, the attractiveness of the formal care sector to potential workers is undermined by negative perceptions that are related to poor working conditions, stressful working environments, lack of clearly-defined career paths and lack of development opportunities<sup>8</sup>.

LTC provision in Europe is characterised by significant differences between (and within) countries, mainly in the way it is organised (by public, for-profit or non-governmental providers), delivered (home care versus institutional care), financed (in cash benefits, in kind benefits or out-of-pocket payments) and how resources are generated (via general taxation, mandatory social security and voluntary private insurance). Furthermore, a substantial part of LTC is provided by informal family carers, but the extent to which this informal care is supplemented by formal, publicly provided care also varies widely. Unsurprisingly then, there are large cross-country variations in terms of access to/eligibility for LTC. Furthermore, a high proportion of externalised tasks are provided within

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<sup>1</sup> A range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with daily living activities and/or are in need of some permanent nursing care. For detailed definitions, see Annex 2.

<sup>2</sup> Services provided by licenced providers, either in the home or outside the home of the care-dependent person.

<sup>3</sup> In line with the 2006 United Nations (UN) Convention on the Rights of Persons with Disabilities.

<sup>4</sup> Care provided in a residential setting for elderly people living in accommodation with permanent caring staff.

<sup>5</sup> Care provided in an institutional setting for care-dependent persons who do not permanently reside in the institution.

<sup>6</sup> European Commission (2018), The 2018 Ageing Report, Economic and budgetary projections for the 28 EU Member States (2016-2070), Directorate-General for Economic and Financial Affairs, [download here](#).

<sup>7</sup> Informal care is provided by informal carers (such as relatives, spouses, friends and others), typically on an unpaid basis and in the home of the care recipient (European Commission 2018).

<sup>8</sup> EU Skills Panorama (2014) Skills for social care Analytical Highlight, prepared by ICF GHK and CEDEFOP for the European Commission.



the hidden economy: the personal and household services (PHS) sector has one of the highest levels of undeclared work.

Along with the diverse situations in Member States, some additional factors make EU policy coordination challenging:

- the complexity of LTC: the mix of health and social care, further complicated by the lack of sufficient coordination between the two; the mix of formal and informal care; and
- monitoring difficulties, due to the informal nature of most LTC services, an absence of EU agreed outcome indicators and (reasonably) comparable data.

Yet, while there is no one-size-fits-all policy solution, Member States are confronted with similar challenges:

- an **access and adequacy** challenge due to the underdevelopment of publicly funded formal LTC services and a lack of complementarity between formally and informally provided LTC;
- a **quality** challenge, as demographic changes will increase the tensions between volume of care and its quality;
- an **employment** challenge, especially for women, who are often informal carers; and finally
- a **financial sustainability** challenge, linked to population ageing and increasing public spending for long-term care and closely scrutinised by the European Commission's Directorate-General for Economic and Financial Affairs (DG ECFIN) since 2001.

The high profile given to the right to LTC in the European Pillar of Social Rights opens up opportunities to develop a more ambitious action plan for the EU which is able to respond to the challenges of the next few years.

### **A Synthesis Report from the European Social Policy Network**

In support of the Commission's analysis and forthcoming initiatives, the European Social Policy Network (ESPN) was asked to conduct a description and analysis of the national long-term provisions and the challenges ahead, with a focus on LTC for the elderly (65 or over).

In response to this mandate, this Synthesis Report: a) provides a brief description of the main features of national LTC systems in Europe; and b) analyses the abovementioned four challenges of national LTC systems identified in the 35 countries under scrutiny. The report also identifies national reforms aimed at tackling these challenges. Finally, it presents a brief overview of national LTC indicators.

The report's primary purpose is to illustrate the main challenges and trends in national policies through a limited number of examples. Countries which have developed along similar lines are listed in brackets so that the reader interested in reading more about these can examine the 35 ESPN national experts' reports<sup>9</sup>. In producing their reports, national experts cite many different sources in support of their analysis. References to these are not included in the present report. Readers wishing to follow up the original sources are again invited to consult the individual expert reports.

This Synthesis Report draws on the national contributions prepared by the 35 ESPN Country Teams<sup>10</sup>. It was written by Slavina Spasova, Rita Baeten, Stéphanie Coster, Dalila Ghailani,

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<sup>9</sup> Please note that the countries in brackets are provided as a matter of example and the list is not necessarily exhaustive.

<sup>10</sup> For a presentation of the ESPN Network Core Team and the 35 ESPN Country Teams, see Annex 5. The 35 ESPN national experts' reports can be [downloaded here \(ESPN page on the European Commission website\)](#)

Ramón Peña-Casas and Bart Vanhercke of the ESPN's Network Core Team<sup>11</sup>, with helpful comments and suggestions from the ESPN Country Teams and from colleagues in the Network Management Team<sup>12</sup>. Comments and suggestions from the European Commission are also gratefully acknowledged, while the usual disclaimer applies.

## **SUMMARY, CONCLUSIONS AND RECOMMENDATIONS**

### **Summary**

Based on the in-depth national contributions prepared by the 35 ESPN Country Teams, the Synthesis Report puts forward the following key findings.

#### **a) Main features of national long-term care systems**

##### **Interinstitutional and territorial fragmentation**

In most countries, LTC for the elderly is not a distinct social policy field. LTC provisions in many countries are indeed characterised by a fragmentation of responsibilities and consequently a lack of integration between health and social aspects of LTC provision. LTC is typically funded from different sources and organised at different – horizontal and vertical – levels.

The health system is responsible for the care provided by health professionals, while services related to supporting the care-dependent person in the activities of daily life are usually organised by the social sector. Only some countries organise their system in a way which integrates health and social care horizontally (e.g. DK, IE, PT). In most countries, this horizontal split between the health and social sectors is accompanied by a vertical division of responsibilities, with powers attributed at different institutional levels: national, regional and local (e.g. AT, BE, BG, CH, CY, CZ, DE, EE, EL, ES, FR, HR, HU, IT, LI, LT, LV, MK, NO, PL, RO, SI, UK).

##### **Towards the prioritisation of home-based care**

In many countries (e.g. AT, DE, DK, ES, FI, FR, IS, LI, LU, NO, SE, SI), home care (care provided in and around the elderly person's own home) has priority over residential care (where the dependent person lives in a residential setting). However, in many countries formal home care services for the elderly remain underdeveloped (e.g. BG, CY, EE, EL, ES, HU, IE, MK, PL, RO, TR).

In order to enable the elderly to live independently and to keep them physically, mentally and socially active as long as possible (and thus in order to prevent reliance on care services and social isolation), prevention and rehabilitation strategies are of the utmost importance. However, only some countries have successfully implemented such strategies (e.g. DE, DK, LU, PT, as well as more recently FR, UK/England and Scotland).

Similarly, in many countries residential care facilities for the elderly are underdeveloped (e.g. EE, EL, HR, HU, MK, PL, RO, TR), while in others supply has been reduced as a result of policies aiming for deinstitutionalisation<sup>13</sup> (e.g. DK, FI, IS, NL, SE, NO). Since demand largely exceeds supply in many countries, a private commercial sector for those care-dependent persons who can afford it (e.g. CY, EL, HU, MK, MT, PT, RO, RS, TR, UK) and ineffective use of healthcare provisions (e.g. extended stay in hospital awaiting discharge) have emerged.

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<sup>11</sup> The authors are from the European Social Observatory (OSE, Brussels). They wish to thank Paola Signorelli (University of Milan) for her graphical support.

<sup>12</sup> We wish to thank Denis Bouget (European Social Observatory and European Trade Union Institute), Hugh Frazer (Maynooth University, Ireland) and Eric Marlier (Luxembourg Institute of Socio-Economic Research, LISER) for their very useful comments on the draft Synthesis report and in particular for fine-tuning the policy recommendations.

<sup>13</sup> A process of partial replacement of institutional care by home care and community-based services.

## **Funding arrangements**

Public funding for LTC services and cash benefits can be made dependent on the care needs of the dependent person, their income and assets and the availability of family carers. In nearly all countries, out-of-pocket payments (OOPs) are required both for home care services and residential care. Most of these schemes are funded from general taxation.

### **A significant role for informal care**

LTC relies heavily, in all 35 European countries covered in this Synthesis Report, on the care provided by informal carers, mainly spouses and children of the care-dependent person. In most cases, they are women. In some countries, family responsibilities between children and parents are enshrined in law (e.g. HU, LV, LT). Countries vary greatly in the extent to which the informal carer is supported by public policies. A limited number of countries grant cash benefits directly to the carer (e.g. CH, FI, HU, IE, UK) and many countries have care leave schemes, that allow caring relatives to take some time off from gainful employment or to reduce their working time.

## **b) Main long-term care challenges in national systems**

### **Access and adequacy challenges**

Institutional settings and local and regional differences strongly affect effective access to LTC services and benefits. The fragmentation of provisions between healthcare services and social services often leads to a lack of coordination between entities which affects waiting periods and administrative procedures (e.g. BG, CY, CZ, EE, FR, LT, LV, RS, SI, UK). In addition, regional responsibilities for LTC have resulted in disparities in LTC provision in many countries.

Homecare services and community-based LTC are the most difficult to access, since they are underdeveloped in many countries. There is a clear division between European countries in this respect. Home and community-based services are most developed in the Nordic countries (DK, FI, IS, NO, SE) and some continental countries (e.g. AT, BE, DE, FR, LU, NL). By contrast, those in need of LTC in Southern (e.g. CY, EL, ES, MT, PT) and Eastern European countries (e.g. BG, CZ, EE, LV, LT, MK, PL, RO, RS, SI, SK) and the UK face insufficient availability of home care provision or provision often targeted at persons with a high degree of dependency.

One of the consequences of the priority given to home care and community-based provision has been that the availability of residential care has been decreasing in several European countries over the past 25 years. ESPN experts from Nordic countries indeed report a significant process of deinstitutionalisation and emphasis on the development of home care. In Southern Europe (e.g. ES, IT, PT), however, there is a clear trend towards increasing the number of LTC beds for people aged 65+, due to changes in labour market structure (more women working), increase in the pensionable age and changes in the family structure (and norms). In Eastern Europe the situation is less clear-cut. Indeed, in some countries there has been a slight but steady decrease in the number of residential beds since the 2000s (e.g. LV) while in other countries there has been a certain increase in the number of residential homes (e.g. BG, EE, LT, RO).

Crucially, the challenge of insufficient availability of residential care affects all regions in Europe. As pointed out above, the Nordic countries and many continental countries have steadily reoriented their LTC policy mix towards home care and community care. However, the ESPN country reports show that deinstitutionalisation is a complex issue. Deinstitutionalisation is not a problem per se but becomes a concern when it is not matched with a sufficient increase in more and affordable home care and community-care provision. Thus, deinstitutionalisation should be part of an overall reshuffling of LTC provisions: it is not a "cheap" option and residential facilities should be accessible and affordable.

In addition to structural factors, effective access to home care has been hindered in some countries by the economic and financial crisis, which has resulted in cuts in public funds and /or a tightening of the eligibility criteria (e.g. DK, EL, ES, HR, IE, UK).

### **The quality challenge**

The quality of LTC is key to maintaining and improving the quality of life of frail elderly persons, both in residential and home care settings. The most common approach to monitoring quality in EU countries is the use of a set of pre-determined standards and requirements, for accreditation, licensing or registration of providers (e.g. CY, CZ, DE, ES, FI, IE, LI, LT, LV, NL, PL, PT, RS, RO, SI, SK, UK). However, this mainly applies to residential facilities and rarely to home-based services. Additional information on the quality of care is sometimes, but not systematically, taken from user satisfaction surveys or an analysis of complaints.

When focusing on the quality challenge, one must also consider the working conditions for the people who provide services. The attractiveness of the sector remains low, as it is often depicted negatively, due to poor working conditions and job precariousness (low income, lack of training, high workload and high level of strain) which leads to a severe shortage of qualified professionals.

### **The employment challenge**

In all the countries under scrutiny, there is a high incidence of informal care. The lack of accessible formal LTC facilities is mentioned by the ESPN experts as the main reason for the expansion of informal care. Other reasons include the poor quality of LTC (e.g. IT, MK, UK), the highly biased subsidisation of LTC (CY), the shortage of institutional and community services (e.g. HR), the non-affordability of LTC (e.g. IT, MK) and, last but not least, the traditional model of intergenerational and familial relations. Moreover, despite cultural changes, new attitudes and relative progress in the distribution of the caregiving burden, women continue to assume responsibility for and carry out most caregiving. This negatively impacts on female labour market participation. Data show that women are far more likely to reduce their working hours or leave employment in order to provide care than men.

Domestic workers, often migrant women, also play an important role in LTC provision at home in several countries. The main reasons for this are the high costs of professional care services, the lack of support for persons of working age with dependent relatives and the lack of access to formal home care services or residential care services. Migrants' qualifications and working conditions in LTC settings are important issues to be tackled in many countries.

### **The financial sustainability challenge**

Expenditure on LTC has been increasing over the past 20 years in many of the 35 countries under scrutiny. It is expected that LTC spending will be high on many countries' agendas, as projections show that public LTC expenditure in the EU is to increase from 1.6% to 2.7% of GDP, i.e. an increase of almost 70%, exerting constant pressure on public finances. However, projections regarding the financial sustainability of LTC vary widely across countries.

Financial sustainability is hampered by the aforementioned horizontal fragmentation of care between health and social entities. The lack of a clear financial strategy by local or regional entities or a bias towards a certain type of care (e.g. residential care) may also lead to unpredictable LTC spending.

## **c) Reforms**

LTC provision has been subject to several reforms over the past 10 years (2008-2018) in most of the 35 countries under scrutiny. There have been three main trends with regard to different aspects of LTC: a) readjustments to the LTC policy mix and specifically moves away from residential care towards home care and community care, b) efforts to enhance financial sustainability and c) improving access to and affordability of care, including by improving the status of informal carers.

#### d) Measuring long-term care challenges

Indicators to measure access, adequacy and financial sustainability are available in most countries. However, the quality of LTC is a multidimensional phenomenon which remains very difficult to grasp: data are often available only on an ad-hoc basis and often do not cover the quality of care. Comparing countries on these dimensions is therefore highly problematic.

#### Conclusions

National LTC arrangements for the elderly (65+) vary substantially among the 35 countries under scrutiny in terms of organisation, funding and types of care offered. However, there are three trends and challenges common to many of them.

First, most European countries face issues relating to access to and financing of LTC systems, due to the **institutional and geographical fragmentation** of LTC provision. This is problematic, also regarding the quality of LTC which remains a critical factor in maintaining and improving the quality of life of frail elderly people both in residential and home care settings.

Second, there has been a clear **trend towards prioritising home care**. However, home care services and community-based care are the most difficult to access in many countries, since they are underdeveloped. One of the consequences of the importance given to home care and community-based provision has been that the availability of residential care has been decreasing in several countries over the past 25 years. Indeed, in countries with a long tradition of residential care, especially the Nordic countries, the process of de-institutionalisation is highly visible. However, Southern and Eastern European countries have been increasing residential places, even though the demand for care considerably – and increasingly – exceeds the supply. In this context, several ESPN experts have pointed to a strong long-term trend towards the privatisation and marketisation of LTC and rapid growth of a commercial sector (e.g. BE, DE, DE, FI, LT, RO, UK). Homecare also goes hand in hand with prevention and rehabilitation strategies, to enable the elderly to live independently and to keep them physically, mentally and socially active for longer. Nevertheless, only some countries have successfully implemented such strategies (e.g. DE, DK, LU, PT, as well as more recently FR, UK/England and Scotland).

Third, in all 35 countries analysed there is a **high incidence and expansion of informal care**, mainly due to the lack of accessible formal LTC facilities, the poor quality and the high cost of LTC as well as the traditional model of intergenerational and familial relations. Despite cultural changes, new attitudes and relative progress in the distribution of caregiving tasks, women continue to take responsibility for and carry out the bulk of caregiving. This negatively impacts female labour market participation. In spite of these challenges, only a limited number of countries have well-developed services (e.g. training, counselling, respite services) tailored to informal carers. Last but not least, domestic workers, often migrants, play an increasingly important role in informal care in many countries: the issues of their qualifications and working conditions need policy responses in many countries.

## Recommendations

This part of the Synthesis Report primarily proposes recommendations to the 35 countries under scrutiny and to the European Commission. These recommendations build upon those suggested by the 35 ESPN Country Teams in their national reports.

### a) Recommendations to countries

#### Development of formal home care and community-based care

1. The development of home care and semi-residential services should be a priority in all countries. This should be supported by appropriate funding for these types of provision in order to ensure their accessibility and affordability.
2. The development of home-based services should go hand in hand with strong prevention and rehabilitation policies, to ensure that people can continue to live for as long as possible in their own home if they so wish. Home care should be available to all persons with LTC needs and not only to the most care-dependent elderly.
3. Efforts to better integrate health and social services are essential in ensuring adequate home care. The development of multidisciplinary care plans between the different parties involved constitute an important tool.
4. Countries should consider investing more in training of people who provide home care and community-based care in order to improve the quality of this type of care.
5. Countries should consider reinforcing the process for monitoring the quality standards of home and community-based care.

#### Residential care facilities

6. While prioritising home care over residential care, countries should avoid policies which reduce the supply of residential institutions without providing sufficient home-based services. An appropriate national policy mix should be found, which provides sufficient residential care facilities. Planning of the number of care places should be based on an objective assessment of the population's needs, adapted to the regional situation.

#### Cash benefits

7. Where cash benefits are provided, payment should be made subject to proof that it is used to pay for care. If cash benefits are used to recruit domestic workers, this recruitment should be made conditional upon a formal employment contract with the care worker. If the cash benefit is used to compensate the informal carer, the involvement of the carer should be defined in a multidisciplinary care plan.

#### Informal carers

8. Stronger support for informal carers should include:
  - information, training and counselling (tele-assistance services might be an effective tool);
  - respite care, to allow informal carers to take a break from caring tasks;
  - regular checks on the ability and willingness of informal carers to bear the burden of care as well as meeting their own needs;
  - improved ways of sharing care tasks among more than one informal carer;
  - improved social (security) rights for informal carers, enhanced possibilities to remain in the labour market (e.g. part-time carers' allowances) and to return to it;
  - the development of adequate LTC arrangements in order to support the labour market participation of informal carers (mostly women);
  - adequate leave to take care of dependent relatives, currently not available in all countries, so that carers (mostly women) are not obliged to work part-time or leave the labour market. Flexible working arrangements and reduced working hours should be available to people with caring responsibilities to prevent them having to leave the labour market;

- possible enhanced LTC benefits in kind and carers' leave in order to achieve a high level of employment and a sustainable work-life balance for middle-aged workers with dependent relatives.

#### Domestic workers

9. Specific attention should be paid to the role and situation of migrant domestic workers, especially their status, qualifications and working conditions.

#### Financial sustainability of LTC

10. Countries should aim to gather and update evidence and data on sustainability in order to plan the funding of the LTC policy mix (benefits and services).
11. More effective and cost-efficient measures should include an even stronger emphasis on rehabilitation and social investments (e.g. in prevention strategies, innovative technologies and social services).

#### Enhancing quality of care

12. Countries should apply stricter standards to the various providers and above all should extend their scope to cover home care. Effective checks on and supervision of the quality of care should be reinforced.

### **b) EU-level recommendations**

1. In implementing Principle 18 of the European Pillar of Social Rights on LTC<sup>14</sup>, the EU should give attention to all strands of LTC and ensure a balanced approach between the various strands that reflect the different needs of dependent elderly people. While home care and community-based services are becoming a key strand of LTC provision, residential care still plays an important role in LTC and will continue to do so in the future. It is therefore important to closely monitor its accessibility, affordability and quality. Semi-residential care should also be a priority for investment as it can play a significant role somewhere between home care and residential care.
2. Monitoring and reporting on the adequacy and the quality LTC should be built into the European Semester process, with the use of Country Reports and Country-Specific Recommendations for those countries lagging behind.
3. The EU should continue to foster the exchange of learning and good practice on the development of LTC provision through peer reviews, the collection of case studies and support for networks of practitioners and providers.
4. The EU should give more consideration to the potential for job creation in the LTC sector.
5. The use of EU funding (notably the European Social Fund [ESF]) should be promoted to develop home care, assist in the improvement of skills and support for informal carers (e.g. training, counselling, respite care) as well as professional services, especially in countries with the least developed LTC systems.
6. Exchange of information is needed between the EU and other data producers, in particular the OECD and the World Health Organisation, to improve knowledge and monitoring of LTC needs and provision. The EU's Social Protection Committee and its Indicators Sub-Group can play an important role in this respect.
7. Where data allow (availability and robustness), the EU should consider breaking down LTC indicators into age groups.
8. Member States should agree on a common set of indicators to assess the quality of LTC. To do so, a major step forward would be to reach an agreement on a common EU definition of quality of care.

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<sup>14</sup> "Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services".

## 1. Description of the main features of the long-term care system(s)

This section provides an overview of the main characteristics of systems for long-term care (LTC) for the elderly in the 35 countries analysed and outlines the various related policies across Europe. Section 1.1 discusses core features of the governance and financing of the systems. Section 1.2 addresses the array of available formal services for LTC. The cash benefits available for care-dependent elderly people are described in Section 1.3, while the role of informal carers and the support schemes available to them is discussed in Section 1.4.

### 1.1 Governance and financing

In most countries, LTC for older people is not a distinct social policy field. Many ESPN experts point to the fragmentation of responsibilities and policies and the consequent lack of integration between health and social aspects of LTC provision. LTC is typically funded from different sources and organised at different levels, both horizontally and vertically.

In most countries there is, first of all, a horizontal sharing of responsibilities between the health and social care sector in terms of regulation, funding and service provision (e.g. AT, BE, BG, CH, CY, CZ, DE, EE, EL, ES, FR, HR, HU, IT, LI, LT, LV, MK, NO, PL, RO, SI, SK, UK [apart from Scotland]). Many ESPN experts highlighted that this horizontal division hampers coordination of care and in some countries the fragmentation even hampers service provision, due to political discord on who should pay what (e.g. LT). Some countries have managed to organise their system in a relatively integrated manner between health and social care (e.g. IE, DK, UK/Scotland, PT). More recent efforts to improve coordination between the health and social strands of LTC have been made in Norway, but also, to some extent, in Hungary and France. In Norway, the role (including financial responsibility) of the municipalities in the overall system has been strengthened to this end. Strikingly, since 2015 the Netherlands has, with the aim of ensuring financial sustainability, moved in the opposite direction: from an integrated national scheme towards a scheme involving various governance levels and with responsibilities split between health and social care.

This horizontal split between the health and social sector is in many countries accompanied by a vertical division of responsibilities, with competences split between different institutional levels: national, regional and local. In what follows we will discuss this division of responsibilities on regulation, funding and care provision for respectively the health and the social LTC services.

LTC for the elderly provided by health professionals such as nurses physiotherapists and general practitioners is typically regulated and funded at national level (e.g. BE, CH, CY, CZ, EL, FR, HR, HU, IE, LI, LT, LV, MK, NL, PL, RO, SI, UK) and sometimes at the regional level (e.g. DK, IT).

Social care for the elderly, which includes care services that aim to help the care-dependent person to carry out activities of daily life (such as household tasks, eating etc.), is funded and regulated at the national (e.g. BG, CY, EL, HU, IE, IT, LU, MK, MT, SI), at the regional or local level (e.g. DK, FI, LV, NO, UK), and often as a mix between these three levels (e.g. AT, BE, CH, ES, FR, HR, HU, IS, LI, LT, NL, PL, RO, RS, TR). Ensuring provision of social services is often a responsibility of the regions<sup>15</sup> (e.g. AT, BE, CH, ES, FR, HR, IT, MT, NL, RO) and municipalities (e.g. BG, DK, EE, EL, IT, LT, CY, FI, IS, NL, NO, RO, SI, TR, UK). Home care is most often provided by the municipalities. Some countries also have state-run LTC services, in particular for residential care (e.g. BG, EL, HR, LV, MT, SI, RS, TR, UK) or homes run by pension funds (e.g. MK). LTC care can be provided by public

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<sup>15</sup> "Regional" can have different meanings in the European countries. Here we use this term to denote any intermediate level between the national level and the local level, i.e. municipalities. For instance, in Belgium the regional level, in this particular context, refers to the Communities, which are federated entities. In some countries the regional level may include different intermediate levels. For instance, in France, it covers "Départements" and "Régions". For more information on territorial division of responsibilities, we invite the reader to check the Thematic reports of countries concerned.



providers/municipalities, not-for profit organisations, private for profit providers and individuals, usually contracted or co-funded by the municipalities (e.g. AT, BG, BE, CY, CH, CZ, ES, FI, IS, LV, MT, NL, NO, SI, TR). Care providers may also be contracted by care insurance bodies (e.g. DE).

In some countries, non-healthcare related responsibilities for LTC (including its funding) have been decentralised towards the regions (e.g. BE, ES, FR, NL) and the municipalities (e.g. NL, RO, UK/England). ESPN Experts stressed that decentralised policies made the funding unstable and vulnerable (e.g. BE, ES, NL, RO). In the UK (England), OOPs are widespread and are the result of cuts in central government funding to local authorities. Budgetary motives often played a role in decentralisation policies (e.g. ES, NL, RO). In many countries the financial burden on municipalities for co-funding services has substantially increased (e.g. BG, NL). In some countries decentralisation of competencies has made it possible to regroup some of the responsibilities previously strictly divided between the health and social sector (e.g. BE, FR,) and to ensure more integrated care (e.g. FR).

In many countries, the important responsibilities of the regions and municipalities in both (co-) funding and care provision, result in considerable regional/municipal differences in care provision, eligibility criteria and out-of-pocket payments (OOPs) (e.g. BE, CH, CZ, ES, FI, IT, NL, RO, SE).

## 1.2 Formal care services

In this subsection we will discuss first the healthcare related LTC services and next the services related to social care. For both types of services, we first discuss the kind of services provided, followed by a description of the eligibility criteria for access to publicly funded care, including the assessment of the care needs. We finally consider the OOPs to be paid by the service users.

The healthcare system usually covers the LTC services provided by health professionals, in particular nurses and physiotherapists, both at home and in institutions. Home care can include nursing care (personal care, medication, etc.) and physiotherapy/rehabilitation. In most countries, LTC has been separated from hospital care, although psychiatric hospitals may provide LTC to elderly patients with mental health problems. In some countries, there are specialised nursing hospitals and nursing departments in general hospitals (e.g. LT, MK, SI). Stays in these facilities may be time-limited, until the patient is admitted to a LTC facility (e.g. LT, SI). In Portugal, discharge of elderly people in need of LTC from hospitals is prepared by specialised patient discharge teams. Residential nursing homes can be part of the healthcare system or may receive financial payment from the healthcare system for the nursing/physiotherapy activities they carry out (e.g. EL, LI). LTC health services may also include palliative care and teams that provide care to the terminally ill (e.g. EL, CZ, HR, LT, MK, PT) and hospices (e.g. BG, CY, CZ, HR).

Access to health services is subject to the individual's healthcare coverage, and in principle eligibility is based on medical assessment and prescription (e.g. BE, CH, LI, LT, MK, PL, SI). Health services are in many countries free of charge, while in others relatively limited out-of-pocket payments may apply.

The range of social services for care-dependent elderly people can vary widely between and within countries in terms of the care provided. Social care includes home care, semi-residential care and residential care. The services can be strongly intertwined with healthcare related LTC services.

Home care first of all, includes assistance in the activities of daily life (bathing, clothing, eating, shopping, cooking, etc.). This can be provided by professional services or by individuals. In some countries (e.g. BG, FI, RO, SE, DK) the elderly can appoint a person to carry out care tasks – often a female family member – provided that they enter into an employment contract with the public authorities. In Sweden, this rarely happens in practice. Home care furthermore includes subsidised food services (meals on wheels or meals provided in a service centre) (e.g. BE, DK, FI, HU, MT, PT, RS, SI), alert systems

through which the elderly can connect to a help post in case of need (e.g. BE, FI, HU, LV, MT, UK), nursing and technical aids and devices such as nursing beds (e.g. DE, DK, EE, FI, LV, UK), support to adapt private houses (e.g. DE, DK, FI, FR, RO, UK), social counselling (e.g. EE, FI), tele-assistance (e.g. ES, FI) and handyman services (e.g. FI, MT).

In many countries home care has priority over residential care (e.g. AT, DE, DK, ES, FI, FR, IS, LI, LU, NO, SE, SI). The Nordic countries in particular have made major efforts to make it easier for people to stay as long as possible in their own homes and to reduce the number of people living in institutions (e.g. DK, FI, IS, NL, SE).

In order to enable the elderly to live independently as long as possible and thus to prevent the reliance on care services, some countries have emphasised prevention and rehabilitation (e.g. DE, DK, LU, PT, as well as more recently FR, UK/England and Scotland). In Denmark, the elderly are offered a preventive visit that focuses on functional, psychological, medical, and social resources and challenges. Prevention also includes initiatives aimed at keeping older people physically, mentally and socially active and at combating social isolation (e.g. DK, FR, MT, PT, RS, SI). Rehabilitation aims to prevent loss of functional capacity or to maintain or improve such capacities.

To ensure coordination of home care services, in some countries a multidisciplinary-care plan is drawn up, with the involvement of all the relevant actors, often including the informal carer and the care-dependent person (e.g. ES, FI, FR, LI and recently CY). Social services also inform and advise all those involved in the specific care situation (e.g. AT, FI, MT).

In several other countries, home care services for the elderly are underdeveloped (e.g. EE, EL, HR, HU, MK, RO, TR). As a result, only a limited number of people in need of LTC can enjoy these services. In still other countries, important efforts have been made recently to strengthen home care (IE, HU, LV), often with support from the European funds (e.g. BG, EL, EE, IT, LT, SI, RS). In recent years, several countries have tightened their eligibility criteria, restricting services to individuals with the most severe care needs (e.g. EL, HU, IE, SE, UK/England). This tightening of eligibility has usually been driven by austerity policies. In some countries, measures seriously restricting access to services were taken in response to the 2008 financial crisis (e.g. EL, IE, UK/England).

Semi-residential care is care provided in an institutional setting for care-dependent persons who do not permanently reside in the institution. It includes centres where the frail elderly can be cared for only during the day, or during the night. Day care is provided in nearly all countries, night care much less so (e.g. DK, BE, ES, MT). It can relieve caring relatives or other caregivers during the day (or the night). Short stays (for a limited number of days) in a care/nursing home can relieve the caregiver during a short break, or allow rehabilitation for an elderly person, for instance after hospitalisation (e.g. AT, BE, DE, ES, FI, FR, LI, LU). Sheltered housing is also covered by the concept of semi-residential care. These facilities house frail elderly people living independently but in a relatively protected environment, with a certain level of support, often closely linked to a care/nursing home (e.g. AT, BE, BG, DK, EL, FI, MK, SI).

Residential care, refers to care provided in a residential setting for elderly people living in accommodation with permanent caring staff. It includes care facilities specifically for the elderly or incorporated into institutions for disabled people. Residential care is provided in nursing homes in nearly all countries, but also comprises centres for social rehabilitation and integration (e.g. BG, EE) and care in foster families (HR, MK), where frail elderly people are housed in small groups in a family environment.

Some countries have a strongly developed residential LTC sector for the elderly (e.g. SI). In many other countries, residential care facilities for the elderly are historically underdeveloped (e.g. EL, PL, RO, HR, MK, RS, TR), in others supply has been reduced as a result of policies aiming for deinstitutionalisation (e.g. see Section 2). In many countries demand largely exceeds supply (e.g. CY, EL, HU, LV, MK, MT, PT, RO, RS, TR). These institutions are concentrated in urban areas. They can usually freely set their prices and often there is less supervision of the quality standards of the care offered (e.g. CY, CZ).

Experts point to the questionable quality standards in many commercial institutions (e.g. CY; see also Section 2.1.2).

Eligibility for publicly funded LTC services (including through health insurance schemes, long term care insurance schemes and state budgets) can be subject to the care needs of the dependent person, his or her income and assets and the availability of family carers.

To define care needs, a home visit is usually carried out by the social services. The assessment of care needs is increasingly based on a functional assessment, using a scale defining the degree of care dependency (e.g. AT, BE, DE, ES, HR, HU, MK, LT, LU, LV). In Poland and the Netherlands such a system only applies to health-related LTC. In Macedonia, no particular minimum level of dependency has been defined. An objective and standardised scale to assess care needs could prevent favouritism in the allocation of care, which might be crucial in a context of supply shortage. In some countries the relevant authorities carry out an evaluation of the needs, without the use of an official classification (e.g. BG, PL, NL). In the UK/England, only those with substantial or critical level needs are eligible for publicly-funded LTC. Residential care is often reserved for the persons with most severe care needs (e.g. DK, ES, FI, IS, LU, NO, SE). Eligibility for the highest level of benefits can also be based on the nature of (severe) disabilities (mental or bodily disabilities, blindness, etc.) (e.g. EL, LV, MK, PL), sometimes combined with lower level benefits for less care-dependent people (e.g. MK). Public funding can be subject to means-testing (e.g. CY, HR, MK, TR). In some countries, access to public LTC services is subject to means-testing and/or asset testing (e.g. UK, EL and RS for home care), and may be reserved for citizens with no family support (e.g. BG, EL, LV, PL, UK, TR) or above a certain age (e.g. for home care in EL). In some countries, before deciding on the provision of home care services, the (municipal) assessment body first searches for individuals or social networks to take on the responsibility for care (e.g. NL, EE).

Subsidies may be available for buildings, infrastructure (BE) operational and maintenances costs (RS) or to cover the deficits of the public institutions (HR, LI). The salaries of employees may also be (partially) covered (RS).

In nearly all countries, out-of-pocket payments (OOPs) may be required both for home care services and for residential care. In some countries, the full price is directly paid by the resident (e.g. AT, EE). In some countries, home care services are free of charge (e.g. DK, TR and LU) or charges are very low (e.g. MT, BG, SE, Scotland, Wales and Northern Ireland). OOPs for home care are means-tested in the UK.

Accommodation costs (meals, housing) in residential settings are usually borne by the residents (e.g. AT, BE, CH, DE, DK, FR, LU, MK, NL, SI). In case of insolvency of the cared-for, the family bears these costs in many countries (e.g. BE, EL, HU, LV, MK, RO,). There may be a cap on the price (e.g. HR), on the total amount to be paid by the resident (e.g. DK, SE) or on the amount as percentage of the income (and assets) due (e.g. AT, HU, IE, IS, LT, LV, MT, NO, NL, RO) in public care homes. In many countries, a certain amount or percentage of the residents' income is safeguarded as pocket money (e.g. AT, IS, LU, LV, MT, UK).

OOPs can also depend on the income of the resident (e.g. HU, IE, IT, LT, LV, MT, NL, NO, PL, RS, SI, UK,) or the income of both of the resident and his family (e.g. MK, RO). In some countries a cash benefit can be used to (partially) cover the cost of the formal services, both for home care and residential care (e.g. AT). In most countries, municipalities (e.g. AT, BE, DE, LT, LV, NL, RO, SI), the state/region (e.g. AT, IE, FR, LU, MK) or insurers (e.g. CH) cover the costs of those care-dependent persons who themselves, or their relatives, are unable to pay the cost of the care. Accommodation costs for residential care are usually borne by the resident.

Some experts point to adverse incentives generated by different funding sources. For instance, in the Czech Republic, the considerable differences in costs for the LTC clients often result in the hospitalisation of people who need social care.

### 1.3 Cash benefits for the care-dependent person

In some, mostly Nordic, countries, formal services have priority over cash benefits (e.g. DK, FI, IS, NO, SE, UK), while in others the LTC system is predominantly based on cash benefits (e.g. AT, CY, IE, IT, LT, RO). In some countries, beneficiaries can choose between cash, formal care or a combination of both (e.g. AT, CY, DE, LU, NL, UK), in others such a combination is not possible (e.g. ES). A choice can also be required between a personal assistant (such as a family member employed by the municipality) or an equivalent monthly indemnity (e.g. RO, UK).

Some cash benefits are rooted in longstanding benefit schemes for severely disabled people (e.g. EE, EL, FI, HR, HU, MK, RO, SK, RS, UK) and may have been extended to include some specific old age disabilities such as dementia (e.g. PT). Other schemes have been established from the mid 90ies onwards, to address the challenges of an ageing society and rising demand for LTC services (e.g. AT, DE, BE, FI, CZ, CY, LU, ES, FR, MT, NL), even if most of the latter are not exclusively targeted at the elderly.

Most schemes providing cash benefits are funded from general taxation. However, the schemes in Germany are based on mandatory contributions and the system in Luxembourg and Belgium/Flanders are funded by a mix of contributions and taxes. In Sweden, it is up to the municipalities to decide whether or not to set up a (rather limited) cash benefit scheme.

The eligibility criteria for these cash benefits vary considerably, as do the way they can be used, the amounts paid and the take-up. Eligibility for cash benefits can depend on 1) the degree of care dependency, 2) income and assets and 3) age of the care dependent person; often eligibility depends on a combination of these criteria. The granting of the benefit can furthermore be made conditional upon the usage of the amount for specific types of care or care providers.

In some countries, two or more kinds of cash benefits exist in parallel for those dependent on care, funded from different sources, with different eligibility criteria, and paying different amounts. Some cash benefits can be cumulated, others are mutually exclusive, for instance because they target different population groups (e.g. groups with different social security coverage or of different ages).

As an example, in the UK there are potentially two cash benefits for older people. The first is the "attendance allowance" intended to meet extra disability-related costs. There are no requirements on how this is spent and it is administered and allocated through the UK-wide social security system. The attendance allowance is not dependent on the claimant's income or assets. The second is a cash personal budget targeted at those eligible for publicly funded LTC, who can receive a cash personal budget instead of services in kind and employ their own carer (close co-resident relatives are usually excluded). The usage of this allowance is closely monitored. It is available from local authorities, using the same assessment and eligibility processes as access to LTC services (including income test and co-payment requirements).

The right to and amount of the cash benefit usually depends on the degree of care dependency (e.g. AT, CY, CZ, ES, IT, FI, FR, LI, LU, LV, NL, NO, PT, SI, UK).

In some systems the benefit is reserved for people with severe disabilities (e.g. CY, EL, HR, HU, MK, RO, RS, SK, TR). The eligibility for (e.g. CY, HR, MK, PT, TR) and the amount of the benefit (e.g. ES, FR, SK) can also depend on the income of the beneficiary. In Malta the cash benefit is only granted to elderly people on a waiting list for admission to long-term residential care. In some countries the amounts vary according to the age of the recipient. In Poland, a (rather small) nursing benefit is universally granted to all individuals aged 75 or more, irrespective of their need for care.

In some countries no specific requirements on the use of the benefit are established (e.g. AT, IT, LT, RS, SI, SK and UK for the attendance allowance). Often however the spending of the cash benefit is subject to strict requirements to only use the money to pay formal services and/or domestic workers/home assistants (e.g. CY, ES, FR, LU, NL, UK). Formal

care services can even be paid for directly by the funding body (e.g. DE, LU, UK and LI for residential care) or payment can be made subject to a proven use of third-party assistance or a contractual relationship with a licensed service provider (e.g. ES, FR, LI, NL, UK). In some countries the amount of the benefit varies depending on whether it is used for formal or informal care and on the kind of services used (e.g. CY, DE, ES). It can also depend on the care defined in the individual care plan (e.g. ES, FR).

Cash benefits can be used to recruit a domestic worker or to pay the informal carer. In Malta and Turkey, cash benefits can only be used for this and not to pay for formal care. The beneficiary can usually make the arrangements and recruit the domestic worker or the informal carer himself. Sometimes a formal employment contract has to be shown (e.g. ES, CY, LI, MT, NL, UK). The care allowance may increase if more than one domestic worker is necessary (e.g. AT, CY). Benefits used to pay an informal carer can also be made subject to certain conditions: that there is a long-standing caring relationship between the cared-for person and the carer (e.g. ES), that there are no accredited service providers available (e.g. ES), or that the carer is a family member (e.g. TR). In France, spouses are not eligible for a caring allowance and in the UK a personal budget cannot usually be used to pay a close co-resident relative.

Besides the officially recruited domestic workers, in many countries domestic workers, often migrant women, are recruited by the care-dependent person or his family, without a proper employment contract or work permit (e.g. CY, RO, IT). In countries with no strict requirements on the use of the cash benefit, this benefit is frequently used to recruit a domestic worker, often for undeclared work (e.g. CY, IT, LT, LV, RO). Alternatively, the worker may be paid out of pocket by the care user.

The take-up of the different kinds of cash benefits and the use thereof largely depend on the characteristics of the scheme. In many countries, most beneficiaries use the cash benefit to pay an informal carer (e.g. AT, CZ, DE, LU, ES), often in combination with the use of formal homecare services (e.g. AT, DE, LU). By contrast, in France only 8% of those receiving a cash benefit use it to pay an informal carer. This could be partly because the cash benefit in France cannot be used to pay the spouse of the care-dependent person. In Austria there are indications that informal care is especially utilised for individuals with few functional impairments, whereas above a certain level of functional impairments informal care primarily supplements formal home care. The care allowance is often considered as an additional income for the family or for the informal carer (CZ, PL, SI). In the Czech Republic the provision of cash benefits did not accelerate the development of formal home care, contrary to expectations.

Several ESPN experts mentioned that the aim of providing cash benefits to pay formal providers is to supplement the shortage of public care services with financial support to purchase care from private providers (e.g. ES, LV, MT, UK).

Care-dependent persons can furthermore receive other benefits, such as reduced OOPs for healthcare (e.g. CY, MK), tax deductions for care expenses (e.g. FI) or transport services (e.g. LT, PT).

#### **1.4 The role of informal carers**

Without exception LTC relies heavily, in the 35 countries under scrutiny, on the support provided by informal carers. These are above all family members, mainly spouses and children of the care-dependent person. Besides the key informal carer, other individuals such as neighbours and voluntary organisations can also be involved in supporting care-dependent elderly people.

In some countries family responsibilities between children and parents are enshrined in law (e.g. LV) and even in the constitution (e.g. HU, LT). For elderly people in residential facilities, family responsibility is formally enshrined in an obligation to cover the out-of-pocket payments if the care-dependent person is not able to pay for care. This applies in many countries (see Section 1.2 above).

Countries do however vary greatly in the extent to which informal carers are supported by public policies. Specific benefits to support informal carers are often underdeveloped (e.g. CH, DK, SI) and even non-existent (e.g. EE, EL).

Some specific formal home care and day/night care may support the informal carers (see Section 1.2 above). Some countries furthermore actively involve the informal carer in the design of the multidisciplinary care plan, which sets out the responsibilities of the various formal and informal carers in the care process (e.g. LU, ES, FR). To relieve the informal carers for some days from care responsibilities and to allow them to take some holidays, many countries provide respite care. This can take the form of formal services, such as a short stay in an institution or a stand-in at home (e.g. AT, DE, FI, LT, MT, LU, NL) or a cash benefit to pay for formal care services for a limited period (e.g. CY, FR).

Cash benefit schemes, allowing the care-dependent person to provide the informal carer with financial compensation for the loss of income from employment and to ensure social insurance coverage, can alleviate financial pressure on the informal carer (see Section 1.3 above).

In some countries the informal carer can receive a cash benefit (e.g. CH, FI, HU, IE, SK, UK). Such schemes can act 1) to replace lost income, linked to social protection coverage, and 2) as an acknowledgement (often symbolic) for the work of caring. The schemes can require that the informal carer has no (e.g. PL, UK) or only a limited number of employment hours outside the house (e.g. HU, IE). In Finland, a contract must be drawn up between the carer and the municipality. Cash benefits can be means-tested (e.g. IE, SK) and they can be limited to persons giving care to a severely disabled person (e.g. SI, SK). In some countries the benefit can be shared between two persons (e.g. IE). In Norway, a benefit is provided to persons taking care of a terminally ill person. There can be wide variations in cash benefit schemes between municipalities (e.g. CH, EE, FI, LV, NO, SE). In some countries, cash benefits for the carer are rather symbolic, and meant as a recognition of the work done by the carer (e.g. CH).

Many countries have care leave schemes, that allow caring relatives to take some time off from gainful employment or to reduce their working time (e.g. AT, BE, FR, AT, HU, IE, IT, LU, NL, UK). Different schemes can exist, e.g. for supporting a care-dependent person or for care in the terminal phase of life (e.g. AT, BE, FR). In some countries employees are entitled to this sort of replacement benefit under certain conditions. In others, there is no such legal entitlement and the leave is conditional upon the approval of the employer (e.g. AT). The financial benefit related to the care leave can vary greatly. In some countries beneficiaries continue to receive a full salary (IT, LU), in others they receive limited financial compensation (e.g. AT, BE) and in others the care leave is unpaid (e.g. FR, HU, IE, HR). In some countries part-time care leave is possible (e.g. AT, FR). Usually, care leave schemes are time-limited (e.g. AT, BE, IT).

Some schemes provide, under certain conditions, social insurance coverage for informal carers (e.g. AT, CZ, DE, EE, FI, IE, LT, LU, MK, NO, UK) or a reduction of the premium to be paid for such coverage (e.g. ES). Tax credits can also be allocated to the informal carer (e.g. IE). Nursing courses can be offered to informal carers (e.g. DE, ES) and information, advice and counselling (including through hotlines, online platforms and tele-assistance) can be provided (e.g. AT, FR, ES, NL). In Ireland, recipients can avail of activation services once their period of caring ends. Finally, municipalities sometimes support voluntary organisations in their caring activities for the elderly (DK, IS).

### **1.5 Marketisation of Long-term care**

Several ESPN experts have pointed to a strong long-term trend towards the privatisation and marketisation of LTC (e.g. BE, DE, FI, LT, UK).

In some countries (SE, UK/England), private for-profit and non-profit institutions have developed as a result of deliberate policies to increase competition and create markets in LTC provision. In many countries, private for-profit care institutions qualify for public funding (e.g. BE, DE, DK, EL, ES, FI, FR, SI, SE, UK) or public authorities contract a number

of beds in commercial homes (e.g. MT, TR). ESPN experts in these countries highlight the rapid growth in the commercial sector. Shortages in formal care have encouraged some countries to set up cash benefit schemes, to enable care-dependent people to purchase care from private providers (e.g. ES, LV, MT). Some ESPN experts highlight that the establishment of personal care budgets will boost the market for private for-profit providers (e.g. FI).

In countries with severe shortages of publicly provided formal care, a private commercial sector for those care-dependent persons who can afford to pay for it themselves has emerged (HU, LV, MK, MT, RO, RS, TR, EL, UK). Box 1 illustrates some cases of marketisation of LTC services.

**Box 1: Examples of marketisation of long-term care services**

*In England, 89% of domiciliary services and 94% of residential beds for older people are supplied by private providers. The residential market in particular is dominated by several large chains backed by private equity capital and reliant on risky financial structures.*

*In Sweden, there has been a dramatic increase in privately provided LTC, and the entire increase is the result of the growth of for-profit – in contrast to non-profit – providers. The LTC sector has been highly deregulated but remains publicly financed. County councils and municipalities can contract out services to private service providers. Private actors are given the opportunity to start a clinic where they choose and then send the bill to the county council. The county councils cannot decide where the clinics shall be located, for example depending on where the need is greatest.*

*In Germany, in 2015, 41% of all nursing homes were private for-profit, 54% private non-profit and 6% public. In home care, as many as 63% of providers were private for-profit, 36% private non-profit and 1% public.*

*In Ireland, about three-quarters of the formal care services are provided in the for-profit sector. Private commercial providers are increasing their share of the sector in a context where nursing home occupancy rates are high at 94% and demand outstrips supply. In 2013, 66.8% of all long-stay beds were provided by the private sector, 10% by the voluntary sector, and only 23.1% by the public sector. Most places are majority-funded by the state, regardless of the sector.*

*In Finland, by 2010 elderly care was already the biggest budget line of private social services and this trend is about to grow further, mostly from the public purse. For example, in the city of Oulu, half of LTC services are currently bought from private companies and the city has decided to cover all further needs by buying in services from private companies. Most probably, the share of private providers will expand when the ongoing SOTE-reform (reform of the whole Finnish social and health care service system) opens up more possibilities for choosing between public and private providers. Personal care budgets will also expand the use of private care providers (on the Finish reform see also Section 2.2).*

## **2 Analysis of the main long-term care challenges in the country**

This section first provides an analysis of the main challenges facing national LTC systems (Section 2.1). The second part discusses how European countries deal with these challenges by describing recent reforms and on-going policy debates (Section 2.2).

### **2.1 Assessment of the main challenges in LTC**

This section focuses on the main challenges facing national long-term systems identified in the 35 countries under scrutiny: these are access to and adequacy of LTC provision (2.1.1); the quality of LTC provision and jobs (2.1.2); issues related to the employment of the carers (2.1.3) and finally the financial sustainability of national systems (2.1.4).

#### **2.1.1 The challenges of access and adequacy**

##### **Access to long-term care: deinstitutionalisation and beyond**

Section 1 described the wide variation among the 35 countries analysed with regard to the LTC provided. Despite this variety between systems, effective access<sup>16</sup> can be seen as depending mostly on two key elements: a) the country's institutional LTC structure and territorial division and b) the policy mix of LTC provision available: home care, community care, residential care, as well as cash benefits and benefits in-kind.

The institutional structure and territorial division of LTC competences have a strong impact on the effective access to LTC services and benefits. As described in Section 1, in several countries the responsibility for LTC provision is divided between healthcare services and social services. Several ESPN experts argue that such a horizontal division may lead to a lack of coordination between entities which has adverse effects for the recipient: e.g. waiting periods, administrative procedures, fragmentation of services, and a high risk of non-take up (e.g. BG, CY, CZ, EE, FR, LT, LV, RS, UK). Many ESPN experts report that the territorial division of LTC provision leads to disparities in LTC provision in their country. There are issues linked to formal territorial division (e.g. federal entities, regions and municipalities) and certain consequences inherent in the territorial structure (e.g. urban/rural; remote areas that are difficult to access, etc.). In federal states or states with significant devolution of powers to some regions, there may be considerable differences in the quantity and quality of care provision (e.g. AT, BE, ES, UK). Moreover, several ESPN experts report differences in access among regions and municipalities because of their size and the funding opportunities available (e.g. BG, CZ, FI, FR, IT, LT, LV, NO, SE, UK). In addition, effective access to care is often hindered in rural and remote areas (e.g. BG, FR, NO, SK).

The policy mix of available LTC provision unsurprisingly differs among the 35 countries under scrutiny and can even vary within a country (e.g. regions, urban/rural areas). Despite these differences, also in terms of outcomes, there are certain clear tendencies among particular groups of countries (e.g. Northern countries, Southern European countries and Eastern European countries). In general, all national reforms and strategies have emphasised care at home (see Section 2.2) but this has led to very different policy mixes and outcomes.

Home care services and community-based care represent the biggest challenge in terms of effective access, since in many countries they are underdeveloped. There is a clear split between European countries in this respect. Home and community-based services are most developed in all the Nordic countries (DK, IS, FI, NO, SE) and some continental countries (e.g. BE, DE, FR). On the other hand, several experts from Southern (e.g. CY, EL, ES, MT, PT) and especially Eastern European countries (e.g. BG, CZ, EE, LV, LT, MK, PL, RO, RS, SI, SK) report insufficient availability of home care provision, which is often targeted at persons with a high degree of dependency. Some of these trends are quite strongly visible

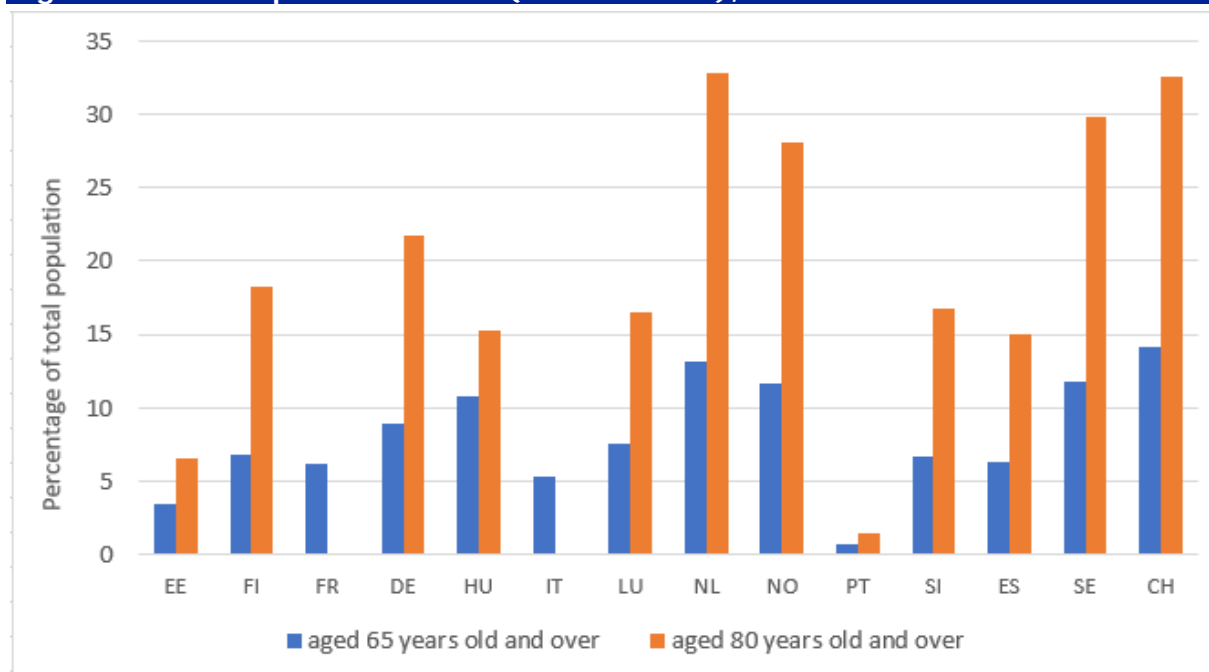
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<sup>16</sup> This section refers to challenges in "effective access" to LTC provisions. As discussed in Section 1, in general citizens have "legal access" provided that they meet the eligibility conditions.



when looking at the OECD indicator on LTC recipients at home<sup>17</sup> as a share of the population aged 65 or over (see Figure 1).

**Figure 1: LTC recipients at home (65+ and 80+), 2014**

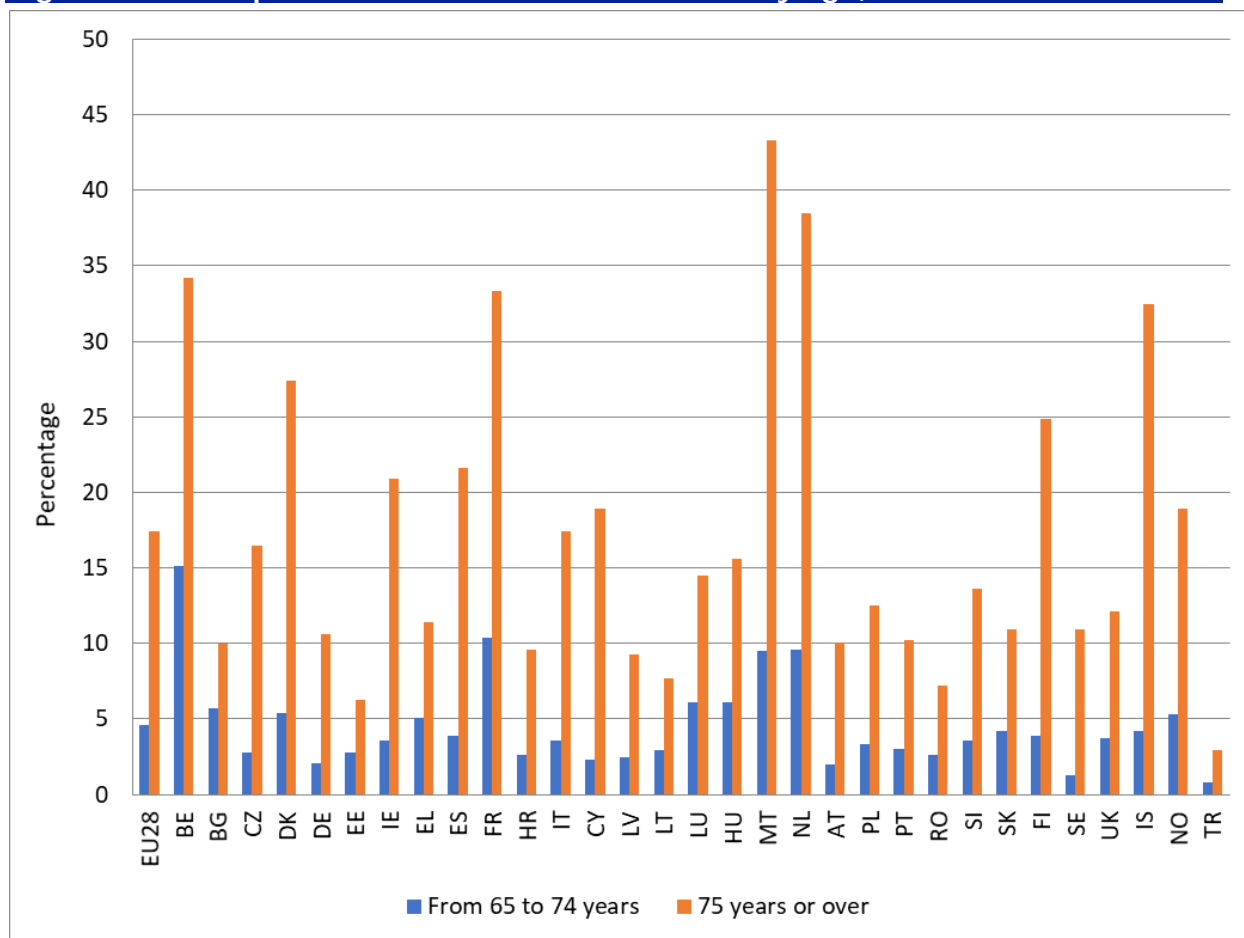


Source: OECD; \* ESPN countries not included in the dataset AT, BG, CY, EL, HR, IS, IE, LV, LI, LT, MK, MT, RO, RE, SK, TR; \*\*No data for the years considered in the graph: BE, CZ, DK, PL, UK \*\*\* No data for 80+ for FR and IT

In Nordic countries such as Sweden (11.8%), Norway (11.6%) and Finland (6.8%), the values are among the highest; the figures reach 29.8%, 28.8% and 18.3%, respectively, for the 80+. In some Continental countries there are similar tendencies regarding the percentage of LTC recipients at home of the population aged 65 or over: this is the case in Germany (8.9 %), the Netherlands (13.1%) and Switzerland (14.8 %); for those aged 80+, these values reach, respectively, 21.9%, 32.8% and 32.6%. In contrast, percentages of LTC recipients at home are quite low in Eastern and Southern European countries: for instance, 3.5% (65+) and 6.5% (80+) in Estonia, and 0.7% (65+) and 1.4% (80+) in Portugal.

Another indicator — self-reported use of home care services of the population aged 65 or over — allows for a broader comparison between the 35 ESPN countries and shows similar tendencies. The Nordic (e.g. NO, SE) and continental countries (BE, FR, NL) score among the highest values while Eastern European countries display among the lowest values. In all countries except for Bulgaria, the percentages of self-reported use of home care services are on average at least double, and in some cases even four times higher, for persons aged 75+ (see Figure 2).

<sup>17</sup> People receiving formal (paid) LTC at home. This term also covers the use of institutions on a temporary basis to support continued living at home —such as in the case of community care and day care centres as well as respite care. Home care also includes specially designed or adapted living arrangements for persons who require help on a regular basis while maintaining a high degree of autonomy and self-control. The services received by LTC recipients can be publicly or privately financed. Excluded from the indicator: disabled persons of working age who receive income benefits or benefits for labour market integration without LTC services. See more details online (OECD Health Statistics 2017).

**Figure 2: Self-reported use of home care services by age, 2014**

Source: Eurostat [hlth\_ehis\_am7u]; \* ESPN countries not included in the dataset: CH, LI, MK, RS

In addition to the abovementioned structural factors, effective access to home care provision has been hindered in some countries by the economic and financial crisis, which has led to cuts in public funds and/or a tightening of the eligibility criteria (e.g. DK, EL, ES, HR, IE, UK). Ireland, Croatia and Sweden have refocused home care towards individuals with the most severe care needs. In Denmark, the total hours of home services provided decreased by 18 %, and the number of persons receiving home help decreased by 12 % between 2010 and 2016. Likewise, the Portuguese ESPN experts report a recent drop in the number of places available within the home-based health and social care teams. In Ireland there has been a significant decline in the home care sector: home help services have decreased from over 55,000 in 2008 to under 47,000 in 2016; the number of beneficiaries decreased by almost 10,000 between 2008 and 2012. There were approximately 4,600 people on waiting lists for home care in 2017 in Ireland.

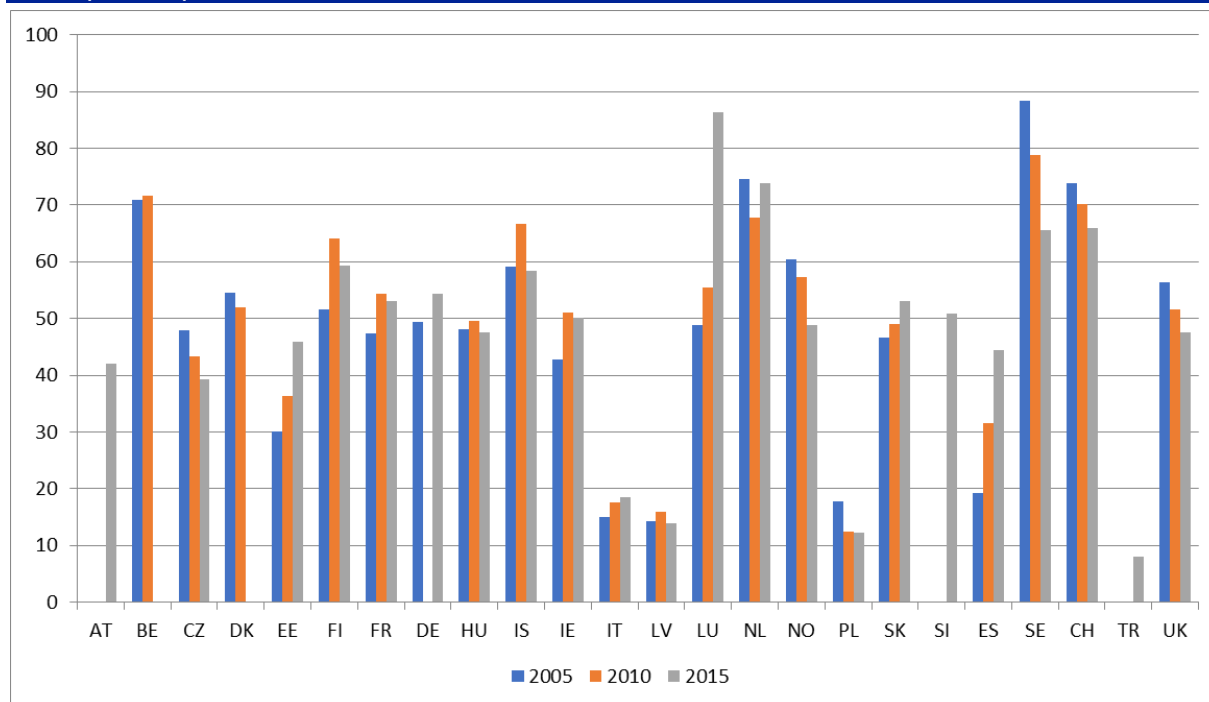
One of the consequences of the importance attached to home care and community-based provision has been that the availability of residential care has decreased in several countries over the past 25 years<sup>18</sup>. However, there are substantial differences between countries with a long tradition of residential care, such as the Nordic countries and some Continental countries, and Southern and Eastern European countries which do not have such a tradition. Data show that Nordic countries have significantly reduced the number of residential beds over the past 25 years<sup>19</sup>. However, in some of these countries, new residential places were created between 2005 and 2010 (FI, IS). ESPN experts from these countries report a significant process of deinstitutionalisation and greater emphasis on the

<sup>18</sup> World Health Organisation (WHO), Nursing and elderly home beds per 100,000 population.

<sup>19</sup> Ibidem.

development of home care. The number of residential beds for persons<sup>20</sup> aged 65+ has steadily diminished since 2005 (DK, NO, SE), becoming a common trend especially after 2010 (FI, IS, NO, SE) (see Figure 3).

**Figure 3: Beds in residential long-term care facilities (65+, per 1000 population), 2005, 2010, 2015**

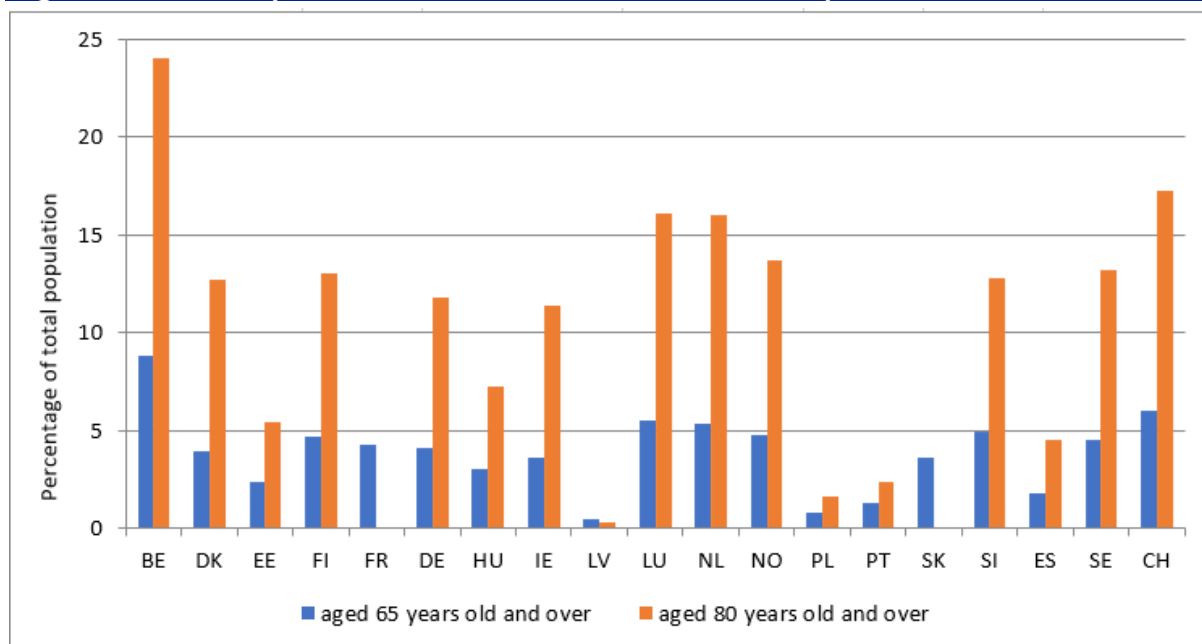


Source: OECD; \* ESPN countries not included in the dataset: BG, CY, EL, HR, LI, LT, MK, MT, PT, RO, RS; \*\*No data for the years considered in the graph: 2005: AT, SI, TR; 2010: AT, DE, SI, TR; 2015: BE, DK

At the same time, Nordic countries still have among the highest percentages of LTC recipients in residential facilities<sup>21</sup> (see Figure 4).

<sup>20</sup> Residential LTC facilities comprise establishments primarily engaged in providing residential LTC that combines nursing, supervisory or other types of care as required by the residents. Excluded from the indicator: hospital beds reserved for LTC and beds in residential settings such as adapted housing that can be considered as the individual's home. See more details [online](#) (OECD Health Statistics 2017).

<sup>21</sup> People receiving formal (paid) LTC in institutions (other than hospitals). LTC institutions refer to nursing and residential care facilities which provide accommodation and LTC as a package. Included also in the indicator: persons who receive LTC from paid LTC providers, including non-professionals receiving cash payments under a social programme, recipients of cash benefits such as consumer-choice programmes, care allowances or other social benefits which are granted with the primary goal of supporting individuals with LTC needs based on an assessment of needs. Excluded from the indicator: persons receiving LTC in hospitals and disabled persons of working age who receive income benefits or benefits for labour market integration without LTC services. The services received by LTC recipients can be publicly or privately financed. See more details [online](#) (OECD Health Statistics 2017).

**Figure 4: LTC recipients in institutions (other than hospitals), 2014**

Source: OECD; \* ESPN countries not included in the dataset: AT, BG, EL, CY, HR, IT, LI, LT, MK, MT, RO, RS, TR; \*\*No data for the years considered in the graph: CZ, IS, UK\*\*\* No data for 80+ for FR and SK

In Continental Europe, there have been some less pronounced trends. The number of residential beds (65+) has indeed only slightly increased in France, Germany and the Netherlands and has remained stable in Belgium. The only exception is Luxembourg, where the number of beds per 1,000 inhabitants increased from 41.1 in 2001 to 83.7 in 2016. At the same time, all these countries have among the highest values of LTC recipients in institutions, with Belgium topping the charts at 8.8 (65+) and 24% (80+). National data from Germany show that in 2015, around 2.86 million people required LTC, of which around one third (0.78 million) were living in nursing homes.

In contrast to the developments in Nordic and Continental Europe, there is a clear trend towards increasing the number of LTC beds for 65+ in Southern Europe (e.g. ES, IT, PT), notably due to changes in the labour market structure (more women working), increase in the pensionable age and changes in family structure. For instance, in Italy the number of beds increased from 12.2 in 2000 to 18.5 in 2015. However, there are important regional differences: the coverage of residential and home care services in Southern Italy is (at least) half that registered in Centre-Northern Italy. Based on national data, the ESPN Portuguese team highlights the fact that even though there has been a steady increasing trend in the number of residential beds, only 8,400 beds of the 14,640 established as a target had been created by the end of 2016. Interestingly, in Spain, in the beginning of the 2000s there was an oversupply of residential places - these were not occupied mostly due to their cost or because of a cultural preference for care provided by relatives at home.

In Eastern European countries the situation is less clear-cut. According to OECD data, in some countries there has been a slight but steady decrease in the number of residential beds since the 2000s (e.g. CZ, LV, PL)<sup>22</sup>. However, these data should be viewed with some caution. For instance, the Polish ESPN team highlights that in the social sector the number of beds remains stable. In other countries<sup>23</sup>, national data show that there has been

<sup>22</sup> OECD data, LTC beds per 1,000 population aged 65+

<sup>23</sup> World Health Organisation (WHO), Nursing and elderly home beds per 100,000 population (see Annex 1, Figure A1).

a certain increase in the number of residential homes (e.g. BG, EE<sup>24</sup>, LT, RO). The reasons for the increasing need for LTC are similar to those in the Southern countries: a steep increase in the old-age dependency ratio (esp. in BG), changes in the family structure and an increase in the pensionable age (esp. for women). Moreover, several ESPN country reports point to young and middle-aged people emigrating, which challenges the “familialist”<sup>25</sup> model of caring for the elderly at home. For instance, in Romania, the total number of public homes for the elderly increased from 98 in 2009 to 123 in 2016, while there was a spectacular increase in the number of private homes, from 51 to 246, for the same period. The number of users (total public and private) rose from 7,379 to 14,590. Thanks to that, the proportion of pending applications out of the total capacity – for both private and public institutions – decreased from about 40% in 2009 to about 14% in 2016, reflecting a fairly constant “active demand” for institutionalisation. In Bulgaria, 11,000 people were placed in 161 homes for adults and elderly people needing institutionalised LTC in 2016. This number has remained virtually unchanged since 2003, leading to waiting lists of people amounting to one third of the existing capacity in 2017. In the Czech Republic in 2016, there were 37,247 beds in homes for the elderly and almost 67,000 unsettled applications. In Lithuania, in 2014, 47% of the elderly in need of LTC were on a waiting list for residential care, with an average waiting time of six months.

Nevertheless, there has been a steady creation of institutional places in most Southern and Eastern European countries, and a growing demand for residential places. Simultaneously, although strategies have been put in place to increase home care and community-based care, ESPN experts report an underdevelopment of these services in terms of variety and sufficient supply. For instance, in Lithuania, only three out of 60 municipalities were able to provide a sufficient variety of social services for the elderly in 2017.

Regardless of geographical region or countries’ LTC policy mix, all countries in Europe are facing the challenge of insufficient availability of residential care for older people. As pointed out above, the Nordic countries and many continental countries have steadily reoriented their LTC policy mix towards home and community care. Several ESPN experts highlight an explicit process of deinstitutionalisation. However, deinstitutionalisation is a very complex issue. Deinstitutionalisation is not a problem per se: ESPN experts show that it becomes a concern when it is not matched with a sufficient increase in more and affordable home care services and community-care provisions. Thus, deinstitutionalisation should be part of an overall reshuffling of LTC provision: it is not a “cheap” option and residential facilities should be accessible and affordable.

Although all the Nordic countries have refocused their LTC policy mix in this direction, the outcomes seem to be very different. In Sweden the significant downsizing of residential care since the 1990s has in practice raised access thresholds so that only the most dependent older people can access institutional care. Moreover, these cutbacks in institutional care have not been sufficiently offset by an increase in home help services, and this has led to an important share of informal care (see Section 2.1.3). In contrast, in Denmark, deinstitutionalisation is coupled with measures to avoid a shortage of care and most recently with a renewed emphasis on rehabilitation measures. Such measures have become a compulsory part of the home help offered prior to the calculation of the elderly person’s need for personal and practical home help.

Some ESPN experts, in particular those from Eastern European countries, also stress that deinstitutionalisation should be considered according to the age group. While it has shown good results for children (especially in many eastern countries), deinstitutionalisation of

<sup>24</sup> OECD data, LTC beds per 1,000 population aged 65+.

<sup>25</sup> Familialism is related to society models where care duties are traditionally provided by family and there are scarce, publicly provided alternatives to this family care. For further discussion, see: Saraceno C. (2004), ‘De-familization or re-familization? Trends in income tested family benefits’, in Knijn T., Komter A. (eds.), *Solidarity Between the Sexes and the Generations: Transformations in Europe*, Cheltenham, UK, Edward Elgar Publishing, pp. 68-88; see also Bouget D.; Saraceno C. and Spasova S. (2017), *Towards new work-life balance policies for those caring for dependent relatives?* in Vanhercke B.; Sebastiano S. and Bouget D. (eds.), *Social Policy in the European Union: State of Play 2017*, Brussels: European Trade Union Institute and European Social Observatory, pp. 155-179.

services for the elderly may lead to inadequate coverage of those in need of care, as these countries have still underdeveloped home and community-based care systems (e.g. BG, HR, SI).

Finally, with regard to cash benefits, all countries provide cash benefits for dependent persons and only a few countries provide allowances for the carer (see Section 1 and *Bouget et al. 2016*). In general, problems with effective access to benefits for dependent persons may be linked to eligibility conditions, as these often require a degree of disability, meaning that in some cases only heavily dependent persons have access to them (e.g. BG).

In some countries, the cared-for person is free to use the cash benefit to pay for care (see Section 1.3). For instance, data from Austria show that the majority (2016: 42%) of the recipients of LTC cash benefits were looked after in home-based informal care provided by relatives or friends, without using formal care services; alternatively, people were looked after by their relatives or friends at home and at the same time received formal outpatient (mobile) care services (2016: 32%), while 21% of LTC cash benefit receivers lived in nursing homes and related institutions (inpatient care) and about 5% were looked after by privately hired carers at home (so-called “24-hour care at home”). By contrast, in France only 8% of those receiving a cash benefit use it to pay an informal carer. The care allowance is often considered as an additional income for the family or for the informal carer (e.g. CZ, PL). In the Czech Republic the provision of cash benefits did not speed up the development of formal home care, contrary to what was expected.

Access to benefits for care may be hampered by strict requirements with regard to the family relationship with the cared-for person, the employment status of the carer and the residence of the carer.

### **The unknown factor: adequacy of long-term-care**

For the purposes of this Synthesis report as well as for the ESPN national Thematic Reports, we estimate the overall LTC system as “adequate” if it provides sufficient and affordable social protection to cover the existing needs for LTC care. Sufficiency and affordability of LTC has been assessed by the ESPN experts according to the national context and the limited data available. The examples in Box 2 illustrate some of the issues related to affordability of homecare and residential care.

#### **Box 2: Affordability of home care and residential care**

*The UK ESPN experts estimate that far fewer people receive publicly-funded social care compared to the pre-crisis period and there is extensive unmet need as a consequence. An estimated 1 in 8 older people now lack help with vital everyday care tasks, including just under 1 in 5 who need help with bathing, getting out of bed or using the toilet but receive no help. Lack of social care is argued to have a major impact on hospitals, causing increasing numbers of emergency admissions and significant delays in discharging patients who have finished treatment. Between 2013 and 2015, there was a 31% increase in hospital bed use by patients awaiting discharge. The supply of home care is also affected by market failure – companies going out of business/handing back contracts to local authorities because of lack of funding.*

*In Lithuania in most municipalities home care is provided only on weekdays and during work hours.*

*In Croatia, a few services are available, but only a limited number of people in need of LTC use them. For instance, the “assistance at home” service was provided to only 3,258 persons older than 65 at the end of 2015.*

*In Flanders (Belgian region), the total cost of one hour of home care in 2011 was 34 euros, of which 4.94 euros was an own contribution from the user, i.e. 14.5% of the total cost. For home help the figures were respectively 32 euros and 6.22 euros or 19.4% of the total cost.*

*In the Czech Republic, the cost of home services and a lack of information are two main barriers to greater use. The monthly care allowance for heavy dependency would cover only approximately two and a half hours of care per day.*

*In Germany, the purchasing power of benefits has decreased considerably. The increases in benefits to date have not compensated for this decline in purchasing power. In 2014, the private costs of LTC amounted to 36.6% of the total expenditure on LTC.*

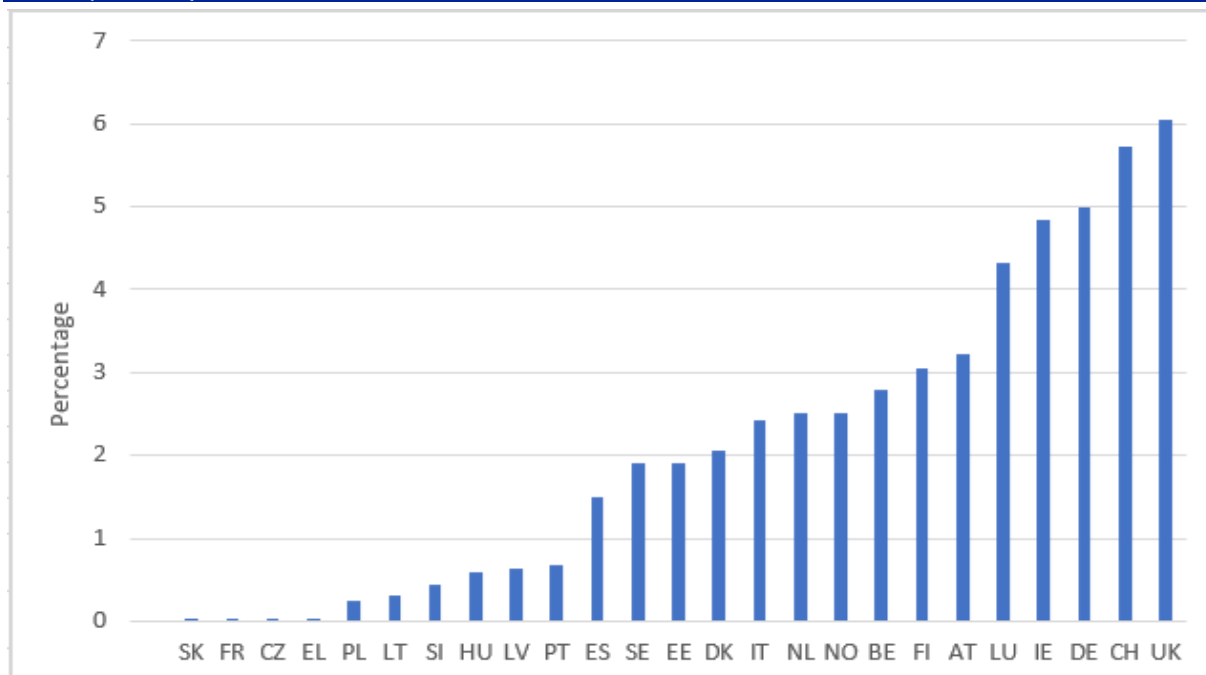
*In France, residential care homes are considered to be expensive, with the average remaining cost to be met by residents estimated at between €1,470 and €1,758 per month (excluding social housing benefit for the poorest).*

*In Germany, in 2017, benefit recipients had to pay €1,691 per month (May 2017) for residential care: this is considered expensive considering national standards.*

*In Romania, access to residential institutions is limited by the ability to pay an income-dependent monthly fee corresponding to an average daily allowance by the family or legal guardian (stipulated in a financial contract with the institution). There has been a significant decrease in state subsidies (see Section 2.2) which correlates with an increase in beneficiaries' contributions. In the case of public homes under the responsibility of local authorities, beneficiaries' contributions rose from 26% in 2012 to 30% in 2016; for private homes, the beneficiaries' own contributions even increased from 56% to 74% over the last 4 years.*

Some insights into adequacy may be also provided by the level of out-of-pocket payments and voluntary insurance for LTC (health)<sup>26</sup> measured as a share of the current expenditure on health (see Figure 5; for the overall expenditure on LTC see Figure 6, Section 2.1.4).

**Figure 5: Voluntary schemes/household out-of-pocket payments of long-term care (health), 2015**



Source: OECD, *Health expenditure and financing*, Voluntary schemes/household out-of-pocket payments of Long-term care (health) as a share of current expenditure on health. \* ESPN countries not included in the dataset BG, CY, HR, IS, LI, MK, MT, RO, RS, TR.

<sup>26</sup> Healthcare is financed through a mix of financing arrangements including government spending and compulsory health insurance ("Government/compulsory") as well as voluntary health insurance and private funds such as households' out-of-pocket payments, NGOs and private corporations ("voluntary"). Figure 5 shows only the expenditure on LTC as a share of current expenditure on health (GDP) by voluntary health insurance and by private funds such as households' out-of-pocket payments, NGOs and private corporations. See more details [online](#) (OECD health spending).

The United Kingdom (6%), Switzerland (5.9%), Germany (5%) and Ireland (4.8%) top the charts in terms of voluntary private insurance and out-of-pocket spending while France, Greece and the Czech Republic have among the lowest levels. As already mentioned, the UK and Ireland, for instance, have made important cuts in their public spending on LTC.

## 2.1.2 The quality challenge

### Quality of long-term care: how to enforce minimum standards?

Due to the ageing population, the demand for LTC services is projected to increase substantially and rapidly, creating even more tension between the volume and the quality of care. Despite many efforts to improve the quality of care — notably through accreditation systems and the constant refinement of standards — the quality of LTC still remains a problematic issue in most EU countries. And yet quality care is vital to maintaining and improving the quality of life of frail elderly people in both residential and home care settings. National experts describe severe shortcomings in the quality assurance of care services (e.g. EL, MK, RO, UK) and Lithuania even reports concerns regarding human rights abuses in institutions for the elderly. Only very few countries depict a much more optimistic situation with regard to the quality of care (e.g. DK, SE). Thus, in Denmark, a recent survey showed that in 2015, a large majority of beneficiaries were satisfied with the personal and practical help they received both in their own home and in nursing homes. Some Research has emphasised that in terms of quality the Swedish LTC system stands up excellently in international comparisons (Swedish Association of local Authorities and Regions, 2015, OECD 2013).

The requirements in place vary substantially according to the type of care, i.e. residential care or home care. Whereas the home care sector remains mostly unregulated, residential care is governed by stricter requirements.

The most common approach to monitoring quality in EU countries uses a set of pre-determined standards and requirements (e.g. CY, CZ, DE, ES, FI, IE, LI, LT, LV, NL, PL, PT, RS, RO, SI, SK, UK)<sup>27</sup>. This set of requirements aims to regulate mainly residential care facilities and nursing homes and in some very rare cases home care. Most EU countries emphasize a willingness to require providers in the sector to comply with quality standards, whether using an accreditation system, licenses, or a registration process.

Such an accreditation process makes it possible to assess the quality of care based on minimum standards established with regard to employment (staff ratios and qualifications), infrastructure, living environment and some quality outcomes, although the latter remain underdeveloped. The accreditation process usually involves on-site inspections and quality assessments in order to ensure that the providers meet the established quality standards needed to continue to provide good care (e.g. CY, CZ, IE, LT, PT, RS, SI, UK) (see Box 3 for illustrations). These quality control measures seem to be a first step to ensuring quality commitment, but in some cases, evidence in the national reports reflects problems due to limited resources, a lack of qualified inspectors and/or a lack of transparency in the process (e.g. CZ, LT, RS). Detailed evidence on sanctions in the event of non-compliance with the standards is scarce. In specific cases, licenses or accreditation may be withdrawn and institutions closed (RS, RO). In Serbia, 212 private homes for the elderly were closed in January 2018 as the norms were not respected.

Differences may also occur between the social and health sectors. In some countries, the health sector has clear and well-established standards (PT, SI) in comparison to the social sector, with some exceptions for residential care institutions. Quality assurance in the social sector sometimes reflects the home care situation, which is characterised by a lack of defined standards and certification rules for the staff (e.g. PL). In some other countries,

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<sup>27</sup> See complementary information in OECD/EU (2013), *A Good Life in Old Age? Monitoring and Improving Quality in Long-term Care*, OECD Health Policy Studies, Éditions OCDE, Paris



the registration and inspection regimes cover both residential and home care services (e.g. UK).

It is worth mentioning that standards may be imposed at national level but also by the regions, provinces, or municipalities (e.g. AT, CH, IT). This can lead to discrepancies within a national context.

**Box 3: Setting of requirements and minimum standards in long-term care: illustrations**

*In Latvia, all providers of LTC services must register with the Ministry of Welfare and must meet quality requirements such as those related to the number and qualification of staff, the accessibility of care premises or the adjustment of providers to the needs of recipients. Quality inspections should be carried out to assess all providers every year, but in reality, only some can be assessed due to a lack of resources.*

*In Lithuania, quality standards have been set for residential care institutions according to regulations from the Ministry of Social Security and Labour. Despite supervision of the implementation of standards by the Ministry's Department of Supervision of Social Services, the assessment system is not fully functioning.*

*In Portugal, providers of LTC must follow accreditation procedures. The standards are organised around three general areas: the structure (number of beds, human resources); the process (registration procedures for the assessment of risks etc.) and outcomes (occurrence of injuries, infections, falls etc.). Additionally, some specific standards are set for different types of inpatient unit. Inspections are conducted on a sample of providers.*

*In Ireland, the Health Information and Quality Authority sets standards for residential care and announces regular inspections of nursing homes.*

*In Poland, quality standards established for residential care institutions cover three main domains: employment, procedures and accommodation standards, separately for the health and social sector.*

Although various standards are applied in many EU countries, it remains unclear whether and to what extent these arrangements actually guarantee high quality standards. Information on the outcomes is relatively scarce. Some countries indicate that they resort to user satisfaction surveys (e.g. BE, CY, DE, DK, LT, NL, SE, UK) or examine the complaints received from patients and relatives (e.g. LV, NO, PT) to obtain a better idea of the quality of services. Other countries have developed a set of national indicators (see also Section 3) aiming to improve quality and enhance safety for patients (e.g. DK, FI, NO, PT, SE).

### **Quality of long-term care jobs**

When focusing on the quality challenge, it is important to consider the quality of care services not only for beneficiaries but also for the people who work and provide services. The quality of care services indeed seems to be intrinsically linked to a shortage of qualified professionals (e.g. AT, BG, CZ, DE, LI, MK, NO, RO, UK). The attractiveness of the sector remains low, as it often has a negative reputation and is associated with poor working conditions and job precariousness.

In all countries under scrutiny, the LTC sector is characterised by a low level of income. A vast majority of ESPN country reports refer to poor working conditions with high levels of strain, high workloads, insufficient training, lack of decent rest time and in some cases lack of support and autonomy and high psychosocial risks but some exceptions remain (e.g. FI). Norway underlines other concerns such as the prevalence of part-time work and the high sickness rate. Finland shows evidence of relatively good well-being for employees in general although the workload intensifies in home care settings, as people receiving care in their homes are in poor health conditions. In France, it seems that the situation has

even worsened in nursing homes as the number of residents has increased but the staff ratio remains stable.

Conditions of employment may vary substantially between the health and social sectors (e.g. PL) or between the types of facility (private units vs public facilities) (e.g. CY). In Poland, there are major differences between health and social systems: conditions of employment are regulated and wages are higher in the health sector. In Cyprus, the public LTC sector employs civil servants; nurses and social workers are all university graduates. Employees have higher wages and better conditions of employment. The private sector is characterised by informal care workers with low levels of qualification.

Although some countries clearly point to a lack of training development (EL, ES, TR), others have started to develop specific programmes (e.g. LI, PT, MK). According to national experts, some countries face problems related to over-education in the sector, which reflects an inefficient use of the labour force. In Lithuania, for example, 64% of home helpers have university degrees.

### **Measures available to support family carers in providing good and quality unpaid care**

The situation among EU countries shows clearly a lack of measures available to support family carers (e.g. CZ, EL, ES, IE, MK, NL, PT, SE, SI, TR). A few countries such as Poland and Finland provide support for family carers. Some countries highlight, however, the availability of guidance, counselling, training and education for carers (e.g. AT, CY, EL, DE).

#### **2.1.3 The employment challenge**

This subsection discusses the impact of LTC obligations on the employment of carers. Insufficient provision of formal care hinders female labour market participation. Women are indeed more likely than men to assume care responsibilities for elderly family members with long-term needs. The employment challenge also covers the need to address informal/undeclared work in LTC and to open up skills validation and upskilling to informal learners to assist them in becoming LTC professionals.

#### **Incidence of informal care and impact on female employment participation**

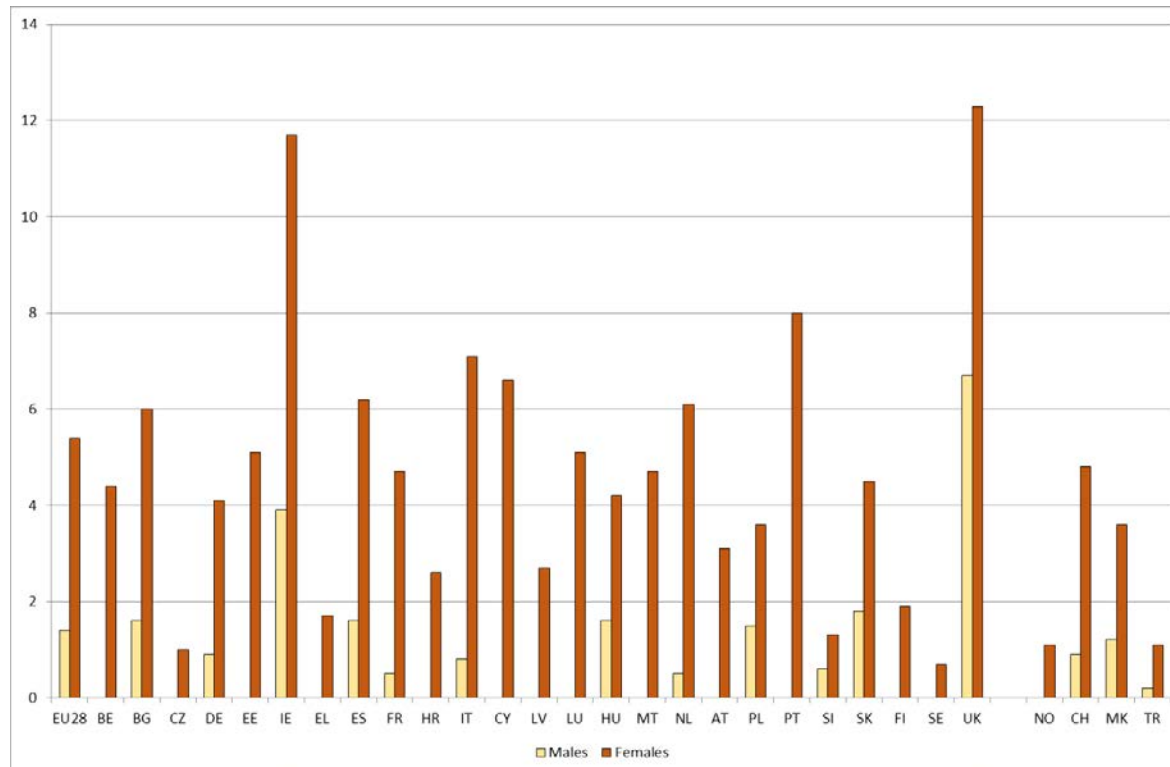
A high incidence of informal care has been reported by the ESPN experts in most of the countries (e.g. AT, BE, CY, CZ, EE, EL, ES, HU, HR, IE, IT, LT, LV, PL, SE, SI, SK, TR, UK; see also Section 1.4 1). The shortage of accessible formal LTC facilities is mentioned as the main reason for the expansion of informal care. Other reasons include the poor quality of LTC (e.g. IT, MK, UK), the highly biased subsidisation of LTC (CY), the shortage of institutional and community services (e.g. HR), the non-affordability of LTC (e.g. IT, MK) and last but not least the traditional model of intergenerational and familial relations. Indeed, in some countries family care is firmly established in society (e.g. BG, CY, EL, ES, LT, LV, MT, PL, PT). Some changes are expected in the near future though. In Malta, for instance, the decreasing availability of intra-family care, the dwindling family size and the increased mobility of young couples, is creating a lively debate about “who” is to provide LTC for elderly parents. In Latvia, intensive emigration is a real challenge for the care of elderly, as about 20% of the Latvian population have emigrated from the country during the 21st century.

There is a similar pattern across Europe: informal care is mainly provided by women. Despite cultural changes, new attitudes and relative progress in the distribution of caregiving responsibilities, women continue to take responsibility for and to carry out the bulk of caregiving. According to the Spanish ESPN report, women are the main informal carers for dependants: they represent around 62.4 % of the informal caregiving population. In Finland 60% of all working women and 40% of working men provide care weekly or daily: cash-for-care initiatives have therefore been criticised on the basis that it would lock women into their traditional homemaker roles.

Understanding the effect of informal care for an elderly person on labour market outcomes is important for developing policies targeted towards caregivers. The low employment rate of older women (aged 54-64) may reflect the fact that women are more likely than men to assume care responsibilities for elderly or dependent family members with long term care needs (Eurostat, 2016).

Negative impacts on female labour market participation have been reported by several ESPN experts (e.g. CH, CY, CZ, EE, EL, ES, FI, HU, IE, IT, MT, LV, PL, PT, RO, SK, TR, UK). However, national experts from Austria, Denmark, Germany and the Czech Republic report a lack of empirical evidence or valid data. Women are far more likely to reduce their working hours or exit employment altogether. Based on the data from the Labour Force Survey (LFS), Figure 6 shows that looking after children or incapacitated adults was the main reason for inactivity for 5.4% of inactive women aged 50-64 years old in 2016 in the EU28. The percentage for men was 1.4%. With respectively 11.7 % (compared with 3.9% for men) and 12.3% (compared with 6.7% for men), Ireland and the United Kingdom have the highest shares of female inactivity on the grounds of care. By contrast, the lowest shares can be found in Turkey (1,1% compared with 0,2% for men) and Slovenia (1,3% compared with 0,6% for men).

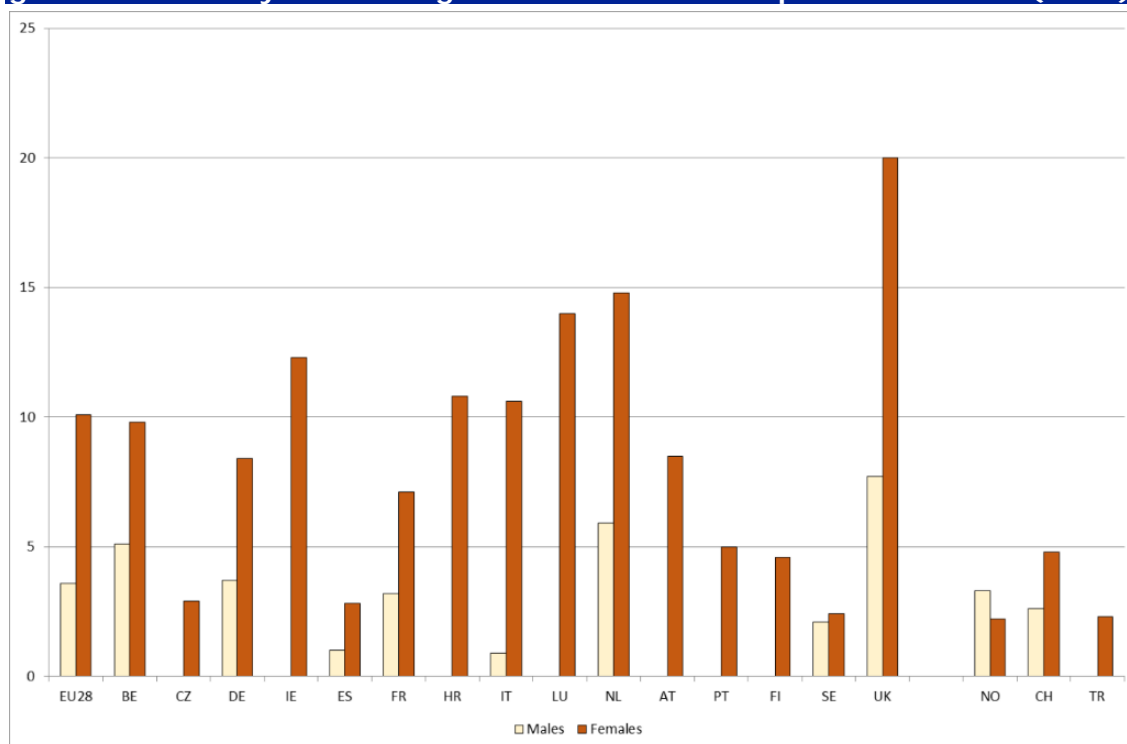
**Figure 6: Percentage of inactive men and women (50-64) not working on the grounds that they are looking after children or incapacitated adults (2016)**



Source: Eurostat, LFS, [lfsa\_igar]; \* ESPN countries not included in the dataset: LI, RS; \*\*No data for 2016 in DK, LT, IS; \*\*\*No data for male cares in 2016 in AT, BE, CY, CZ, EE, EL, FI, HR, LV, LU, MT, NO, PT, SE; \*\*\*\* No breakdown by sex in RO.

Other LFS data (Figure 7) show that, on average in the EU, 10.1% of female part-timers aged 50-64 (against 3.6% of male part-timers) explain the fact that they work part-time on the grounds that they are looking after children or incapacitated adults. The highest percentages are found in the United Kingdom (20.0% of women, compared with 7.7 % for men), the Netherlands (women 14.8% compared with 5.9% for men), Luxembourg (women 14.0%, no data for men) and Ireland (women 12.8%, no data for men). By contrast, the lowest shares can be found in Spain (2.8% of women, compared with 1% for men) and Norway (2.2% of women, compared with 3.3% for men).

**Figure 7: Percentage of men and women (50-64) working part time on the grounds that they are looking after children or incapacitated adults (2016)**



Source: Eurostat, LFS, [lfsa\_epgar], \* ESPN countries not included in the dataset: LI, RS; \*\*No data for 2016 in BG, CY, EE, EL, HU, IS, LV, LT, MK, RO, SI, SK \*\*\*No data for male cares in 2016 in AT, CZ, FI, IE, HR, LU, PT, TR; \*\*\*\* No breakdown by sex in MT.

The provision of adequate care leave may help female carers to maintain a foothold in the labour market. Care leave schemes allowing caring relatives or others to take some time off from gainful employment or to reduce their working time exist in many countries (e.g. AT, BE, FR, HU, IE, IT, LU, NL, NO, see also Section 1.4). However, Cyprus and Croatia do not have care specific leave schemes (or flexible time arrangements for carers). In Malta, persons employed in the public sector/public administration are in an advantageous position in view of the set of family friendly measures that are open to them, but which are not available for workers in the private sector. Although these measures in Malta are not specifically intended to assist carers with dependents requiring LTC, they can be used in such circumstances<sup>28</sup>.

Some ESPN experts pointed out the need to increase awareness and knowledge about the entitlement to carers' leave. In Belgium, more efforts to increase awareness and knowledge about the entitlement to carers' leaves and LTC benefits in cash and in kind are needed in order to avoid a low take-up rate. In France, although there are no specific data on how many working carers take advantage of carer leave to achieve a satisfactory work-life

<sup>28</sup> The exact level of take-up, specifically related to LTC, is not available.

balance, a 2015 survey suggested a very low-take up (7%). Most carers were unfamiliar with the leave provisions. In fact, carers tend to use standard leave (sick leave) or even annual leave, rather than specific carer leave, which is either unpaid or with a low allowance.

In the Czech Republic, the government has recently improved the position of family members providing LTC for their relatives by introducing, from June 1<sup>st</sup> 2018, a new sickness insurance allowance called “long-term caregiver’s allowance”. The carer, whether employed or self-employed, will be compensated for the loss of earned income from work which had to be interrupted, at the same rate as in the case of short-term care, i.e. 60% of the daily assessment base, during the period when he/she provides care for a family member (maximum 90 days). The employee cannot be dismissed and, after the termination of his/her care responsibilities, he/she is guaranteed a return to the same job under the new regulation in the Labour Code.

In Poland, there is a strong disincentive for carers to undertake employment, since care-related benefits are targeted at individuals who resign from employment and the benefits – when received – cannot be combined with any form of employment.

### **The role of domestic workers, migrants and undeclared work in home care**

In the context of informal care provision, many ESPN experts (e.g. AT, CH, CY, ES, EL, IS, IT, LI, MT, PL) underlined the specific role played by migrants in informal care provision, as families frequently fall back on them to assist with care tasks for the elderly. The main reasons reported are the growing inability of families to provide an adequate response to increasing care needs (e.g. MT), the high cost of professional care services (e.g. CH, IT), the lack of support for persons of working age with dependent relatives (e.g. CH), the lack of access to home care services (e.g. PL) or residential care services (e.g. IT). Some problems related to qualifications (e.g. EL) and working conditions (e.g. CH, EL, IT) have been reported with this form of informal care (see Box 4).

#### **Box 4: Role of migrants in informal care provision: issues reported**

*In Switzerland, care migrants (mostly from Eastern Europe) are often not protected by labour law and do not have formal qualifications for dealing with diseases (e.g. dementia), and with the demanding context of fulltime care services. They are vulnerable to exploitation. Recently, the Swiss national parliament and cantonal administrations began to address these problems.*

*In Italy, most migrant care workers have irregular contracts and the quality of their employment conditions is low. The same can be said about Greece where unskilled female migrant carers are hired by the dependent’s family on the basis of an oral agreement and not of a formal employment contract.*

*In Poland, migrant carers (typically from Ukraine or Belarus) are not monitored, are paid fully out-of-the pocket and typically not registered, contributing to creating a grey zone in the economy.*

*In Spain and Cyprus, migrant domestic helpers primarily engaged in domestic work provide informal care to dependents without having the required training for care.*

*In Austria “24-hour care” at home is almost entirely provided by migrant workers, mainly from Slovakia and Romania. It has been legalised since but the rules in place still provide a framework for unfavourable and precarious working conditions, as well as for limited de facto access to social protection rights due to the wide take-up the self-employment status.*

*It is unlikely that there is a large amount of undeclared work in informal care in Ireland, as there are strong norms around familial and local care in the sector while it is relatively easy to receive a carers’ benefit. However, there may be irregular undeclared work notably, in regard to overnight stays.*

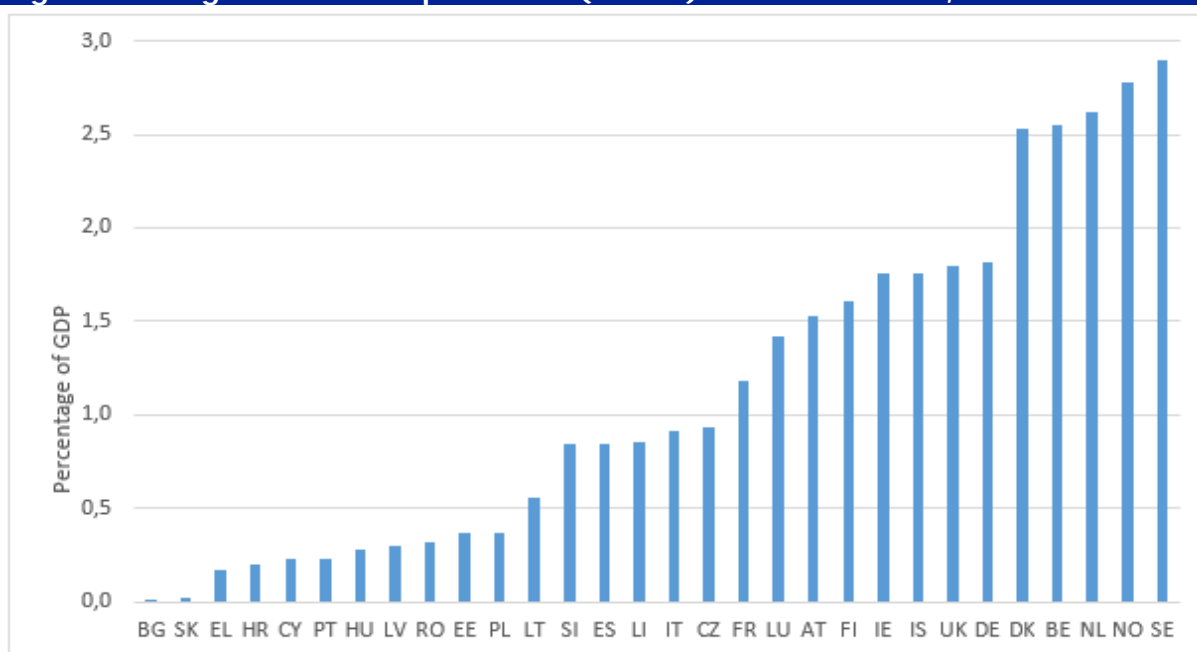
### Initiatives to open up skills validation and upskilling/ to informal learners

Moves towards skilling or upskilling, or indeed skills validation to informal learners to assist them in becoming long-term care professionals, have only been reported sporadically by ESPN experts, with some important exceptions. In **Portugal**, training and empowerment of informal carers is included in the National Programme for Health, Literacy and Self-care launched by the Ministry of Health in March 2016, although this programme is still merely a paper tiger. In **Norway**, there are no dedicated strategies to provide formal training to informal carers wishing to become LTC professionals, but the labour market service (NAV) can help all job seekers who lack formal training to obtain the relevant qualifications. These services are also available to former informal carers who aim for a career as a health-care professional. The Social Protection Institute (SPIRS) in Slovenia is organising courses for informal carers<sup>29</sup> that are free of charge for the participants. However, there has been no discussion of skills validation for informal learners to assist them in becoming LTC professionals. In **Cyprus**, the training of informal carers in order to help them acquire the necessary caring skills and competencies is mainly the responsibility of nurses with the home care services as well as staff nurses at hospitals, Non-Governmental Organisations and other community and non-profit organisations.

#### 2.1.4 The financial sustainability challenge

Expenditure on LTC in terms of GDP has been increasing over the past 20 years in many of the 35 countries under scrutiny. Currently, Nordic and Continental countries are among the leaders in expenditure in LTC (e.g. SE 2.90%, NL 2.62%, BE 2.55%, DK 2.53%) while Eastern European countries score the lowest values at around 0.3% (e.g. BG 0.01%) in 2015 (see Figure 8). The same regional pattern emerges if the components of LTC are taken separately, i.e. in-patient and home-based care (see Annex 1, Figures A2 and A3).

**Figure 8: Long-term care expenditure (health) in terms of GDP, 2015<sup>30</sup>**



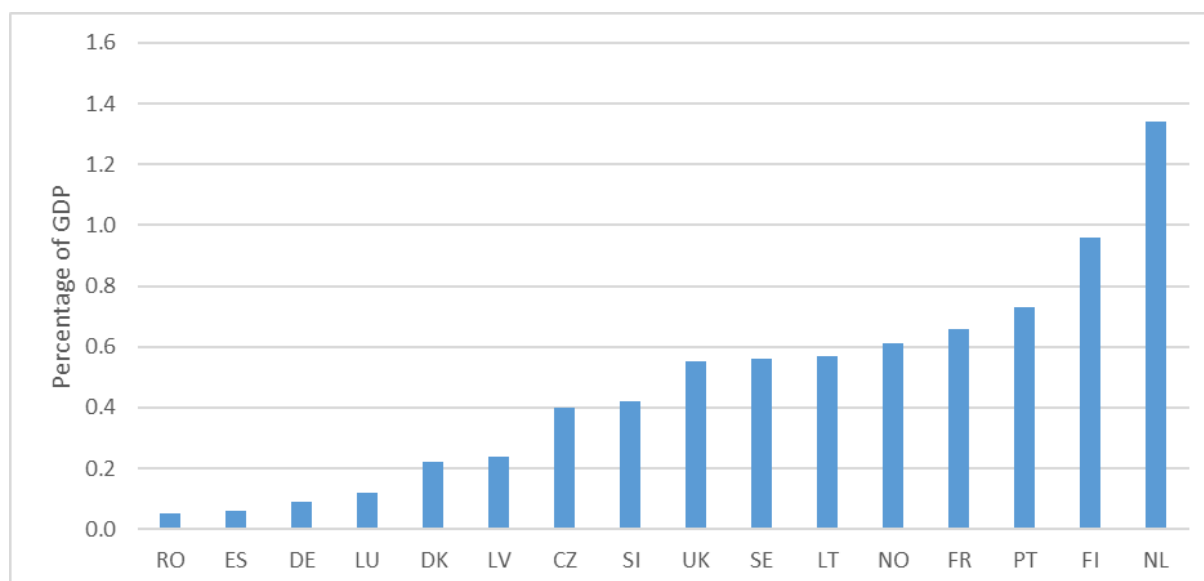
Source: Eurostat, Health care expenditure by function [hlth\_sha11\_hc], \* ESPN countries not included in the dataset MK, MT, RS, TR \*\*No data for the year considered in the graph: CH

<sup>29</sup> A course is organised at least once a month; each lasts eight weeks, with a minimum of two hours per week.

<sup>30</sup> LTC (health) means a range of medical and personal care services that are consumed with the primary goal of alleviating pain and suffering and reducing or managing the deterioration in health status in patients with a degree of long-term dependency. Personal care services (ADL) should be considered as LTC (health). For more details see [online](#) (OECD Healthcare expenditure statistics).

By contrast, for the LTC component (social)<sup>31</sup>, expenditure in terms of GDP is highest in the Netherlands (1.34%), Finland (0.96%) and Portugal (0.73%) (see Figure 9).

**Figure 9: Long-term care expenditure (social) in terms of GDP, 2015**



Source: Eurostat, Health care expenditure by function [hlth\_sha11\_hc], \* ESPN countries not included in the dataset MK, MT, RS, TR; \*\*No data for the year considered in the graph: AT, BE, BG, HR, CH, CY, EE, EL, HU, IE, IS, IT, LI, PL, SK

It is expected that long-term spending will be high on many countries' agendas, as projections show that public LTC expenditure in the EU is to increase from 1.6% to 2.7% of GDP, i.e. an increase of almost 70%, exerting constant pressure on public finances (European Commission 2016).

However, projections vary widely between countries. Nordic countries and Eastern countries are expected to spend generously on LTC (European Commission 2016). According to the most recent Austrian projections, public spending on LTC services, according to different scenarios, will increase from currently 1.27% of GDP to 1.42%-1.85% of GDP by 2030 and then further to 1.94%-3.59% by 2060 (see Section 2.2). In Bulgaria, projections estimate that the population aged 65+ will increase from 20.4% in 2015 to 32.7% in 2060, triggering much higher demand for and expenditure on LTC than for the present period. In contrast, in Italy, financial sustainability issues are not a priority, given the relatively limited level of expenditure on LTC and the fact that projections show a limited growth in expenditure over the next 15 years.

Looking into the different challenges facing national LTC systems, financial sustainability may be made more difficult by several issues. Similarly to the adequacy challenge, financial sustainability may be affected by fragmentation of care: lack of coordination between health and social entities; the lack of clear financial strategies of the territorial entities responsible for LTC may also lead to unpredictability of LTC spending. The UK ESPN experts highlight that the lack of a long-term financial strategy is a major issue in England – involving a failure of public funding to keep pace with demographic trends; cuts in central government funding to local authorities; and short-term measures that increase local authorities' reliance on (inequitable) local sources of revenue. ESPN country reports also

<sup>31</sup> Assistance care services (IADL) are considered as LTC (social). The indicator may refer to ancillary services (non-specified by function), the healthcare or LTC related services non-specified by function and non-specified by mode of provision, which the patient consumes directly, in particular during independent contact with the health system and which are not integral part of a care service package, such as laboratory or imaging services or patient transportation and emergency rescue. For more details see [online \(Eurostat Healthcare expenditure statistics\)](#).



highlight inequalities in funding of the LTC policy mix (e.g. more generous financing of residential care). Box 5 provides some examples of country-specific challenges.

### **Box 5: Financial sustainability of LTC systems: country-specific challenges**

*In Finland, municipalities face significant differences in the scope of services and funding as their size varies a great deal. The average yearly municipal cost for social and health care services is €2,940 per capita. However, the variation is huge: the cheapest municipal bill is €1,980 and the most expensive is 4,689€ per capita.*

*Romanian ESPN experts highlight the unpredictability of local funding. The financing of LTC is indeed split among various sectors, Ministries/Agencies and administrative levels. In addition, the capacity of local budgets to pay for benefits (especially labour-intensive social services) is rather low. The residential facilities under the responsibility of the local authorities receive the lowest proportion of state subsidies (decreasing from 12% in 2012 to 2.6% in 2016), followed by the private facilities (with a reduction from 7.3% in 2012 to 3.6% in 2016).*

*In Ireland, there is a bias towards residential care. As of 2015, approximately 60% of the budget for supporting older people was spent on long-term residential care, effectively catering for only about 4% of the population aged over 65. The average costs to the public purse of home care service subvention have been kept low during the crisis and have even decreased. For example, the more service-heavy Home Care Packages the average yearly cost per person declined from €10,000 in 2009 to €6,999 in 2014.*

*In Austria, 71% of all spending on LTC was covered by the public sector, in 2015. Over the last 15 years the number of recipients of long-term-care cash benefits (plus approx. 62% between 1999 and 2015) has increased to a much larger degree than overall spending on LTC as a % of GDP, which has risen by about 20% over the same period.*

Some ESPN country reports point to the fact that informal care can be perceived as one of the pillars ensuring financial sustainability even though difficult to measure (e.g. AT, IS, PT, ES, BG). In Portugal the work performed by informal carers is estimated to represent over 2% of GDP (while formal care is estimated at 0.2%). The Dutch ESPN experts report that the LTC priority of the government is oriented towards a more effective use of informal care, encouraging people to first involve their own social network for the provision of some care tasks.

As discussed in Section 1, LTC provision is often split between healthcare and social care and is financed in most cases by contributions for health care /general taxation and general taxation (social care). Only Germany, Luxembourg and Flanders (Belgian region) have implemented a specific LTC scheme financed by social contributions.

In order to ensure the sustainability of this LTC scheme, Germany has been increasing the social contribution rates since the scheme began in 1996, up to 2.55% (2.80% for childless insurance members) in 2017. At the same time, LTC expenditure has steadily increased in recent years, from €14.3 billion in 1997 to €28.3 billion in 2016. In 2016, 24.0% of total expenditure was attributable to care allowances, 13.4% to home care (in kind) and 38.5% to residential care. Importantly, since 1997 LTC insurance has recorded revenue surpluses. In 2016, the difference between income from contributions and total expenditure was 3.13%. Similarly, in Luxembourg, total expenditure has risen over the years. However, while between 2012 and 2015 there was a limited surplus or almost equal revenue and spending, in 2016 the scheme reported a substantial surplus.

Many of these examples highlight the fact that financial sustainability and LTC adequacy are inextricably linked (see also Section 2.1, as well as ILO 2018). If the system is financially unsustainable it can endanger the adequacy of LTC provision, leading to underfinancing and spill-over effects for other social protection spending (e.g. hospitals). Vice-versa, if a system does not provide adequate care, this may jeopardise financial



sustainability, the employment of both professional and informal carers and the quality of care. This may in turn result in serious reliance on state budgets. Although there is no such thing as an optimum LTC policy mix, many European countries are facing problems with LTC access and affordability due to the limited provision (including underfinancing) of home care and community-based services.

## **2.2 Reforms and ongoing policy debates in long-term care**

LTC provision has been subject to several reforms in most of the 35 countries under scrutiny over the past 10 years (2008-2018). There have been three main trends with regard to different aspects of LTC care: a) a readjustment of the LTC policy mix, moving away from residential care towards home care and community-care, b) measures addressing financial sustainability and c) better access and affordability of provision, including improvements to the status of informal carers.

The progressive replacement of residential care by home care services has been high on the reform agenda of most of the countries (e.g. AT, BG, DE, DK, EE, FR, FI, IS, MT, NO, SI). As discussed in Section 2.1, the outcomes of these developments for the beneficiaries depend strongly on the overall LTC policy mix and the availability and the quality of home services provided. While there have been some successful examples (e.g. DK, IS, NO, NL), many countries, especially in Eastern and Southern Europe, have underdeveloped home-based care services (e.g. BG, EE, ES, HR, PT). Moreover, some ESPN country reports emphasise the lack of clear funding and implementation strategies in national programmes (e.g. BG, HR). In most cases, these services are in the course of development. For instance, in Bulgaria, although many municipalities have implemented the EU-supported model of integrated care at home, a funding mechanism for these home integrated nursing and care services is missing.

As for the financial sustainability issue, there have been various trends across Europe, such as decreasing funding for residential care, increasing the out-of-pocket payments required from beneficiaries, raising the contributory rates for LTC insurance (DE, LU) or tightening eligibility conditions for benefits (e.g. PT). Budgetary restrictions were implemented during the crisis and the post-crisis period in several countries (e.g. DK, ES, PT, IE, UK). For instance, in Spain a budgetary adjustment made to the long-term programme in 2012 is thought to have resulted in a 37,405 drop in beneficiaries by 2015. Moreover, the government ceased to require social security payments from non-professional home carers in July 2012.

In some countries, reductions in the funding of LTC services have not been crisis-related. Surprisingly, the Hungarian ESPN expert highlights that access to home care grew rapidly during the crisis years and was cut back afterwards (raising the hypothesis that job creation was an important aim of the government). Similarly, the Swedish ESPN experts point to the fact that the gradual tightening of eligibility criteria was not triggered by the financial crisis but started well before and continued after the crisis. Rather, it was driven by other political priorities, i.e. lowering taxes with increased responsibility given to municipalities.

Another major trend in several countries has been a search for ways to improve the access and affordability of LTC provision. These measures range from providing increasing funding for some components of LTC to tackling the status of informal carers (see Box 6).

**Box 6: Examples of reforms aimed at improving access, affordability and quality of formal LTC services**

**Increased LTC funding (e.g. EE, RO)**

*Estonia has been tackling the shortage of home care services by allocating additional funds from the EU structural funds during the period 2014-2020. The government has decided that 49 million EUR will be used to relieve the burden of family members who currently take care of disabled people. Additionally, 28.3 million EUR from the European Social Fund and 5.3 million EUR of co-financing from the government was allocated to local governments, for the development of social services, in 2016.*

**Measures to tackle interinstitutional and territorial LTC fragmentation (e.g. AT, DE, FI, PL, RO, SE)**

*Several countries have undertaken reforms to optimise and clarify the responsibilities of the public authorities and territorial structures responsible for LTC (e.g. changing the entities responsible for benefits, transferring competences).*

*As of 2017, Romania has been implementing measures recentralising some LTC costs, from local authorities to the state budget.*

**Improving eligibility conditions and benefit levels (e.g. AT, DE, IT, MT)**

*Germany has extended eligibility for benefits by amending the definition of “in need of care” and the associated assessment method. This is expected to improve the adequacy of benefits, particularly for persons suffering from dementia. Moreover, recent reforms have allowed more flexibility in combining different types of benefits and establishing incentives for informal care, mainly in order to enhance opportunities for relatives to provide informal care at home.*

*Austria, as of 2018, prohibits recourse to the assets of persons living in inpatient LTC facilities, as well as recourse to the assets of their relatives.*

*Malta has introduced a “Carer at Home” scheme. Applicants need to be over sixty years of age and the carer (who cannot be a family member) needs to have a recognised qualification.*

**Recognising and improving the status of informal carers (e.g. AT, FR, CZ, PT, PL)**

*Since 2007, Austria has been implementing a “24-hour care” programme, in order to legalise private informal LTC arrangements, offering the carers (mostly migrants from Slovakia and Romania) the option of self-employment or dependent employment and providing public financial co-funding.*

*In France, since 2010, there have been several reforms aimed at supporting care leave for informal carers, as well as respite options, training and education. Moreover, the formal definition of “informal carer” can be considered as a step forward, as it constitutes a genuine recognition of the work done by this type of carer.*

*In Poland, in 2015, the government introduced benefits to support the labour market re-integration of individuals previously engaged in care responsibilities, using subsidised employment measures.*

*Portugal, having introduced various support measures for informal carers (respite care, training) over the past 5 years, is currently examining the possibility of creating a legal status of informal carer, which, if approved, would result in profound changes to informal care.*

**Improving the status of formal carers**

*Several countries reported reforms addressing the quality of jobs and professionalisation needs in the sector (e.g. BE, CH, PL, PT, DE).*

**Improving the quality of LTC provisions (e.g. DE, FR, RO)**

*In 2012, Romania adopted a law regulating the quality of social services and in 2015 established minimum standards for service providers of residential and non-residential care for elderly and disabled people. This provision led to the withdrawal of accreditation of many providers.*

**Special care for elderly people with specific diseases (e.g. DE, DK, EL, FI, IS, NO)**

*In 2017, Denmark, launched a national plan called "A secure and dignified life with dementia", which includes a package of specific measures for elderly people with this disease.*

*In 2016, Greece adopted the "National Action Plan for Alzheimer's-Dementia disease 2015-2020" which entails, among other things, the creation of special care units (day-care centres, etc.) for persons suffering from such diseases as well as the provision of support to carers of these persons.*

**New ways (including e-services) to deal with old-age dependency**

*A few countries have been trying to develop the use of innovative technologies, mostly with the aim of enabling elderly people to live an autonomous life at home (e.g. DK, NL).*

In addition to these reforms affecting individual parameters of the LTC system, more comprehensive reforms are on-going in a few countries (e.g. CY, FI). The whole Finnish social and health care service system – including LTC – will be overhauled when the social and health care reform ("SOTE") comes into force (in 2020). This reform is expected to result in an important territorial reorganisation of LTC, introducing new personal budgets and more room for private for-profit service providers to operate. It will thus open up even more opportunities for private companies.

Similarly, some ESPN experts have pointed to a long-term trend towards the privatisation and marketisation of care (e.g. DE, FI, LT, UK, see also Section 1.5). Some others have also emphasised the role of NGOs (e.g. MK, RS).

**On-going policy debates**

There are significant on-going debates in some countries, often supported by strategic policy documents (e.g. BG, CZ, ES, HR, PT, PL, SK, SI, LU, LI, UK).

In the UK (England), there are growing pressures for new policies to ensure funding sustainability, for example through a social insurance approach. Debates are also focusing on the impact of Brexit on the care workforce; 7% of care workers are from other European Economic Area countries and 9% from non-EEA countries. Restricting recruitment from overseas would have a major impact on recruitment in London and SE England, where almost 40% of the care workforce are non-British born.

In 2016, Portugal created a working group to study the establishment of a legal status for informal carers. Several other countries have set up institutions (political commissions, inter-ministerial institutions etc.) to assess the current situation and reflect on the future of LTC (e.g. BG, CZ, ES, SI).

Some ESPN experts expressed criticism (e.g. BG, PL, HR, RS, SI) of the lack of clarity on funding mechanisms and strategies for the implementation of national programmes. In Bulgaria, for instance, three years after the 2015 Health Act, there is still a lack of clarity as to the details and procedures for integrated development and provision of LTC services, including case management and financial arrangements.

### 3 Analysis of the indicators available for measuring long-term care

This final section presents various indicators available at national level to measure the access, adequacy, quality and sustainability of LTC as well as the impact of caring responsibilities on employment.

Many national indicators are at hand to measure access and adequacy, as well as financial sustainability. Indicators such as the number of beneficiaries and the number of providers are those most frequently used by countries to assess access and adequacy, and are usually provided both for inpatient and outpatient care. Additional indicators, such as the number of hours per week of professional home care received, waiting time or lists were also mentioned by some national experts (see Table 1). Regarding financial sustainability, most countries provide indicators on LTC expenditure (home-based and residential care) (see Table 2). Some countries have included indicators of efficient use of resources and user involvement, used to assess the sustainability of LTC (e.g. NO).

**Table 1: National indicators – Access and adequacy**

Access and adequacy <sup>32</sup> indicators		Countries	No indicator available
Number of beneficiaries	Inpatient care	IT, AT, BE, CZ*, DE, ES, HR*, DK, EL, FI, FR, HU, IS, LU, MK, PT, SE, SI, LT, LV, RO, RS, UK	MT, CY, LI
	Outpatient care	IT, AT, CZ, DK, EL, ES, FI, HU, LU, LV, MK, SE, SI, TR, LT, RS, UK**	
	Day care services	AT, ES, HU, LT, LV, PL, RO, RS, SI	
	Not specified	NL	
Number of providers/structures	Inpatient care	AT, BG, CZ*, FI, HU, PL, PT, SI, TR, SK, LT, LV, RO, RS,	
	Outpatient care	AT, CZ*, HU, PT, SI*	
Number of unsuccessful applicants / pending applications		CZ, RO, DK, ES, NL, PT, TR, SK, SI	
Waiting lists			
Number of home help hours provided		BE, IE, SI	
Ratio number of beds: number of inhabitants; capacity		CZ, FI, IS, LT, LV, PL, PT, RO, SI, SK, TR	
Cost of care / cost related to dependency		BE, FR, LU, NL, RO, SE, SI, UK	

\*Social care; \*\* social care (excludes care purchased privately) ° public home care

<sup>32</sup> As mentioned in Section 2, we estimate the overall LTC system as “adequate” if it provides sufficient and affordable social protection to cover the existing needs for LTC care. Some indicators are estimated by the ESPN experts to address both access and adequacy. This is the reason why we put them in the same column.

**Table 2 National indicators- Financial sustainability**

Indicators – Financial sustainability		Countries	No indicator available
LTC expenditure	LTC in general	AT, BE, BG, CH, CZ, DE, ES, HU, IS, IT, LU, NL, SI, UK <sup>o</sup>	MT, CY, DK, EE, EL, HR, LI, TR, SK
	Inpatient LTC	AT <sup>o</sup> , LT*, LV, PL, RO, , RS, , SI	
	Home-based LT care	AT <sup>o</sup> , RO, PL, LT*, LV, SI	
Public spending		AT, BE, HU, LU, SI	

\*Only healthcare sector, <sup>o</sup>Excludes care purchased privately

As discussed in Section 2.3, quality of LTC is a multifaceted phenomenon which is therefore very difficult to capture. According to many ESPN national experts, measuring and monitoring the quality of LTC care services therefore remains a difficult and challenging task. The information collected in the 35 ESPN country reports shows that indicators to measure the quality of LTC are very diverse. Crucially, many aspects of the quality of outcomes are not covered by existing national indicators. National indicators for measuring quality range from an assessment of living conditions (level of comfort, etc. ...) to the number of injuries, the number of user complaints and indicators related to user satisfaction or staff ratios (see Table 3).

Some attempts have been made to take into account the inherent multidimensional nature of LTC. Thus, a few countries have developed a more formal set of national quality indicators (e.g. DE, DK, NO, PT). National indicators in Norway address six dimensions: efficiency; safety and security; user involvement; coordination and continuity; resource efficiency; and availability and just distribution. The different dimensions are related to the three main features of quality: structure, process and outcomes of care, referring to the Donabedian framework<sup>33</sup>, traditionally used to assess the quality of healthcare. Along the same lines, Portugal provides indicators such as (among others) the ratio of beds, workforce and the existence of resting areas for relatives (structure); the existence of registration procedures for the assessment of various risks (social risk, falls etc.) (process); and the occurrences of adverse events such as pressure ulcers, falls and infections (outcomes).

In a 2013 research paper, the OECD has suggested a framework based on three core categories which underpin the concept of quality of LTC: effectiveness of care and safety, patient-centeredness and responsiveness and care coordination (See OECD/UE, 2013). The framework also includes structural factors, linked to the workforce, the care environment and the use of technologies. Based on these dimensions and the information provided by ESPN national experts, one can summarise the national indicators used to assess the quality of LTC (see Table 3).

ESPN experts pointed out the following issues regarding indicators assessing the quality of LTC. First, the information is not always available on a regular basis but rather on an *ad-hoc* basis (specific surveys etc.), resulting in a lack of continuity in the data available. Second, it is important to consider the quality of care not only for beneficiaries but also for the personnel who provide these services, notably in terms of job quality and well-being (e.g. exposure to psychosocial risks). Thirdly, the analysis of the quality of informal care is still problematic, as information is scarce by definition.

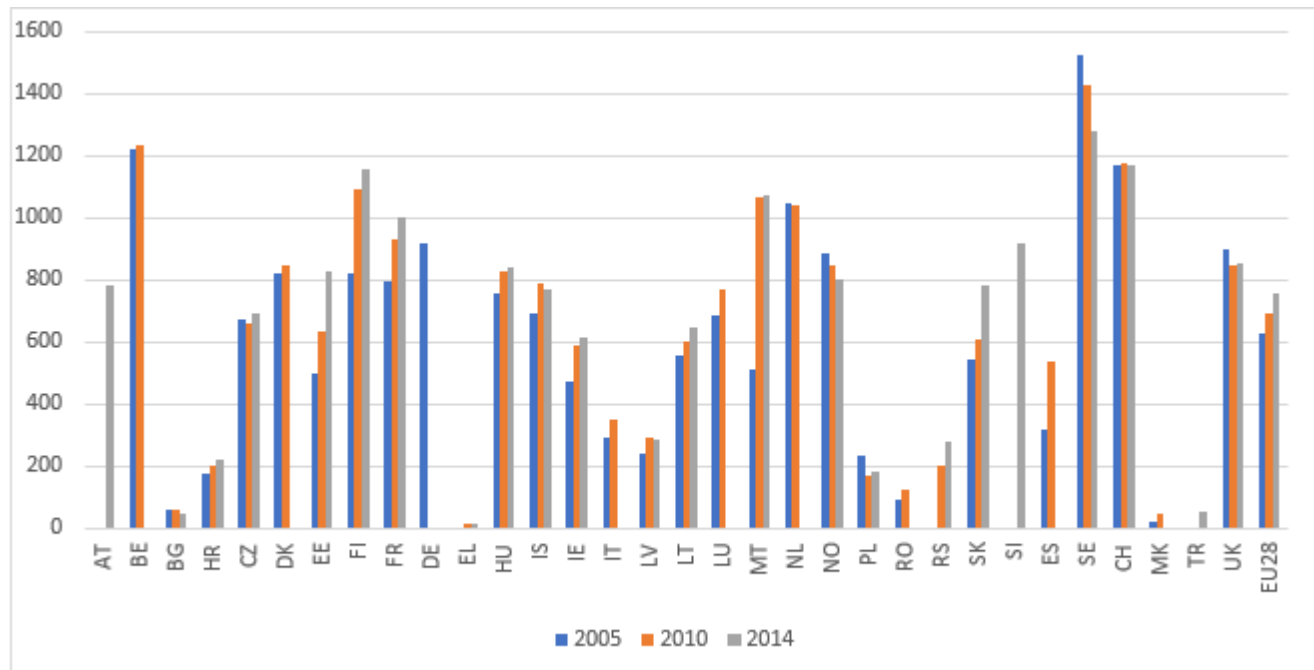
<sup>33</sup> The Donabedian framework is a conceptual model initially developed to evaluate the quality of healthcare. It was later extended to the LTC sector. The framework aims to assess the quality of care according to three dimensions: structure, process and outcomes. We want to thank Marcel Fink for pointing this framework out to us. For complementary information, see Donabedian (1966)

**Table 3: National indicators- Quality of care**

	Quality Indicators		Countries
Outcomes	Effectiveness of care and user safety	Clinical aspects, injuries, falls, etc...	BE, CH, DE, DK, FI, FR, IS, LV, NO, PT, SE, LT, LU
	Patient-centeredness and responsiveness	User satisfaction / user experience	CY, DE, DK, IS, LT, NL, SE, SI, UK
	Care coordination		FI
Structural factors	Workforce	Staff, ratio	AT, BE, DE, DK, EL, LU, LV, MK, NO, PL, LT, RS, SI
		Continuity of staff	SE
		Rate of sickness	NO
		Skills/level of education	NO, LV
	Care environment	Infrastructure	IS, FR, LV, NO
	ICT	Safety technologies	FI
Other indicators	User complaints		LV, RS
	Unmet needs		IT, UK, SI
	Timeliness of services	Waiting time / waiting lists	DK, LV, NO, PT, TR, SI, SK
	Well-being of staff / working conditions		FI, LT, SI
	% of compliance with inspected outcomes		IE

Tackling LTC issues requires accurate data and evidence. In this respect, Austria and Switzerland report an improvement in LTC datasets. In Switzerland, the federal government has provided a new dataset on LTC institutions: this includes data on the number of patients in nursing homes, time of residence, number of personnel per occupant as well as the percentage of qualified LTC nurses, cost per day, the intensity of care as well as the cost-effectiveness of the institution. In Austria, the LTC database provided by *Statistik Austria* is an attempt to harmonise the data on individuals receiving LTC benefits and services, care personnel as well as spending carried out by various facilities.

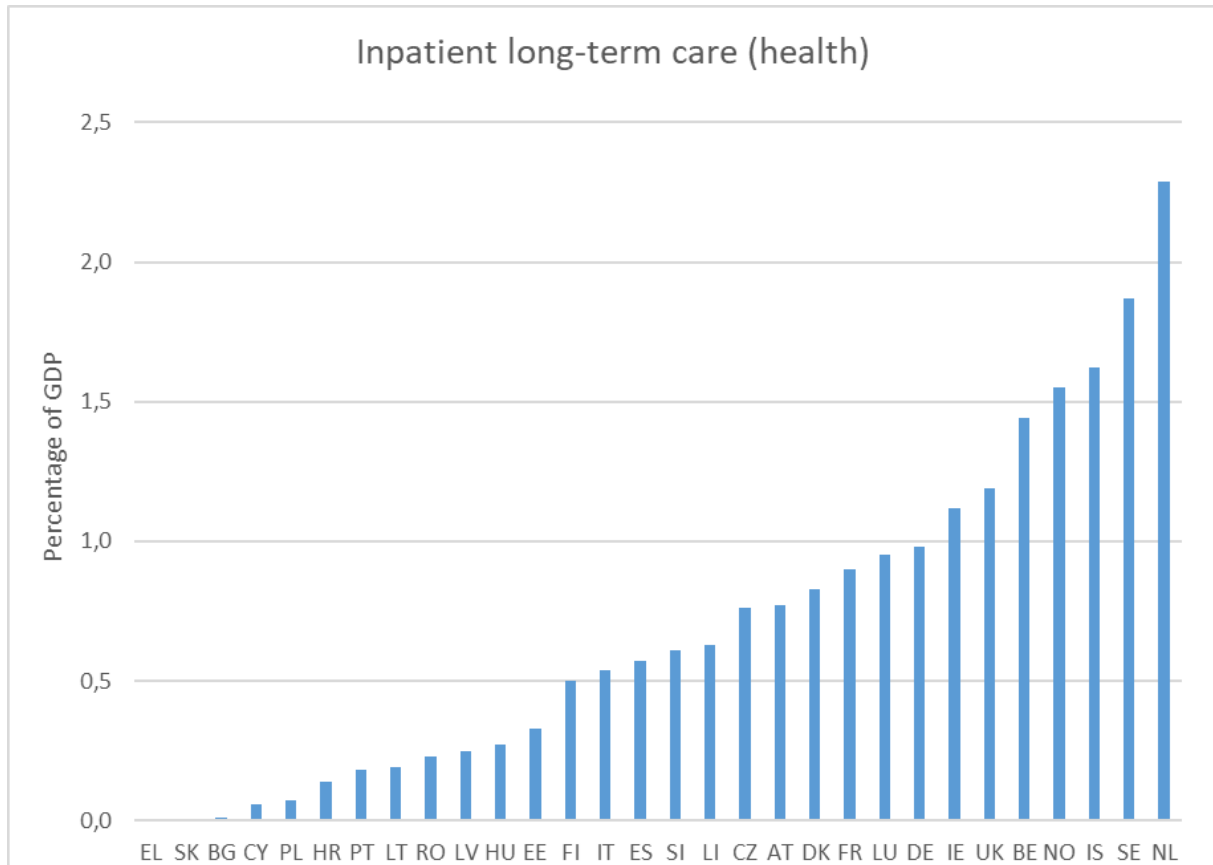
## ANNEX 1: FIGURES

Figure A1: Nursing and elderly home beds per 100,000 population, 2005; 2010 and 2014<sup>34</sup>

Source: World Health Organisation (WHO), \* ESPN countries not included in the dataset: LI; \*\*No data for the years considered in the graph: CY, PT\*\*\*No data for 2005: AT, EL, SI, TR; 2010 AT, DE, SI; 2014: DE, MK, RO

<sup>34</sup> Beds available for people requiring long-term care in institutions (other than hospitals). The term "long-term care institutions" refers to nursing and residential care facilities (HP.2) which provide accommodation and long-term care as a package. See details [online](#) (WHO).

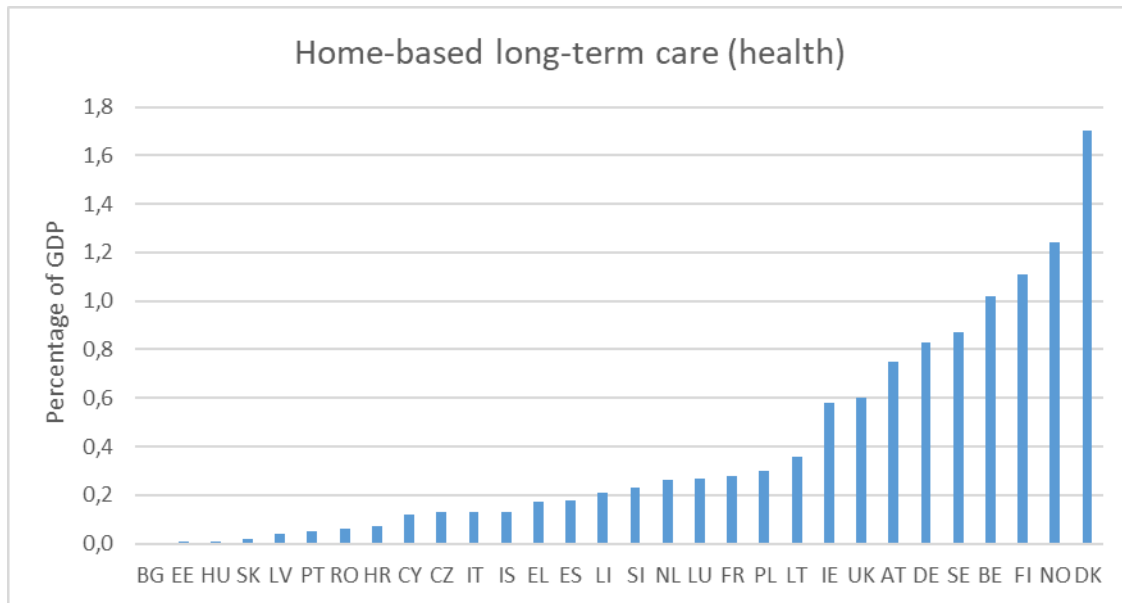
**Figure A2: In-patient long-term expenditure (health), 2015<sup>35</sup>**



Source: Eurostat, Health care expenditure by function [hlth\_sha11\_hc], \* ESPN countries not included in the dataset MK, MT, RS, TR; \*\*No data for the year considered in the graph: CH

<sup>35</sup> Inpatient care means the treatment and/or care provided in a healthcare facility to patients formally admitted and requiring an overnight stay.



**Figure A3: Home-based long-term care (health), 2015<sup>36</sup>**

Source: Eurostat, Health care expenditure by function [hlth\_sha11\_hc], \* ESPN countries not included in the dataset MK, MT, RS, TR; \*\*No data for the year considered in the graph: CH

<sup>36</sup> Home-based care means the medical, ancillary and nursing services that are consumed by patients at their home and involve the providers' physical presence.

## ANNEX 2: DEFINITIONS

### **Long -term care (LTC)**

"A range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with daily living activities and/or are in need of some permanent nursing care" (European Commission and Social Protection Committee, 2014: 11). The LTC system is understood as a mix of social and care services, as well as financial compensation – wholly or partially funded through the statutory social protection system – at local, regional and/or national level

### **Care dependent person**

Person who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depends on help with daily living activities and/or is in need of some permanent nursing care (European Commission and SPC, 2014: 11). For the purpose of this report, the target group is limited to older people (65 and over).

### **Formal care services**

Services provided by licenced providers, either in the home or outside the home of the care dependent person. Providers can be public, profit-seeking or not-for-profit organisations and the care professionals can be employees or self-employed.

### **Healthcare**

The provision of medical services and products by health professionals to patients, inside or outside healthcare facilities, to assess, maintain or restore their state of physical and mental health.

### **Long-term social care**

Services that support the care dependent person in carrying out activities of daily life (bathing, clothing, eating, shopping, cooking, etc.) or support the informal carer in carrying out these tasks.

### **Home care**

Care provided at the home of a person in need of care.

### **Formal home care and Home care services**

In this report these terms are used interchangeably when referred to care provided formally at home.

### **Semi-residential care**

Care provided in an institutional setting for care-dependent persons who do not permanently reside in the institution. It includes centres where the care dependent person can be cared for only during the day, or during the night and sheltered housing where frail elderly people live independently but in a relatively protected environment, with a certain level of support, often closely linked to a care/nursing home.

### **Community care**

The range of non-residential care services.

### **Residential care**

Care provided in a residential setting for elderly people living in accommodation with permanent caring staff.

### **Informal care**

"Informal care is provided by informal carers, such as relatives, spouses, friends and others, typically on an unpaid basis and in the home of the care recipient" (European Commission 2018)

**Informal carer**

Person who provides care, in principle unpaid, to the care dependent older person, outside a professional or formal employment framework. It is in principle a person with whom the care dependent person has a social relationship, such as a spouse, child, other relative, neighbour or friend.

**Domestic worker**

Person recruited by a private household to provide against payment personal and household care in the home of the care dependent person. The worker can have a legal employment contract with the household or perform non-declared work.

**Out-of-pocket payments (OOP)**

Direct payments for healthcare goods and services from the household primary income or savings made by the user. This includes both direct payments without any reimbursements and cost-sharing with third-party payers.

**Integrated care**

Integrated care is a concept that focuses on more coordinated and integrated forms of care provision in response to the fragmented delivery of health and social services. "Integration is a coherent set of methods and models on the funding, administrative, organizational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors. The goal of these methods and models is to enhance quality of care, consumer satisfaction and system efficiency by cutting across multiple services, providers and settings" (WHO 2016).

**ANNEX 3: COUNTRIES' OFFICIAL ABBREVIATIONS****A. EU countries**

EU countries prior to 2004, 2007 and 2013 Enlargements (EU-15)		EU countries that joined in 2004, 2007 or 2013	
BE	Belgium	<b>2004 Enlargement</b>	
DK	Denmark	CZ	Czech Republic
DE	Germany	EE	Estonia
IE	Ireland	CY	Cyprus
EL	Greece	LV	Latvia
ES	Spain	LT	Lithuania
FR	France	HU	Hungary
IT	Italy	MT	Malta
LU	Luxembourg	PL	Poland
NL	The Netherlands	SI	Slovenia
AT	Austria	SK	Slovakia
PT	Portugal	<b>2007 Enlargement</b>	
FI	Finland	BG	Bulgaria
SE	Sweden	RO	Romania
UK	United Kingdom	<b>2013 Enlargement</b>	
		HR	Croatia

In EU averages, countries are weighted by their population sizes.

**B. Non-EU countries covered by the ESPN**

Former Yugoslav Republic of Macedonia (MK), Iceland (IS), Liechtenstein (LI), Norway (NO), Serbia (RS), Switzerland (CH) and Turkey (TR).

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## ANNEX 5: PRESENTATION OF THE EUROPEAN SOCIAL POLICY NETWORK (ESPN), JUNE 2018

### ESPN Network Management Team and Network Core Team

The European Social Policy Network (ESPN) is managed jointly by the Luxembourg Institute of Socio-Economic Research (LISER) and the independent research company APPLICA, in close association with the European Social Observatory.

The ESPN Network Management Team is responsible for the overall supervision and coordination of the ESPN. It consists of five members:

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