

# Analytical paper on Long-Term Care: Older People & Disability

2018

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## 1. Introduction

Structured under three different sections, this paper aims to reflect on long-term care (LTC) with a focus on older persons with a disability in Europe, building upon research, EU statistics and the expertise EPR members have in providing services for elderly care. It presents an overview of the common demographic trends, trends in LTC and the implications and challenges service providers and governments face to meet the needs for accessible, quality and affordable services along with recommendations, ending with an overview of recent EU initiatives addressing LTC in Europe.

**Long-term care** refers to services supporting people who need help in performing activities of their daily living<sup>1</sup> over a protracted period of time due to chronic conditions of physical or intellectual disability (OECD, 2005) who need special help in managing their daily lives. Predominantly, LTC includes assistance with so-called activities of daily living (ADL), such as eating, bathing, dressing, getting in and out of bed or using the toilet. In addition, basic medical services, such as help with wound dressing, pain management, medication, health monitoring, prevention, rehabilitation or services of palliative care may be included. This broad range of services means that LTC touches upon both health and social components.

## 2. Population trends in Europe and disability

People of all ages and for different periods of time may depend on help with performing daily activities. Unpredictable events over the lifetime makes it hard to determine whether and when a person will be needing care, yet older people represent the majority of recipients of LTC (Social Protection Committee and the European Commission, 2014). The demographic situation in Europe reflects the global trend of increased life expectancy, that together with a lower mortality rate and improved health conditions have contributed to the enlargement of the world's population and consequent rise in the number of older persons. Eurostat shows that Europe presents a modest increase in the overall population (+22%) between 1960 and 2015 with 1.7 people aged 65 or older (EUROSTAT, 2016). In Europe, the proportion of citizens aged 65+ over the last decades is among the most evident effects of the improved health status of the population (European Commission (EC), 2008).

However, the growing number of older people in Europe goes hand in hand with an increase of people experiencing some type of disability and, therefore, demand for LTC services is expected to rise in the next decades. Eurostat 2012 data on the prevalence of disability status<sup>2</sup> among European citizens suggests the incidence of disabilities is higher as people grow older (EUROSTAT, 2015). The need for LTC in the older population seems connected to increased dependency due to the prevalence of frailty, multi-morbidity and physical or intellectual disabilities as they age (European Commission, 2015). The different types of dementia can be considered as intellectual disabilities. Approximately 45% of people aged over 65 have a disability. Among the older population, LTC needs are likely to increase after the age of 75 years-old (OECD, 2005). In addition, persons with disabilities can experience “*double vulnerability*”; their support needs may be aggravated by the neurological, physiological and psychological factors linked to their specific condition (Autism Europe, 2003). In addition to the overall population ageing in the European Union, the health status and the ability of older people to live independently influences the growth in LTC needs (EC, 2013).

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<sup>1</sup> See annex for more information

<sup>2</sup> According to the biopsychosocial model applied to the survey, people with disabilities are those who face barriers to participation in any of 10 the life areas, associated inter alia with a health problem or basic activity limitation. Therefore, a person identifying a health problem or basic activity limitation as barrier in any life domain is categorised as disabled ([http://ec.europa.eu/eurostat/cache/metadata/en/hlth\\_dsb\\_prve\\_esms.htm](http://ec.europa.eu/eurostat/cache/metadata/en/hlth_dsb_prve_esms.htm))

### 3. Challenges and recommendations

Drawing from the analysis of current trends of LTC services and population projections<sup>3</sup>, as well as input from members of EPR, the following challenges for long-term care, with a focus on people with a disability, were identified:

According to the European Commission, long-term care services should be characterised by three mutually agreed and interconnected objectives (European Commission, 2008):

- **universal access:** access to services should be affordable for all citizens and not related to the income or wealth situation.
- **high quality:** focusing on more comprehensive quality assurance involving issues such as patients' rights.
- **long-term sustainability:** where the likely increase in LTC demand could be mitigated by preventive approaches and technological developments.

Mitigating the effects of the challenges and ensuring that future long-term care services reflect the principles of universal access, high quality and long-term sustainability across Europe will require comprehensive, effective and well-coordinated changes in current policies and practices in many, if not all, European countries (Social Protection Committee and the European Commission, 2014).

#### Access to and investment in LTC

The financial sustainability of LTC services is perhaps the most pressing challenge LTC services present to each Member State. Public expenditure on health care and long-term care together accounted for 8.7% of GDP and about 15% of total government expenditure in the EU in 2015<sup>4</sup>. Many countries are struggling to provide public universal, affordable and quality LTC services, often related to reduced income following the 2007 financial crisis and budget consolidation initiatives and as a consequence of a shrinking EU working force, governments face difficulties to financially cover the provision of LTC services. Population forecasts and changes in the provision of informal care pose additional challenges to future of financially sustainable LTC services.

Disparity between public social services' development within different EU Member States has led to the current situation where delivery of LTC can vary drastically depending on the country, in some cases prioritising those in higher need of care, although the increased demand for formal LTC services is consistent over Europe. Member States are not financially capable of responding to the growing demand of these services, as a result LTC accessibility has developed into a form of "restricted universalism", whereby services are now largely targeted towards those with the highest levels of caring needs, limited by financial constraints, longer waiting times and budget ceilings, and with a greater reliance on informal care from family members and non-statutory providers (European Council, 2014). Older persons therefore face challenges to access quality LTC services in some EU countries, in some cases related to services' costs or actual availability of services.

**The European Commission must encourage social investment and governments must view expenditure in LTC as essential to ensure all people, including older people, can live in dignity and enjoy quality of life.**

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<sup>3</sup> [http://ec.europa.eu/economy\\_finance/structural\\_reforms/ageing/health\\_care/index\\_en.htm](http://ec.europa.eu/economy_finance/structural_reforms/ageing/health_care/index_en.htm)

<sup>4</sup> [http://ec.europa.eu/economy\\_finance/structural\\_reforms/ageing/health\\_care/index\\_en.htm](http://ec.europa.eu/economy_finance/structural_reforms/ageing/health_care/index_en.htm)

## Quality and person-centred services

Ensuring the quality of LTC services can represent a major challenge in the future; when services face increasing demand and, simultaneously, high pressure on costs. It is a challenge to ensure person-centred LTC services are available and accessible, in particular for those who may experience complex needs, such as ageing people with disabilities that present multi morbidity. Many people with disabilities grow older earlier than other people due to conditions such as acquired brain injury and dementia. Additionally, the type of disability and severity can change over time. It is important to address needs others than bio-medical; what is right for the individual in terms of upkeep or health. EPR members stressed the importance of focusing on the quality of life of users and the importance of leisure and social activities.

As previously noted, investment is needed to meet the LTC needs of their population. The current European Commission has shown a clear focus on growth and employment. Social services and within them LTC, present clear opportunities for investment that would on the one hand help provide quality, affordable and accessible care while also creating jobs to meet the increased need, contributing to growth and improving quality of life of millions of individuals. It is also important that **public authorities contract quality services in public procurement procedures**; ensuring that tendering processes do not lead to the choice of provider based only or mainly on the cost of the services<sup>5</sup>.

## De-institutionalisation<sup>6</sup>, independent living and assistive technology

There is a common trend to move away from the traditional institutional care provision towards more community-based approaches (European Union, 2008; Ilinca, Leichsenring, Rodrigues, 2015). Deinstitutionalisation in long-term care promotes the well-being of those in need of care and may present lower expenditure for healthcare systems (Ilinca, Leichsenring, Rodrigues, 2015). In addition, older people tend to prefer to receiving LTC services in their own homes and this choice seems related to four factors (SWG, 2013):

- *Sharing household*
- *Age-friendly houses*
- *Assistive aids and ICTs*
- *Home-care support*

The prevalence of depressive disorders for older adults living in the community (2-3%) is lower compared to the ones in LTC facilities (about 10%) (World Health Organisation, 2015). The WHO suggests viewing institutions as a “last resort” only when family or home-based options are not available (2002).

EPR member, the Don Carlo Gnocchi Foundation, stresses the importance of promoting independent living and alternatives in order to avoid or to delay older people to move into assisted-living facilities (nursing homes). The foundation offers a variety of services and facilities, including a *Geriatric Assessment Unit (UVG)*, which aims to address each older person’s challenges in order to maintain physical, mental and social individual aspects. The *Day time centre (CDI)* is a support service to the family that has as its main objective the maintenance of the older people in their own home for as long as possible, providing a range of services and social-day-care interventions and the *mini apartments* that are designed for the elderly, singles or couples, who

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<sup>5</sup> For more information and recommendations on public procurement for quality services please see here <https://www.epr.eu/what-we-do/policy-analysis/social-services-sector/>

<sup>6</sup> For more information on de-nstitutionalisation please see EPR’s Analytical paper on Mainstreamed services and De-institutionalisation which can be consulted here: [https://www.epr.eu/wp-content/uploads/Analytical\\_paper\\_Mainstreamed\\_and\\_community\\_based\\_services-I.pdf](https://www.epr.eu/wp-content/uploads/Analytical_paper_Mainstreamed_and_community_based_services-I.pdf)

are still autonomous but need a controlled and protected environment. Support should be ensured for both **informal and formal care**, and mixed and flexible services.

The personal perception of being able to carry out daily activities and living independently plays a crucial role in whether the person needs help (SWG, 2013). Using **an older-person-centred approach**, people aged 65+ should be considered individuals with a great deal of experience, with their own needs and also preferences (World Health Organisation, 2015) who should be able to choose residential or home care. Older people with disabilities can present complex needs and therefore there must be **training of staff** providing long-term care to be able to support different disabilities, particularly intellectual disabilities and people with co-morbidity.

In case residential care is necessary, it is important to carefully assess the needs and expectations of older people with disabilities to change the services accordingly and enable residential structures to provide integrated responses to the user's needs. **Coproduction as a model should be pursued and promoted**, ensuring service users, as experts of their own experience, can co-create services and policy.

One EU report states that technological innovation, to improve the quality of long-term care and to raise the productivity of those who provide it, will play an important role in meeting the multiple challenges which long-term care now faces across the EU (Social Protection Committee and the European Commission, 2014).

On the other hand, innovative organisational approaches and technical solutions could achieve a more efficient use of resources, skills and technology, improve the health and quality of life of older people and caregivers, delay disability, slow the progression of the disease, avoid unnecessary hospitalization and institutional care and increase the sustainability of health and care systems (Social Protection Committee and the European Commission, 2014). EPR member, Marie Homes, stressed the importance of a wider use of assistive technologies solutions to better meet the need of the elderly population. A more effective integration of health and social care and the much **greater use of cost-effective, affordable technology is important, but may also require major additional training and upskilling of staff.**

## Healthy ageing

The WHO argues that the combination of medical and other LTC services should aim to promote a *healthy ageing* approach defined as “*the process of developing and maintaining the functional ability that enables well-being in older age*” (World Health Organisation, 2015). Lafortune & Balesta (2007) point out that by improving the health and functional status would enable elderly people to live independently also in later stages of their life and therefore relying less or later on LTC services to perform daily activities.

A recent study calls for more research on the relationship between healthy ageing and health inequalities to inform policy-makers in finding appropriate solutions in the future, to develop comprehensive multisector and inter-sectoral approaches to support healthy ageing and in particular older adults (Sadana, R. et al., 2016). EPR members suggested that people with disabilities that have older parents who act as carers could benefit from programmes promoting healthy ageing and independent living to mitigate the negative consequences in the case that the parent dies.

## Loss of social network/isolation

Older people with disabilities can be exposed to greater social exclusion. Physical problems can lead to social exclusion and isolation. Losing the social network has a negative impact for the well-being of old people with disabilities. In many cases, older persons limit their physical activity due to fear of injuries and experience an increase of their medicines intake. When people grow older, they also lose substantial parts of their social

networks due to death of friends and relatives and own impaired functioning. This network has in most cases been giving support to the individual in various ways.

### Informal care givers

Informal care is when family members, relatives and/or friends support the person in need of care - even if they receive payments or small sums of money for their services. Each Member State relies on informal caregivers to a different extent and yet, in all countries, this category plays a great deal in assisting those in need of LTC. Smaller families, migration processes of the young generations, more gender-balance in the labour market and other factors may disrupt those LTC systems heavily relying on informal caregivers or lead to other problems such as the use of undeclared immigrant carers (European Commission, 2013).

In contexts where long-term support provision relies on informal caregivers, informal carers might not be able to fully met the needs of elderly people with disabilities as per the concrete needs these users may have.

### Recruitment, retention and training of staff to work with people with disabilities<sup>7</sup>

Staff shortages and high turn-over in the social services sector are related to the poor working conditions many of the staff face. Unsocial hours, predominantly part time or shift work characterise the sector and service providers face competition for contracts which make it challenging to pay decent wages. The majority of social workers are women. In order to improve the working conditions of the staff, maintain a steady work force- which benefits the users who create bonds with staff members- and recruit new staff in order to meet the higher demands of services, adequate investment to boost jobs in the sector should be prioritised.

EPR members highlight it is essential to have staff well trained to work with people with disabilities, particularly those with intellectual disabilities. As outlined in a previous section, they may present more varied needs than other older people. Accompanying the ageing process of persons with disabilities involves a change of focus from psychosocial to biomedical needs as physical problems become the main ones. Helping staff to develop new skills can be useful to better understand the needs of the users and to identify individualised solutions to meet the needs of older people with disabilities.

### Integrated care

People who have multiple care needs usually receive health and social care services from different providers and in different care settings. Health and social care providers have experienced that this often happens without appropriate co-ordination or a holistic approach, leading to various issues for the service user, the (in)formal carer and the family such as gaps in service provision or inadequate support, limited access and information, as well as increased costs to care systems in the form of unnecessary hospital admissions or aggravated health problems (Action Paper, 2016). LTC services should promote **integrated responses** to meet the needs of older people with disabilities.

## 4. National and EU initiatives to tackle the challenges

In recent years, Member States have implemented a series of policy reforms with the aim to increase accessibility, quality and sustainability of long-term care services. Based on the findings of the 2015 Report of the Social Protection Committee, Members State focus on:

**1. Organisation of long-term care systems**

BE, CY, CZ, LU, LV, NL, PL, SE, SI, RO, UK

**2. Financing and cost-sharing**

AT, BE, BG, HU, DE, LU, RO

<sup>7</sup> For more information and recommendations, please consult the research and recommendations EPR co-commissioned with Social Services Europe, found here: <https://www.epr.eu/what-we-do/policy-analysis/social-services-sector/>

<b>3. Preventing dependency</b>	AT, BG, ES, IE, RO
<b>4. Service delivery</b>	DE, HR, IE, RO
<b>5. Assuring and monitoring quality</b>	AT, IE, MT, RO
<b>6. Investing in the long-term care workforce</b>	HU, RO, SE
<b>7. Support to informal carers</b>	AT, BE, CZ, DE, FI, RO

This report shows that the re-organisation of the LTC service provision is high on the agenda of most Member States with a focus on further developing home care services, strengthening integration of care. However, studies show that national policies addressed at covering the demands of LTC are in some cases not well prepared for the future, with a scarcity of financial resources leading to an increase provision of informal care by migrants, who might have irregular situations with no access to social protection themselves.

In order to address the current situation of imbalance between supply and demand of LTC in Europe and in view of the future needs of the European population regarding service provision, the European Union works on LTC in various initiatives.

**a. Social Protection Committee dedicated working group on ageing.** This advisory policy group brings together policy makers from Member States and the Commission to discuss and monitor responses to social policy challenges across the EU. LTC is one of the main social policy strands and the Work Programme 2016 confirms continuity of the thematic work on the topic, pursuing the proposal for developing data and indicators. This proposal was identified as a goal by the 2014 report “*Adequate social protection for long-term care needs in an ageing society*” (SPC, 2016b). This group aims at promoting mutual learning and sharing innovative approaches between Member States to find evidence-based solutions to mitigate the growth of need, ensure efficient care and dignity in LTC.

**b. The MISSOC** (Mutual Information System on Social Protection) was created in 1990 to facilitate the exchange of information and data on social protection issues among Member States. The MISSOC Comparative Table database<sup>8</sup> contains information divided in 12 topics among which there is a specific section on long-term care (Section XII). The available information includes national data on: *Applicable statutory basis, Basic principles, Risk covered, Conditions, Organisation, Benefits, Benefits for informal carers.*

**c. eHealth Action Plan 2012-2020 (2012)**<sup>9</sup> is a roadmap to support Member States in using technology to better meet the needs of the patients, support health care workers and modernise healthcare systems through research and innovation. Specifically, research on the long-term care should focus on innovative solutions to improve disease management, prediction, prevention diagnosis and treatment. It presents and consolidates actions to deliver the opportunities that eHealth can offer, describes the EU's role and encourages Member States and stakeholders to work together and eliminate barriers for fully mature eHealth system in Europe.

**d. European Innovation Partnership on Active and Healthy Ageing (EIP on AHA).** Created in 2011, this is a pilot initiative launched by the European Commission to foster innovation in the field of active and healthy ageing. The European Commission has identified healthy ageing as a major challenge for all Member States and the goals of this strategy are<sup>10</sup>:

- enabling EU citizens to lead healthy, active and independent lives while ageing;
- improving the sustainability and efficiency of social and health care systems;

<sup>9</sup> <https://ec.europa.eu/digital-single-market/en/news/ehealth-action-plan-2012-2020-innovative-healthcare-21st-century>

<sup>10</sup> [http://ec.europa.eu/research/innovation-union/index\\_en.cfm?section=active-healthy-ageing&pg=about](http://ec.europa.eu/research/innovation-union/index_en.cfm?section=active-healthy-ageing&pg=about)

- boosting and improving the competitiveness of the markets for innovative products and services, responding to the ageing challenge at both EU and global level, thus creating new opportunities for businesses.

The concept of European Innovation Partnerships (EIPs) is a new approach to EU research and innovation. By bringing together relevant actors at EU, national and regional levels across different policy areas, the EIP aims to address specific societal challenges and involves all the innovation chain levels.

Numerous resources are available through the portal of the EIP on ADA. The main sections are: *Repository of practices, Funding, Scaling up innovation, Action Groups, Reference Sites, Library, News, Events*. Interested organisations can join partnerships and become actively involved. In the Scaling up innovation section, there are detailed information on international projects focusing on ICT-based solutions for Active and Healthy Ageing and interested organisations can also upload their experience and share it via the EIP on ADA.

The EIP's Actions Groups are an assembly of partners committing to work on specific issues related to ageing. They share knowledge and expertise with peers, giving added-value to their national and local experience and identifying gaps that need to be fulfilled at European level. Currently, the six Action Groups focus on: *Adherence to prescription; falls prevention; functional decline and frailty; integrated care; independent living solutions and age friendly environments*.

## **e. European Pillar of Social Rights**

LTC has recently gained increased relevance in the EU policy making agenda with The European Pillar of Social Rights, the latest major EU social policy initiative, including it within its 20 principles.

Principle 18 states 'Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services'. These principles are now being mainstreamed through the different governance tools the European Union has in place to monitor EU countries progress on a yearly basis. As such, the principles contained within the European Pillar of Social Rights will be mainstreamed within the European Semester, the main macroeconomic and fiscal policy tool to meet the targets underlined within the Europe 2020 strategy. Specific recommendations and reporting on the principles will be addressed to national governments, calling on them to meet these principles.





## 5. References/further reading

- Action paper (2016).** *A joint call for EU action on long-term care with special focus on integrated care* (Available at [https://www.eurodiaconia.org/wordpress/wp-content/uploads/2016/03/LTC-and-IC\\_coalition\\_key-messages\\_10.03.2016.pdf](https://www.eurodiaconia.org/wordpress/wp-content/uploads/2016/03/LTC-and-IC_coalition_key-messages_10.03.2016.pdf)).
- Autism Europe (2003).** *The Rights of Ageing People with Autism. Position paper on ageing persons with autism.* AE EYPD 2003 01/04 (Available at <http://www.autismeurope.org/files/files/ae-eypd-ageing-final-eng.pdf> )
- Colombo, F. et al (2011),** *Help Wanted? Providing and Paying for Long-Term Care*, OECD Publishing. (Available at <http://www.oecd.org/els/health-systems/47836116.pdf> )
- Comas- Herrera, A. et al. (2003).** *European Study of Long-Term Care Expenditure: Investigating the sensitivity of projections of future long-term care expenditure in Germany, Spain, Italy and the United Kingdom to changes in assumptions about demography, dependency, informal care, formal care and unit costs.* Report to the European Commission, Employment and Social Affairs DG. (Available at [http://ec.europa.eu/employment\\_social/soc-prot/healthcare/ltc\\_study\\_en.pdf](http://ec.europa.eu/employment_social/soc-prot/healthcare/ltc_study_en.pdf).)
- eHealth Action Plan 2012-2020 (2012).** Innovative healthcare for the 21st century <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52012DC0736:EN:NOT>
- EPR (2015).** *Mainstreamed services and De-institutionalisation:* [https://www.epr.eu/wp-content/uploads/Analytical\\_paper\\_Mainstreamed\\_and\\_community\\_based\\_services-1.pdf](https://www.epr.eu/wp-content/uploads/Analytical_paper_Mainstreamed_and_community_based_services-1.pdf)
- European Commission (2008).** *Long term care in the European Union.* Employment, Social Affairs and Equal Opportunities DG (Available at <http://ec.europa.eu/social/BlobServlet?docId=2781&langId=en>)
- European Commission (2015).** *The 2015 Ageing Report Economic and budgetary projections for the 28 EU Member States (2013-2060)*, European Economy 3. (Available at [http://ec.europa.eu/economy\\_finance/publications/european\\_economy/2015/pdf/ee3\\_en.pdf](http://ec.europa.eu/economy_finance/publications/european_economy/2015/pdf/ee3_en.pdf))
- European Commission and Economic Policy Committee (2009).** “*The 2009 Ageing Report: Economic and budgetary projections for the EU-27 Member States (2008-2060)*”, European Economy 2/2009. (Available at [http://aei.pitt.edu/43000/1/2009.pdfTerm%20Care/Background%20info/publication14992\\_en.pdf](http://aei.pitt.edu/43000/1/2009.pdfTerm%20Care/Background%20info/publication14992_en.pdf) )
- European Council (2014).** *Employment, Social Policy, Health and Consumer Affairs. Press Release*, 3323rd Council Meeting, Luxembourg, June 2014. ([www.consilium.europa.eu/en/workarea/downloadasset.aspx?id=27324](http://www.consilium.europa.eu/en/workarea/downloadasset.aspx?id=27324))
- EUROSTAT (2015).** *Population by sex, age and disability status.* Available at [http://appsso.eurostat.ec.europa.eu/nui/show.do?dataset=hlth\\_dpeh005&lang=en](http://appsso.eurostat.ec.europa.eu/nui/show.do?dataset=hlth_dpeh005&lang=en)
- EUROSTAT (2016).** *Population structure and ageing*, Available at [http://ec.europa.eu/eurostat/statistics-explained/index.php/Population\\_structure\\_and\\_ageing](http://ec.europa.eu/eurostat/statistics-explained/index.php/Population_structure_and_ageing)
- Ilinca, S., Leichsenring, K., Rodrigues, R. (2015).** *From care in homes to care at home: European experiences with (de)institutionalisation in long-term care*, Policy brief December 2015, European Centre. (Available at [http://www.euro.centre.org/data/1449741582\\_83911.pdf](http://www.euro.centre.org/data/1449741582_83911.pdf) )
- Lafortune, G. & Balestat, G. (2007).** *Trends in severe disability among elderly people: Assessing the evidence in 12 OECD countries and the future implications.* OECD Health Working Papers No. 26, Department for Employment, Labour and Social Affairs, Health Committee (available at <http://www.oecd-ilibrary.org/docserver/download/217072070078.pdf?expires=1484228119&id=id&accname=guest&checksum=252C2942AFA220A409D5BAA4AF15A837>).
- Lawton, M.P., and Brody, E.M. (1969).** *Assessment of older people: Self-maintaining and instrumental activities of daily living*, Gerontologist 9, pag. 179-186, The Gerontological Society of America (Available at [http://www.strokecenter.org/wp-content/uploads/2011/08/lawton\\_IADL\\_Scale.pdf](http://www.strokecenter.org/wp-content/uploads/2011/08/lawton_IADL_Scale.pdf) )

**McCall, N. (2001).** *Long Term Care: Definition, Demand, Cost, and Financing.* in Nelda McCall, editor, *Who Will Pay for Long-Term Care*, Health Administration Press, Chicago, Illinois. (Available at <http://www.ache.org/PUBS/lmccall.pdf>)

**National Down Syndrome Society (2013).** *Aging and Down Syndrome: A Health and Well-Being Guidebook* is dedicated (Available at <http://www.ndss.org/PageFiles/2594/Aging%20and%20Down%20Syndrome%20A%20Health%20and%20Well-Being%20Guidebook.pdf>)

**National Care Planning Council,** *What Is Long Term Care?* (Available at [https://www.longtermcarelink.net/eldercare/long\\_term\\_care.htm](https://www.longtermcarelink.net/eldercare/long_term_care.htm)).

**OECD (2005),** *Long-term Care for Older People*, The OECD Health project, OECD Publishing. (Available at [http://www.keepeek.com/Digital-Asset-Management/oezd/social-issues-migration-health/long-term-care-for-older-people\\_9789264015852-en#.WDLcYoVcGDg#page5](http://www.keepeek.com/Digital-Asset-Management/oezd/social-issues-migration-health/long-term-care-for-older-people_9789264015852-en#.WDLcYoVcGDg#page5))

**Sadana, R. et al (2016).** *Healthy Ageing: Raising Awareness of Inequalities, Determinants, and What Could Be Done to Improve Health Equity*, *Gerontologist*, Vol. 56, No. S2, S178–S193 doi:10.1093/geront/gnw034 (Available at [https://gerontologist.oxfordjournals.org/content/56/Suppl\\_2/S178.full.pdf+html](https://gerontologist.oxfordjournals.org/content/56/Suppl_2/S178.full.pdf+html))

**Social Protection Committee (2015).** *Review of recent social policy reforms 2015 Report of the Social Protection Committee* (Available <http://ec.europa.eu/social/BlobServlet?docId=14927&langId=en>)

**Social Protection Committee (2016).** *2016 Work Programme* (Available at <https://webgate.ec.europa.eu/emplcms/social/BlobServlet?docId=15323&langId=en>)

**Social Protection Committee (2016b).** *2016 ISG Work Programme, SPC/ISG/2016/02/3 FIN* (<http://ec.europa.eu/social/BlobServlet?docId=15990&langId=en>)

**Social Protection Committee and the European Commission (2014).** *Adequate social protection for long-term care needs in an ageing society*, European Union Publications (Available at <http://ec.europa.eu/social/BlobServlet?docId=12808&langId=en>)

**European Commission (2013).** *Long-term care in ageing societies - Challenges and policy options. Social investment package.* Commission staff working document. SWD (2013) 41 final, 20 February 2013. (Available at <http://aei.pitt.edu/45916/>)

**United Nations (2015).** Department of Economic and Social Affairs, Population Division. *World Population Prospects: The 2015 Revision*, custom data acquired via website. (Available at <https://esa.un.org/unpd/wpp/>)

**World Health Organisation (2002).** *Ethical choices in long-term care: what does justice require?* WHO Library Cataloguing-in-Publication Data (Available at [http://www.who.int/mediacentre/news/notes/ethical\\_choices.pdf](http://www.who.int/mediacentre/news/notes/ethical_choices.pdf))

**World Health Organisation (2013).** Case-study 12 Affordable health care in ageing populations: forecasting changes in public health expenditure in five European countries. *The world health report 2013: research for universal health coverage* (Available at [http://apps.who.int/iris/bitstream/10665/85761/2/9789240690837\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/85761/2/9789240690837_eng.pdf?ua=1)).

**World Health Organisation (2015).** *World report on Ageing and Health.* (Available at [http://apps.who.int/iris/bitstream/10665/186463/1/9789240694811\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/186463/1/9789240694811_eng.pdf?ua=1))

## **Annexes follow**

*The European Platform for Rehabilitation (EPR) is the Network of providers of rehabilitation services committed to excellence and innovation. EPR and its members contribute to a society where every person with a disability and persons in other vulnerable situations have access to the highest quality services that create equal opportunities for all and independent participation in society. More information on [www.epr.eu](http://www.epr.eu)*

## 6. Annexes

**Daily activities** can be divided into two categories: Basic Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). The former category includes basic medical services, nursing care, prevention, rehabilitation or palliative care provide, whereas the latter refers to domestic help with lower-level of care (Colombo,F. et al., 2011). Specifically, IADs encompasses activities such as bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet, and controlling bladder and bowel functions (Social Protection Committee and the European Commission, 2014). Furthermore, according to Lawton and Brody's (1969) scale, IADLs includes: ability to use telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, responsibility of own medications, ability to handle finances. Depending on the specific individual condition(s) and national provisions, it is common that support for both ADLs and IADLs is given at the same time.

### Informal and formal care

The wide range of LTC services can be provided either by the relatives/friends of the person receiving care or by professional caregivers, also known as (European Commission and Economic Policy Committee, 2009):

- 1) **INFORMAL CARE:** When family members, relatives and/or friends support the person receiving care - even if they receive payments or small sums of money for their services;
- 2) **FORMAL CARE:** if care assistants provide help based upon some form of employment contract regardless the setting – services can be delivered either at home or in an institution.

It is important to note that these two categories of caregivers operate simultaneously in each Member State and the main difference is the extent to which each healthcare system relies on either formal or informal ones. Informal caregivers play an important role in most European countries providing direct support especially to older people and recent figures claim that the number of informal caregivers is twice of the formal ones (Social Protection Committee and the European Commission, 2014).

LTC provisions differ in terms of service delivering and allocation of public resources. A typology presenting four 'ideal types' of European long-term care regimes can simplify possible comparisons among the different national systems (Ilinca, Leichsenring, Rodrigues, 2015):

	Demand for care	Provision of informal care	Provision of formal care	Countries
<b>Standard care mix</b>	High	Medium/Low	Medium	Germany Austria France United Kingdom
<b>Universal Nordic</b>	Medium	Low	High	Sweden Denmark, Netherlands
<b>Family based</b>	High	High	Low	Spain Italy Portugal Ireland Greece
<b>Transition</b>	Medium	High	Medium/Low	Latvia Poland Hungary Romania Slovakia Czech Republic

LIFE EXPECTANCY BY AGE													
		1960	1970	1980	1990	2000	2014	1960/ 1970	1970/ 1980	1980/ 1990	1990/ 2000	2000/ 2014	1960/ 2014
								%	%	%	%	%	%
1	Austria		70.1	72.7	75.8	78.3	81.6		3.6	4.1	3.2	4.0	
2	Belgium	69.7	71.0	73.3	76.2	77.9	81.4	1.8	3.1	3.8	2.2	4.3	16.8
3	Bulgaria	69.3	71.2	71.1	71.2	71.6	74.5	2.7	-0.1	0.1	0.6	3.9	7.5
4	Croatia						77.9						
5	Cyprus					77.7	82.8					6.2	
6	Czech Republic	70.7	69.6	70.4	71.5	75.1	78.9	-1.6	1.1	1.5	4.8	4.8	11.6
7	Denmark			74.2	74.9	76.9	80.7			0.9	2.6	4.7	
8	Estonia	69.4	70.4	69.5	69.9	71.1	77.4	1.4	-1.3	0.6	1.7	8.1	11.5
9	Finland			73.7	75.1	77.8	81.3			1.9	3.5	4.3	
10	France					79.2	82.8					4.3	
11	Germany	69.2	70.7	73.1	75.4	78.3	81.2	2.1	3.3	3.1	3.7	3.6	17.3
12	Greece	:	73.8	75.3	77.1	78.6	81.5		2.0	2.3	1.9	3.6	
13	Hungary	68.1	69.2	69.1	69.4	71.9	76	1.6	-0.1	0.4	3.5	5.4	11.6
14	Ireland				74.8	76.6	81.4				2.3	5.9	
15	Italy				77.1	79.9	83.2				3.5	4.0	
16	Latvia						74.5						
17	Lithuania		71.1	70.5	71.5	72.1	74.7		-0.9	1.4	0.8	3.5	
18	Luxembourg			72.8	75.7	78	82.3			3.8	2.9	5.2	
19	Malta			70.4		78.4	82.1					4.5	
20	Netherlands				77.1	78.2	81.8				1.4	4.4	
21	Poland				70.7	73.8	77.8				4.2	5.1	
22	Portugal	64.0	66.7	71.5	74.1	76.8	81.3	4.0	6.7	3.5	3.5	5.5	27.0
23	Romania	:	68.2	69.2	69.9	71.2	75		1.4	1.0	1.8	5.1	
24	Slovakia	70.3	69.8	70.4	71.1	73.3	77	-0.7	0.9	1.0	3.0	4.8	9.5
25	Slovenia				73.9	76.2	81.2				3.0	6.2	
26	Spain			75.5	76.9	79.3	83.3			1.8	3.0	4.8	
27	Sweden		74.7	75.8	77.7	79.8	82.3		1.5	2.4	2.6	3.0	
28	United Kingdom					78	81.4					4.2	
	<b>EUROPEAN UNION (28 countries)</b>						<b>80.9</b>						

Table 1 : Source data EUROSTAT ([http://appsso.eurostat.ec.europa.eu/nui/show.do?dataset=demo\\_mlexpec&lang=en](http://appsso.eurostat.ec.europa.eu/nui/show.do?dataset=demo_mlexpec&lang=en))

Table 2 : Source data EUROSTAT(available at <http://appsso.eurostat.ec.europa.eu/nui/submitViewTableAction.do> )

PROPORTION OF POPULATION AGED 60 YEARS AND MORE PROPORTION OF POPULATYION AGED 85 YEARS AND MORE													
		1960	1970	1980	1990	2000	2014	1960/ 1970	1970/ 1980	1980/ 1990	1990/ 2000	2000/ 2014	1960/ 2014
								%	%	%	%	%	%
1	Austria	18.0	20.0	19.1	20.2	20.3	23.8	10.0	-4.7	5.4	0.5	14.7	24.4
	> 85+	0.5	0.7	0.9	1.3	1.8	2.5	28.6	22.2	30.8	27.8	28.0	80.0
2	Belgium	17.6	18.9	18.1	20.4	21.9	23.6	6.9	-4.4	11.3	6.8	7.2	25.4
	> 85+	0.6	0.8	0.9	1.4	1.8	2.5	25.0	11.1	35.7	22.2	28.0	76.0
3	Bulgaria	11.2	14.5	15.5	19.1	21.7	26.7	22.8	6.5	18.8	12.0	18.7	58.1
	> 85+	0.4	0.5	0.5	0.7	0.8	1.7	20.0	0.0	28.6	12.5	52.9	76.5
4	Croatia	:	:	:	:	:	25.1						
	> 85+	:	:	:	:	:	1.6						
5	Cyprus	:	:	:	14.7	15.3	19.3				3.9	20.7	
	> 85+	:	:	:	:	1.1	1.3					15.4	
6	Czech Republic	14.6	18.0	16.9	17.6	18.2	24.3	18.9	-6.5	4.0	3.3	25.1	39.9
	> 85+	0.4	0.5	0.6	0.8	1.2	1.7	20.0	16.7	25.0	33.3	29.4	76.5
7	Denmark	15.4	17.5	19.3	20.4	19.7	24.3	12.0	9.3	5.4	-3.6	18.9	36.6
	> 85+	0.5	0.7	1.1	1.5	1.8	2.1	28.6	36.4	26.7	16.7	14.3	76.2
8	Estonia	:	16.7	16.1	17.1	20.9	24.6		-3.7	5.8	18.2	15.0	
	> 85+	:	0.7	0.8	0.9	1.3	2.1		12.5	11.1	30.8	38.1	
9	Finland	11.2	14.0	16.2	18.4	19.8	26.4	20.0	13.6	12.0	7.1	25.0	57.6
	> 85+	0.3	0.3	0.5	1.0	1.5	2.4	0.0	40.0	50.0	33.3	37.5	87.5
10	France	:	:	:	:	20.4	24.2					15.7	
	> 85+	:	:	:	:	2.1	2.9					27.6	
11	Germany	17.1	19.7	19.2	20.3	23.0	27.2	13.2	-2.6	5.4	11.7	15.4	37.1
	> 85+	0.4	0.6	0.9	1.4	2.0	2.6	33.3	33.3	35.7	30.0	23.1	84.6
12	Greece	13.4	16.2	17.5	19.7	23.3	26.3	17.3	7.4	11.2	15.5	11.4	49.0
	> 85+	:	0.8	0.9	1.2	1.7	2.6		11.1	25.0	29.4	34.6	
13	Hungary	13.8	17.0	17.1	18.9	20.1	24.4	18.8	0.6	9.5	6.0	17.6	43.4
	> 85+	0.3	0.5	0.6	0.8	1.3	1.8	40.0	16.7	25.0	38.5	27.8	83.3
14	Ireland	15.6	15.6	14.8	15.2	15.2	17.5	0.0	-5.4	2.6	0.0	13.1	10.9
	> 85+	0.6	0.7	0.7	0.8	1.0	1.4	14.3	0.0	12.5	20.0	28.6	57.1

15	<b>Italy</b>	13.5	15.9	16.8	20.4	24.1	<b>27.4</b>	15.1	5.4	17.6	15.4	12.0	<b>50.7</b>
	> 85+	:	:	0.8	1.2	2.1	3.1			33.3	42.9	32.3	
16	<b>Latvia</b>	:	17.3	16.5	17.4	21.0	<b>25.2</b>		-4.8	5.2	17.1	16.7	
	> 85+	:	0.8	0.9	1.1	1.2	2.0		11.1	18.2	8.3	40.0	
17	<b>Lithuania</b>	:	15.0	14.3	16.0	19.0	<b>24.3</b>		-4.9	10.6	15.8	21.8	
	> 85+	:	0.6	0.8	1.1	1.2	2.1		25.0	27.3	8.3	42.9	
18	<b>Luxembourg</b>	16.3	18.4	17.7	18.9	19.1	<b>19.2</b>	11.4	-4.0	6.3	1.0	0.5	<b>15.1</b>
	> 85+	:	:	0.9	1.2	1.6	1.8			25.0	25.0	11.1	
19	<b>Malta</b>	:	:	12.0	14.6	16.8	<b>24.7</b>			17.8	13.1	32.0	
	> 85+	:	:	0.2	0.7	1.0	1.7			71.4	30.0	41.2	
20	<b>Netherlands</b>	13.1	14.5	15.6	17.3	18.1	<b>23.5</b>	9.7	7.1	9.8	4.4	23.0	<b>44.3</b>
	> 85+	0.4	0.6	0.9	1.2	1.4	2.0	33.3	33.3	25.0	14.3	30.0	
21	<b>Poland</b>	9.3	12.6	13.2	14.7	16.6	<b>21.7</b>	26.2	4.5	10.2	11.4	23.5	<b>57.1</b>
	> 85+	0.3	0.4	0.5	0.7	0.9	1.6	25.0	20.0	28.6	22.2	43.8	
22	<b>Portugal</b>	11.3	13.7	15.4	18.5	21.5	<b>26.0</b>	17.5	11.0	16.8	14.0	17.3	<b>56.5</b>
	> 85+	0.4	0.4	0.5	0.9	1.4	2.4	0.0	20.0	44.4	35.7	41.7	
23	<b>Romania</b>	:	13.1	13.2	15.5	18.7	<b>23.2</b>		0.8	14.8	17.1	19.4	
	> 85+	:	0.3	0.4	0.5	0.8	1.5		25.0	20.0	37.5	46.7	
24	<b>Slovakia</b>	10.7	13.8	13.3	14.8	15.4	<b>19.9</b>	22.5	-3.8	10.1	3.9	22.6	<b>46.2</b>
	> 85+	0.4	0.4	0.4	0.7	1.0	1.2	0.0	0.0	42.9	30.0	16.7	
25	<b>Slovenia</b>	:	:	:	15.6	19.0	<b>24.2</b>				17.9	21.5	
	> 85+	:	:	:	0.7	1.2	2.0				41.7	40.0	
26	<b>Spain</b>	12.3	13.9	15.2	18.7	21.2	<b>23.5</b>	11.5	8.6	18.7	11.8	9.8	<b>47.7</b>
	> 85+	:	0.5	0.7	1.1	1.6	2.7		28.6	36.4	31.3	40.7	
27	<b>Sweden</b>	16.8	19.5	21.8	22.8	22.2	<b>25.3</b>	13.8	10.6	4.4	-2.7	12.3	<b>33.6</b>
	> 85+	0.6	0.8	1.2	1.7	2.3	2.6	25.0	33.3	29.4	26.1	11.5	
28	<b>United Kingdom</b>	16.9	18.7	19.8	20.8	20.7	<b>23.0</b>	9.6	5.6	4.8	-0.5	10.0	<b>26.5</b>
	> 85+	0.6	0.8	1.0	1.5	1.9	2.3	25.0	20.0	33.3	21.1	17.4	
	<b>EUROPEAN UNION</b> (28 countries)						<b>24.6</b>						
	> 85+						<b>2.4</b>						

Table 3: Source data EUROSTAT(available at <http://appsso.eurostat.ec.europa.eu/nui/submitViewTableActi>)