

# Health

Rising Need for Elder Care in Europe Necessitates New Paradigm for Elder Caregiving Training: A Landscape Analysis<sup>1</sup>

EIT Health – Innovative healtcare solutions of tomorrow

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| Executive Summary7  |
|---|
| Introduction11  |
| 1. Defining the European Elder Caregiver15  |
| 1.1 Informal Elder Caregivers16   |
| 1.2 Formal Elder Caregivers17   |
| <ol> <li>The Current State of Elder Care Across Europe: Uneven</li> <li>Resources Create Variation in Quantity and Quality of Care</li></ol>            |
| 2.1 Quality of Care Diminished by Lack of Standards21   |
|   |
| <b>3. Drivers and Implications of an Ageing Europe: Why the Elder</b><br><b>Caregiving Need Will Continue to Explode</b> 25                             |
|   |
| Caregiving Need Will Continue to Explode  |
| Caregiving Need Will Continue to Explode25<br>3.1 When the Miracle of Longevity Meets Declining Birth Rates25   |
| Caregiving Need Will Continue to Explode25<br>3.1 When the Miracle of Longevity Meets Declining Birth Rates25<br>3.2 Ageing Increases Demand for Care26 |

ert

4

| 4.2 Italy and Spain: Financial Constraints Create Major Gap   |    |
|---|----|
| Between Elder Care Coverage and Need  | 33 |
|   |    |
| 4.3 Poland: Over-reliance on Family Caregiving of the Elderly   | 36 |
| 4.4 Germany: One of the Oldest Countries in Europe Still Trying to  |    |
| Strike a Balance  | 39 |
| 4.5 England: Burden of Elder Care Rests Primarily on Elderly and  |    |
| Their Families  | 42 |
|   |    |
|   |    |
| 5. Innovations in Elder Caregiving Provide Promising Models   |    |
| 5. Innovations in Elder Caregiving Provide Promising Models<br>for Future Responses to Growing Caregiving Needs             | 47 |
|   | 47 |
| for Future Responses to Growing Caregiving Needs  |    |
| for Future Responses to Growing Caregiving Needs<br>5.1 Professional Home Care Improves Care and Enables<br>Ageing in Place |    |
| for Future Responses to Growing Caregiving Needs<br>5.1 Professional Home Care Improves Care and Enables                    | 48 |
| for Future Responses to Growing Caregiving Needs<br>5.1 Professional Home Care Improves Care and Enables<br>Ageing in Place | 48 |





# Executive Summary

This landscape analysis underscores that the gap between the demand for elder caregiving and the supply of elder caregivers is substantial and growing across Europe. The Caregiving and Ageing Reimagined for Europe (CARE) initiative, which is part of the of the European Institute of Innovation and Technology (EIT) – Health Educational CAMPUS, is a first step on the path to a long-term solution. CARE will build education and training that will supplement current elder caregiving skills and create opportunities for the development of thousands of new elder caregivers. It will also provide the guidance and tools for current and emerging institutions in education, healthcare and caregiving itself.

## The main objectives of CARE are to:

- Ensure improved quality of care for seniors based on the self-assessment of need and in consultation with caregivers;
- Increase the numbers of new employed caregivers for the elderly (including and especially amongst the young, unemployed and migrants);
- Improve the quality of elder care delivered by defining standard protocols and building a comprehensive, accessible e-based learning curriculum. This will draw on best practices today in diseases of the elderly (such as Alzheimer's) and general daily care, but also extend to the critical areas of skin, oral and nutritional health, as well as applications for "end of life" value;
- Improve productivity and coping mechanisms for employed, informal family elder caregivers, and enhance sustainability of health systems; and
- Encourage economic growth and job creation across Europe in the health care industry.

## CARE recognises that sustainable systems for ageing populations should be built on strategies that:

- Extend healthy active life in old age;
- Improve competencies amongst older people to self-manage;
- Improve knowledge and support for informal caregivers; and
- Improve competencies of informal and professional caregivers to meet needs that are important to the older person.

Based on this analysis and the CARE objectives, there are seven takeaways to inform how we implement CARE:





### Build on Traditional Approaches to Create New, Better Quality Elder Care.

CARE should aim to enhance and supplement caregiving skills for the elderly to address new elder care needs arising from longevity and other health trends. These include skin health, vision loss, noncommunicable diseases (particularly Alzheimer's and other Dementias) and nutrition.



## Identify and Respond to the Needs of Older People and Caregivers.

CARE should improve knowledge amongst informal and formal caregivers to identify and respond to the needs that are important to the older person. It should improve knowledge amongst formal caregivers to identify and respond to the needs of informal caregivers in their caregiving roles.



#### Support Ageing in Place with Professional Home Care.

While European 20th century elder care has primarily focused on supporting longterm care (LTC) in institutional settings, 21st century longevity demands elder care that supports ageing in place. CARE must define how the needs for care recipients and caregivers differ in the home vs. an institution and map training strategies to ensure a positive and efficient elder caregiving environment that supports physical health and social connection.

# Integrate Elder Care Technologies.



Opportunities abound for integrating technologies into elder care education. They should be seen as an enabler of elder care – not a replacement for caregivers. New technologies can also serve to disseminate standardized training at an accelerated pace and on a more expansive scale, improving care quality and increasing access.



#### Provide Education and Skill Development through CARE CAMPUS.

Education can be the critical and normalizing pathway through which to elevate the standard of elder care. CARE will enable the creation of a body of knowledge to inform and provide the strategic support for higher quality, more effective elder care across all of Europe. CARE will develop systems to assure training in understanding older people's needs and to promote person-centred care in the training of informal and professional caregivers.



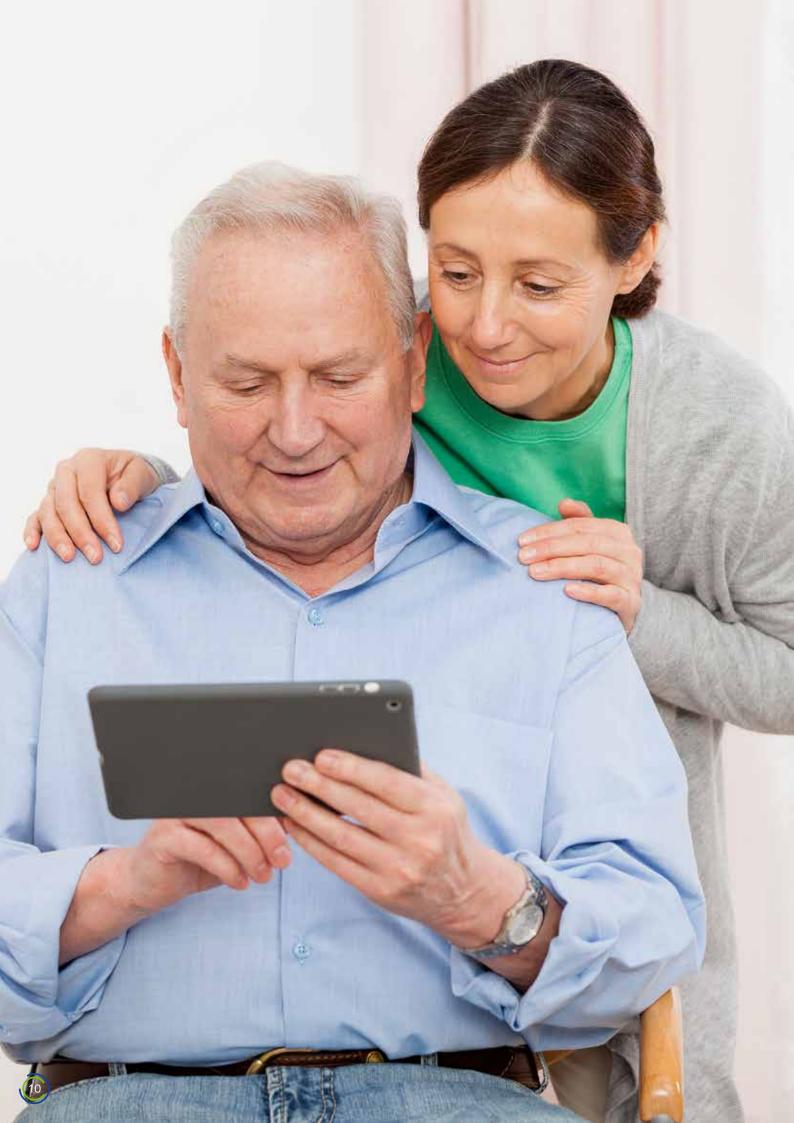
### Drive Toward Sustainability.

Our analysis is clear that the fiscal burden of health care is already challenging and will become unsustainable without strategic and systemic reforms. Public systems will be unable to continue taking care of elders with any degree of quality, unless novel care models and new roles are carved out for public-private partnerships in implementation of training programmes, support and oversight.



#### Pursue Innovative Approaches to Education.

Harnessing cutting-edge educational tools and applying them as never before to elder care is critical for a rapid uptake in training and enhanced skill development across Europe. On-line education will be an important enabler as will be integrating employers and other stakeholders who have an interest in solving 21st century elder care challenges.



# Introduction

It is well-known that the longevity miracle and falling birth rates have the world ageing at an unprecedented rate, with Europe near the front of the pack. By 2060, 155 million Europeans - 30 percent of the total European population - will be aged 65 and older<sup>1</sup>. These demographic shifts are breaking down traditional social structures and placing pressure on existing caregiving resources for Europe's elderly population in the process.

According to conservative estimates, by 2060, 30 percent of the over-65 population (~45 million) will have at least one disability that disrupts activities of daily living. That development alone will double elder caregiving needs across the continent from current levels<sup>2</sup>. The need is even greater for Europeans aged 80+: an age group typically requiring long-term care that is expected to triple by 2060<sup>3</sup>.

At the same time, resources to meet growing elder caregiving needs are strained and dwindling – a trend that is projected to continue in the absence of a well-planned, effective and profound strategic intervention. With the current rates, by 2060, there will be one caregiver for 51 persons of 80 years old or more<sup>4</sup>.

# 2060 trend

 $\dot{\Lambda}$ 



To help pay for the growing ageing population, public expenditures will need to increase just as declining birth rates are likely to contract overall national budgets. The proportion of old to young is becoming dire across Europe, and one clear consequence is the gap between the available supply of elder caregiving support and the exploding need.

Today in many EU countries, family members have shouldered the caregiving burden when institutional or professional home care have not been available or viable and acceptable options<sup>5</sup>. Taking on these elder caregiving responsibilities is often very disruptive to the family as it can take family members out of the workforce and, thus, decrease their earning and purchasing power. It is also very disruptive to national economies: a shrinking workforce due to growing family caregiving responsibilities will slow economic growth and place even greater long-term pressures on social systems to make up the difference<sup>6</sup>. With 21st century longevity rates, this model will become unsustainable as the time required to spend caring for an ageing family member is extended, the number of expensive and complex health challenges increases and working later in life becomes an economic imperative.

An alternative option for families, particularly in Southern and Eastern European countries<sup>7</sup>, has been to turn to undeclared migrant workers for care, placing caregiving in the shadow economy, where there are no institutionalized standards or legal protections for the caregiver and care recipient alike. Eroding standards and quality of caregiving can have an adverse impact on the healthcare system overall as regulation and early intervention become more difficult.

It is time for a new elder caregiving paradigm in Europe that aligns with 21st century demographic realities – a framework that places value on sourcing and training professional elder caregivers, while encouraging healthy and active ageing throughout the life course. The former could help Europe address the current high (and increasing) unemployment rates while also effectively addressing the need for more and better care. The latter could help create a new generation of elderly adults who can delay and diminish their individual care needs.

Training for professional and family caregivers should recognise that family caregiving provides the foundations of care for older people in all countries. It should also recognise that for the majority of family caregivers, the benefits of caregiving within a loving relationship exceed the burdens associated with caregiving.

However, family caregivers have needs in their own right. These need to be addressed in order for them to be effective in their caregiving roles and able to make wider contributions to family, community and the work force.

This new paradigm must also reframe caregiving as larger than a healthcare issue. Elder care in Europe has huge economic costs as public institutions and families take on the overwhelming burden of caregiving.

Building a new generation of caregivers through legitimizing and re-imagining the profession and creating standardized education and training could lend huge economic dividends. Developing consensus on the path ahead is one of Europe's greatest challenges and opportunities.

The following landscape analysis is provided to encourage debate and inform solutions to Europe's caregiving opportunity. It is divided into five sections:

- It defines key terminology used amongst academic experts in the field to align this analysis with existing studies and data;
- 2. It analyses the current state of elder care in Europe in terms of the amount of investment allocated to care and the quality of care provided;
- 3. It discusses the key drivers of rapid ageing on the continent and its implications for the caregiving environment;
- It provides a snapshot of seven countries' long-term care environments in order to show both similarities in the elder caregiving challenge and the diversity of policy responses; and
- 5. It investigates new technologies, policies and approaches being developed in the caregiving field in response to current needs.

## Based on this analysis, we will be able to achieve several goals of CARE:

- Assess current and future elder caregiving education, training and skill development needs;
- Create the core curriculum for elder caregiving in Europe that will be the basis for high-quality care;
- Understand the role of monitoring and valuation of elder caregiving to meet the growing needs of seniors, their family and community caregivers; and
- Identify the needs of older people and family caregivers and address them in order to support care in place.



# 1. Defining the European Elder Caregiver

Elder care in Europe is provided by two groups of elder caregivers – formal and informal. Some countries within Europe rely more heavily on formal elder caregivers, who can be employees of public or private institutions. This differs from European states that dedicate fewer public resources to formal elder care, driving up reliance on informal elder caregivers.



Informal elder caregivers provide help outside of a professional institution or formal framework. They are commonly family members, friends or undeclared migrant workers. Informal caregivers provide approximately 80% of care for the elderly in Europe.

Formal or professional elder caregivers are hired under a legal contract and provide care in the home or in an institution. The majority of formal caregivers are women, and a significant proportion are migrant workers.

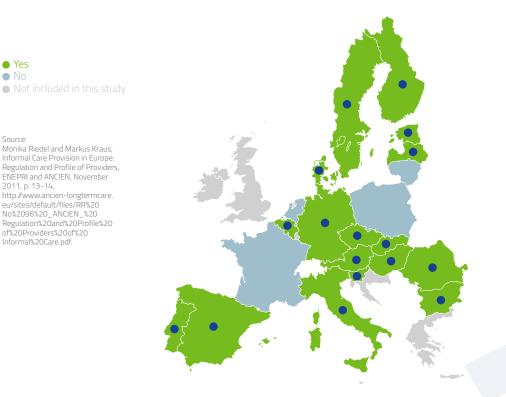


# **1.1 Informal Elder Caregivers**

An informal caregiver is described as an individual "who provides help to someone with a chronic illness, disability or other long-term health or support need, outside a professional institution or formal framework<sup>8</sup>". They are commonly family members, friends or undeclared migrant workers, and have varied levels of training and experience<sup>9</sup>.

Informal elder caregivers can receive national benefits depending on the health status and/or age of the individual for whom they are caring. According to one study of 21 EU countries, 17 countries grant some kind of monetary compensation or benefit to providers of informal care.

Countries That Provide Monetary Benefits for Informal Caregivers



For example, in England and Romania, informal caregivers are granted stipends based on whether the care recipient has a recognized disability. In Spain, financial assistance is granted to pay for personal assistants<sup>10</sup>.

Informal care is sometimes provided by undeclared migrant workers, who are often employed, directly by private households<sup>11</sup>. Though the number of undeclared migrant long-term care workers vary widely, they are particularly common in countries with less robust formal long-term care systems, a tradition of family-based care and large migrant populations<sup>12</sup>.

Informal elder caregiving is the most common form of care across the European Union and it is expected to grow over time unless a profound shift is undertaken to bring caregiving into the formal economy through professional education and training.

# It has been estimated that informal caregivers provide approximately 80 percent of care for the elderly in Europe.

If the current trajectory continues, the number of informal care users in Germany, the Netherlands and Spain will rise 51 percent (to 4.1 million), 66 percent (to 154,000) and 140 percent (to 2.8 million), respectively, between 2010 and 2060<sup>13</sup>. A similar trend exists in other countries as is showcased in the case study section of this report.

# **1.2 Formal Elder Caregivers**

Formal or professional caregivers are hired under a legal contract either by public or private sector employers. Depending on their employer's business model and related contractual arrangement, they provide services either in a family home or institution<sup>14</sup>. On average, across OECD-countries, nearly 30 percent of formal care workers are nurses and 70 percent are personal care workers<sup>15</sup>. Nurses generally have at least three years of training, while personal caregivers do not have any training requirements. As a result, they often lack proper long-term care qualifications<sup>16</sup>.

Migrant workers constitute a significant proportion of the formal long-term care workforce in many countries, in both home and residential settings. For example, in the United Kingdom, Switzerland, France and Germany, foreign-born workers account for roughly 10 percent or more of those employed by community services<sup>17</sup>. Programmes to recruit and train migrant long-term care workers for the formal sector have been particularly successful when they include language courses, access to long-term care training, and cultural education programmes<sup>18</sup>. Formal long-term care jobs in Europe are dominated by women – they make up over 85 percent of the caregiving workforce in Italy, the Netherlands, Spain, Switzerland, and England<sup>19</sup>.



# 2. The Current State of Elder Care Across Europe:

## Uneven Resources Create Variation in Quantity and Quality of Care

Today, there is wide variation in the quantity and quality of caregiving available to elderly populations across Europe. According to Article 168 of the Treaty on the Functioning of the European Union, responsibility for health services, medical care and policies resides with Member States<sup>20</sup>. While the Third Health Programme 2014-2020 of the European Union promotes greater access to healthcare in all EU countries, its  $\in$ 449.4 million budget is dedicated to EU-level cooperation projects, liaising with international organisations, overseeing the functioning of non-governmental bodies and supporting actions jointly undertaken by Member State health authorities<sup>21</sup>. Consequently, resources allocated to health programmes are dependent on national health budgets. These resources are then often managed and distributed at the regional level.

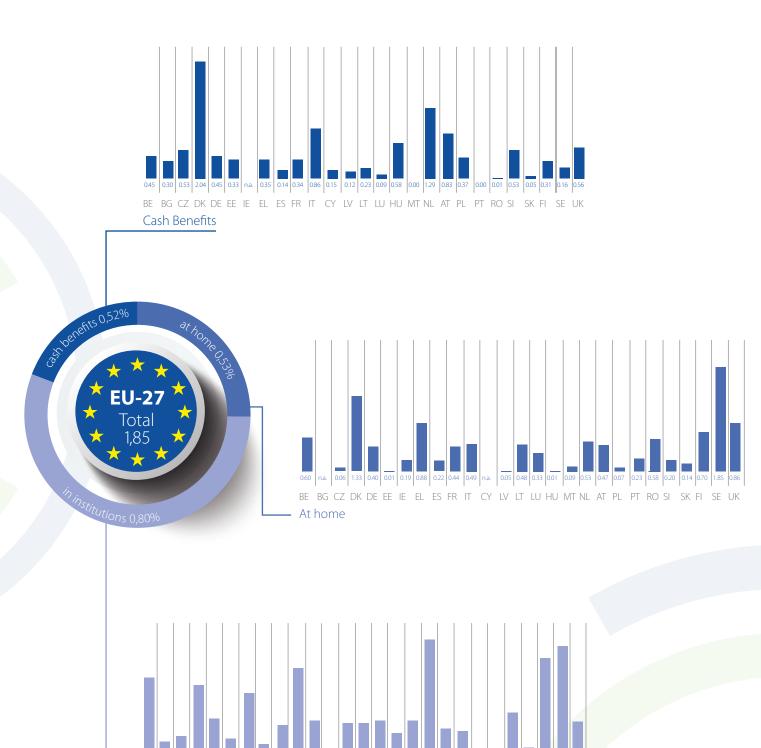
Coverage rates for institutional care – care that is being provided in nursing homes or old-age homes – for Europe's senior population, specifically, vary greatly across EU countries. Iceland provides the greatest coverage at eight percent, while France, Belgium and the Netherlands all have coverage rates just above six percent. Sweden, Norway, Slovenia and Luxembourg have coverage rates between five percent and six percent. And at the lower end of the coverage spectrum, Greece, Lithuania and Poland have coverage rates for institutional care below two percent<sup>22</sup>.

Despite single-digit coverage rates, institutional care is the largest element of public long-term care expenditure in most European countries<sup>23</sup>. The relative expense of institutional care, per recipient, drives this spending: on average in the EU, the unit cost of institutional care is 106 percent of GDP per capita, compared to 36 percent for formal home care<sup>24</sup>. Therefore, home care that meets recipients' needs can deliver a return on investment to national long-term care plans, especially in place of costly institutional care. For example, in some countries, non-disabled adults account for over 30 percent of institutional care recipients, which could signal an opportunity for home care savings<sup>25</sup>.

When looking at public spending on long-term care in general – formal or informal – as a percentage of GDP, the EU-28 spends on average 1.8 percent of its total GDP. Denmark spends as high as 4.5 percent, while Cyprus spends roughly 0.2 percent of GDP<sup>26</sup>.

In general, European countries that dedicate lower levels of public funds to elder care rely more heavily on the informal sector, where the lack of elder care training, education, monitoring and standards is highest. This can be because informal care is necessary when public funds fall short, such as is the case in Spain, Poland and Italy, or it can be chosen public policy as is the case in Austria and Germany<sup>27</sup>. In Germany, 71.3 per cent of those who receive care daily rely exclusively on family and friends, while in Austria, the corresponding figure is 55.1 per cent<sup>28</sup>.

# Public expediture of LTC as % of GDP, by type of care, 2010



 1.30
 0.17
 0.23
 1.14
 0.58
 0.19
 0.92
 0.13
 0.46
 1.38
 0.55
 0.01
 0.51
 0.51
 0.56
 0.20
 0.34
 0.30
 0.08
 0.04
 0.70
 0.09
 1.50
 1.87
 0.56

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 SE
 UK

Source:

Lipszyc, Sail and Xavier, Long-term care: need, use and expenditure in the EU-27 http://ec.europa.eu/economy\_finance/publications/ economic\_paper/2012/pdf/ecp469\_en.pdf More surprisingly, even countries with high levels of public funding for elder care, often still have large informal care dependence. Examples include Belgium, the Netherlands and Denmark, which in spite of relatively high levels of public funding for elder care, rely exclusively on care from family and friends up to 30 percent of cases where care is given daily. In Sweden more than 54.9 percent still rely on family care when care is given daily<sup>29</sup>.

Interestingly, in some cases there is a negative correlation between need for care and funding of care. In part, this may result from spending on preventive healthcare, which aims to promote healthy ageing, thus reducing long-term costs. The prevalence of disabilities among older adults varies greatly across the EU<sup>30</sup>. For example, in the Netherlands, 45 percent of their over-50 population are living without health impairments, yet 5 percent of GDP is dedicated to the elder care sector and 3.7 percent to elder long-term care. Sweden has the lowest percentage of over-75 year olds whose daily activities are limited (32.6 percent), but is one of the biggest spenders on long-term care in the EU (3.6 percent of GDP)<sup>31</sup>. In contrast, Portugal, Estonia and Hungary have very high percentages of adults with limited activities of daily living (ADLs), but spend only 0.2 percent of their GDP on elder long-term care<sup>32</sup>.

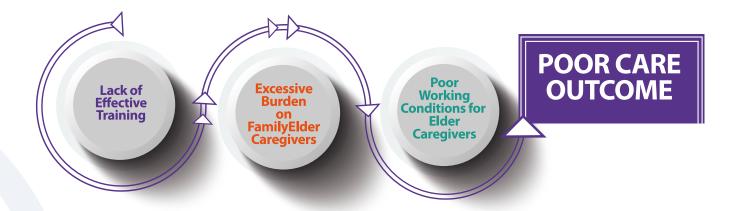
Even with formal and informal care provisions, too many seniors in need still remain without help. In Spain, Greece and Poland, elderly dependents are 30 percent less likely to receive help than those in other European countries<sup>33</sup>. In France, almost one-quarter of older people have unmet health care needs<sup>34</sup>.

# 2.1 Quality of Care Diminished by Lack of Standards

The quality of care available to Europe's elderly population is as important as the amount of care provided, when measuring the strength and sustainability of the European Union's caregiving system. Today, the European Union and its Member States do not have a standard definition or measurement of care quality, let alone a monitoring mechanism to ensure care standards are being met, an overall caregiving strategy, or EU-led caregiving education, training or curriculum. The Social Protection Committee of the European Union sets out objectives for social protection of recipients of long-term care, but the design and financing of elder care remains in the hands of Member States, so by default collaboration and standardization across national borders is lacking<sup>35</sup>. In most EU states, many of the risks to health, independence and well-being of older people are not reported. Training of formal and informal caregivers should include the development of competencies to identify and respond to these risks.

Lack of pan-EU oversight and standards means that the quality of care provided across the continent are subject to national resource constraints and dependent on the presence and effectiveness of national regulatory authorities and/or framework. However, quality standards are not only critical to protect the dignity of those receiving and giving care, but also to prevent inefficiencies that could lead to costlier health outcomes, including hospitalization and re-hospitalization, severe long-term disabilities and premature loss-of-life.

Broadly speaking, three factors drive poor care outcomes:



Sometimes these emerge when there is inadequate funding. Other times, these can emerge when funding is misallocated or poorly managed.

**Lack of Effective Training:** With informal care making up the overwhelming majority of caregivers in Europe, many care recipients are cared for by family members or undeclared migrant workers who do not receive standardized training. More and more, individual families are hiring undeclared migrant workers as live-in caregivers for elderly relatives to cope with the care burden. This practice usually takes place in less-regulated welfare states such as those in Southern Europe, even though undeclared migrant workers often have fewer caregiving qualifications than normally required in professional settings<sup>36</sup>.

**Excessive Burden on Family Elder Caregivers:** More than half of the EU27 population believes that older people rely too heavily on their relatives for care and support, ranging from 42 percent in Denmark to almost 100 percent in Bulgaria<sup>37</sup>. Juggling care and other responsibilities can lead to time management problems and isolation for caregivers while also affecting the quality of care an individual can provide. This strain can also affect the care relationship as well as the health status of the caregiver and care recipient<sup>38</sup>.

**Poor Working Conditions for Elder Caregivers:** There is a positive correlation between poor working conditions and poor quality of care. It has been reported that institutions in the United Kingdom provide the lowest quality of care, Dutch institutions ranked fourth and German institutions were fifth. The Czech Republic received the highest marks in terms of quality of care<sup>39</sup>.





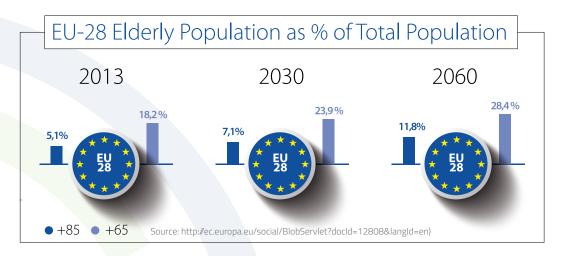
# 3. Drivers and Implications of an Ageing Europe: Why the Elder Caregiving Need Will Continue to Explode

There is still a significant gap between current need for elder care and elder caregiving capacity in most European countries. This gap will widen significantly in the absence of an effective strategic intervention. The main driver of this trend is rapid population ageing that is reshaping the continent's care environment and weakening the effectiveness of EU Member States' traditional strategies for providing care.

# 3.1 When the Miracle of Longevity Meets Declining Birth Rates

Europe is ageing at an unprecedented rate as a result of the convergence of two demographic trends: longer life spans and declining birth rates. Technological advances, and greater access to health care and education means that Europeans are living longer and having fewer children than ever before. A few telling statistics underline the new balance of old-to-young this convergence creates. The over 65 population will increase by at least 50 percent in most European countries by 2060<sup>40</sup>, **with the population of 79+ expected to triple**<sup>41</sup>. At the same time, the young-to-old ratio has sharply declined. In 1985, for every one person aged 80 and older, there were 8.7 people aged 45-64. By 2012, there were only 5.5 people aged 45-64 for every 80-year-old. It is estimated that by 2040, there will only be 2.9 people aged 45-64 for every one 80-year-old<sup>42</sup>. Not surprisingly, the average fertility rate in Europe dropped to just 1.46 births per woman in

Not surprisingly, the average fertility rate in Europe dropped to just 1.46 births per woman in 2002 and the replacement level is 2.1 live births per woman<sup>43</sup>.



Taken together, longevity and declining birth rates in Europe are creating a growing gap between demand for elder care and supply of elder caregivers.

# **3.2 Ageing Increases Demand for Care**

On the demand side, population ageing is and will continue to increase the number of adults needing elder care across Europe. For example, between 2007 and 2060, it is estimated that nearly 44.4 million persons over 65 – double the number today – will suffer from at least one disability that inhibits ADLs<sup>44</sup>. Likewise, the number of Europeans aged 80+ requiring long-term care is expected to triple over the next five decades<sup>45</sup>.

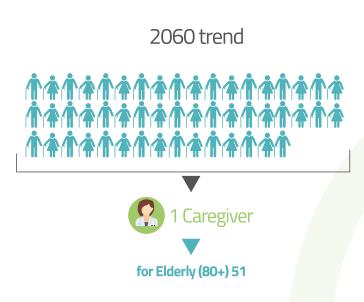
Driving these increases are a number of health challenges that often accompany ageing, including disease onset that cause mental and physical deterioration. Chronic diseases such as Alzheimer's and other dementias, cancers and heart disease all necessitate high levels of long-term care. In the EU, chronic diseases are responsible for 87 percent of all deaths and total roughly 70-80 percent of healthcare costs.

The likelihood of developing dementia in people aged 65+ roughly doubles every five years in Europe and 43 million Europeans will be living with diabetes in 2030<sup>46</sup>. Additionally, social isolation is prevalent across Europe, and lack of social contact and monitoring speeds up physical and mental decline. Almost one in three adults age 55 and older lives alone in Europe<sup>47</sup>. In some countries such as Greece and Hungary, social isolation impacts over 40 percent of adults over 65<sup>48</sup>.

# **3.3 Ageing Decreases Supply of Caregivers**

On the supply side, population ageing places serious stress on elder caregiving resources. Lower birth rates mean fewer people of working age can support public services, both as public employees and as tax payers, or provide elder care to those in need. By 2060, there will be one caregiver for 51 persons aged 80 years or older<sup>49</sup>.

And public expenditure on long-term care is projected to increase an average of more than 90 percent across the EU<sup>50</sup>.



Since families have traditionally shouldered a large percentage of caregiving responsibilities in Europe, changes in family structures brought on by ageing will also change caregiving norms. Declining birth rates means that even fewer children will be available to care for their parents and grandparents although, in some OECD countries, the total number of family caregivers would need to increase by approximately 20 to 30 percent in order to maintain the current ratio of family elder caregivers to elder care recipients<sup>51</sup>.

Even if European families were having more children who could eventually provide care, longevity necessitates a longer work-life and raises the cost of leaving the workforce. Some older adults are not able to retire on time – let alone early to take-on caregiving responsibilities – due to lack of financial planning or economic instability. In a 2010 study, 55 percent of Europeans surveyed expected their working lives to extend beyond the current national retirement age as a result of recent economic issues. Just over one-third were optimistic about policymakers potentially increasing the national retirement age<sup>52</sup>.

Additionally, a study of retirement trends in Europe shows that some countries are already seeing an increase in the percentage of people working past retirement: From 2005 to 2013, the percentage of people age 65 to 69 still working increased from 9 percent to 11 percent in the EU28<sup>53</sup>. And a study completed by Aegon in 2014 shows that people across Europe expect to be working past their traditional retirement<sup>54</sup>.

The global trend towards working later in life has several advantages for individuals and for employers, but a side effect of keeping potential informal caregivers in the workforce is a decreased contribution to family caregiving responsibilities, which exacerbates the growing caregiver shortage.

> **Mike Mansfield** Aegon's Manager of Retirement Research

In the formal care environment, we see additional indications that the supply of caregivers will fall short. For example, in Sweden, data trends project that the supply of care workers must continue to grow in order to meet the expanding need. Sweden projects that the need for care workers will increase by 50 percent by 2050, but the high average age in the largest occupational group (nurses' aides/nursing assistants) will drive the supply of caregiving labour below demand by more than 100,000 persons in 2030<sup>55</sup>.

The following section examines the current state of elder care in more depth in seven countries as well as the trajectory being shaped by changes in elder care demand and supply reviewed above.



# 4. Comparative Case Studies Show Varied Policy Responses to a Similar Challenge

This report has shown that all European countries are ageing at a fast pace, presenting them with similar challenges: strained public finances, labour shortages, a growing burden on families and escalating medical costs. But while European countries share this dilemma, national responses vary with differing models of public support, private involvement and care organisation. To provide insights on these approaches, the five case studies below profile the current long-term care (LTC) systems, future opportunities and possible challenges for seven countries: Denmark & Sweden, Italy & Spain, Poland, Germany and England.

**Denmark & Sweden** – LTC is primarily financed, organised and provided by municipal authorities, who manage a local LTC case management and care provision system. While these systems currently provide extensive coverage, home-based approaches, preventive care and improved care worker recruitment could help to address likely future strains on public finances and the supply of care workers.

**Italy & Spain** – National systems of cash benefits provide a minimum level of LTC, which is supplemented by regional benefits, private spending and family caregiving. However, overcoming regional disparities, shortages in institutional care and a reliance on family caregivers and inexpensive migrant care workers will require measures that support poorer areas, aid dependents' families, "regularize" migrant care and boost care options.

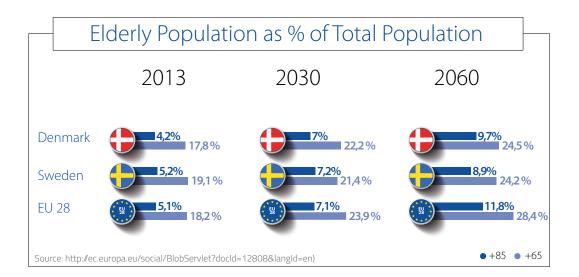
**Poland** – The vast majority of LTC is provided by family members, with limited policy support or private care selection. Given a lack of formal care coverage, low levels of LTC spending and shifting family structures, maintaining the LTC system's viability could require measures that empower working caregivers, improve public responses and promote the growth of the care sector.

**Germany** – The mandatory national LTC insurance funds care based on levels of need is supplemented by private spending and family caregiving. Shifts in LTC training, quality assessment and care integration could address projected difficulties with the supply of care workers, a growing population of ineligible dependents and significant family spending and caregiving burdens.

**England** – Older adults and families provide or purchase much of LTC privately, while local authorities provide public support for those with disabilities, particularly the most severe physical and financial limitations. Transparency, quality and financing reforms could remedy a lack of care coordination, inconsistent local policies and options and strained public finances.

# 4.1 Denmark and Sweden:

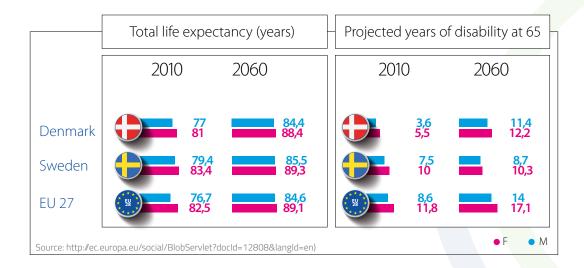
High Public Funding for Care Ensures High Coverage, But Sustainability of the Model in Question



The long-term care (LTC) systems of Denmark and Sweden are among the best organised and well-funded in Europe. However, the accelerating costs and labour demands of an ageing population could strain these extensive LTC systems in the near future. As a result, Denmark and Sweden are launching programmes that prioritize home care, prevention, worker recruitment and quality of care.

#### Long-Term Care: Comprehensive, Local and Publically Funded

In both Denmark and Sweden, the delivery of long-term care is primarily organised and funded through local municipalities, within a framework of national policies. This results in a high degree of public financing for LTC, and a closely monitored level of care that matches a dependent's needs. Substantial local tax rates – upwards of 30 percent in Sweden<sup>56</sup>– enable public expenditures on LTC that are among the highest in Europe<sup>57</sup>. These resources are channelled through extensive local care systems that are well-attuned to the needs and providers in the community, the majority of which are public<sup>58</sup>. In Denmark, a local case managing system manages a variety of care providers, escalating services and specialty care when needed. Further, every Danish citizen over the age of 75 receives two preventive visits per year from a local case manager, who evaluates their needs, and plans for independent living<sup>59</sup>. In Sweden, 290 municipalities coordinate elderly care services, including institutional care, social care, and home nursing, in accordance with designated, individual care plans, while the county councils collaborate in the provision of additional healthcare services<sup>60</sup>. These measures ensure that elderly dependents are receiving an adequate level of care, while also reducing excessive services and spending. Through these local systems, a higher percentage of those over 65 receive care in Denmark and Sweden than in almost any other European country<sup>61</sup>.



#### Sustainability of the Comprehensive, Public Model?

While these LTC systems have performed well so far, Denmark and Sweden may struggle to sustain their commitment to comprehensive public care, as the rapidly growing elderly population threatens to strain financing and create labour shortages. In both countries, the old age dependency ratio is projected to rise from approximately 30 percent in 2013 to around 45 percent in 2060<sup>62</sup>. Sweden already has the highest proportion of the elderly aged 80+ in Europe<sup>63</sup>, and in both countries this population is projected to roughly double to around 9 percent by 2060<sup>64</sup>.

Given these alarming increases, eventual strains on public resources seem likely. According to the OECD, Swedish spending on LTC services will double by 2050<sup>65</sup>, and Denmark is projected to experience a similar increase by 2060<sup>66</sup> And even with sustained public funding, the demand for LTC care workers may outstrip the available supply. In Sweden, the staff needs of the LTC sector are projected to increase by 50 percent until 2050, creating a shortfall of 100,000 workers in 2030<sup>67</sup>, while in Denmark, a significant demand for LTC workers is likely to develop by 2035<sup>68</sup>. This could shift some of the burden of care to family members, who currently play a small role; already Swedish policy-makers are discussing informal caregivers as a critical supplement to formal care<sup>69</sup>. Additionally, private providers could account for a growing portion of LTC services, in both countries. This combination of escalating public expenditures and demand for labour could test the central tenet of these LTC systems: publically funded care for all who need it. However, national and local governments anticipate the rising burden of care, and are actively considering a range of responses.

#### Lowering Costs with Home-Based, Preventive Approaches

Both Denmark and Sweden have embraced publically funded home care and prevention as strategies to alleviate cost pressures and respect seniors' autonomy. Home care and independent living have been primary objectives of Danish LTC policies since the 1980s<sup>70</sup>. Denmark is planning to further develop this strategy by implementing the recommendations of The Home Care Commission<sup>71</sup>. These are chiefly concerned with providing the education and support to allow those with only moderate limitations to care for themselves at home, thereby lowering costs and preserving independence. As the result of ongoing national and local discussions<sup>72</sup>, Sweden has undertaken a similar home care pivot, but more recently and to a lesser extent

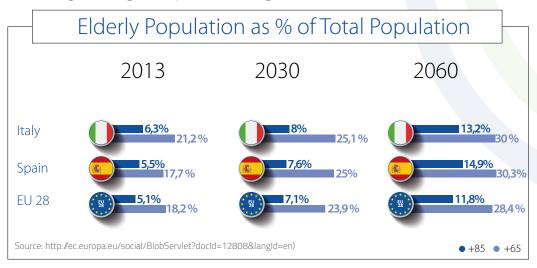
than Denmark. The number of those receiving home care in Sweden increased-12 percent from 2001 to 2006<sup>73</sup>, and currently the number of those 65+ receiving care at home is more than double those receiving care in institutions<sup>74</sup>. In conjunction with home care, the countries are experimenting with prevention and health promotion programmes as a way to lower costs. Denmark, in particular, has pioneered innovative programmes to enable continued independence, including a series of pilots that provide health promotion, preventive health training, and posthospital discharge rehabilitation. These pilots have been successful, with some realizing savings of 13 percent annually by reducing care needs<sup>75</sup>. Similarly, Sweden publishes national guidelines on health promotion and preventive care<sup>76</sup>, and has pursued technology-enabled prevention in particular. The Swedish Institute of Assistive Technology launched a series of pilots for assistive technology, such as tele-health devices and health monitoring applications, some of which generated five Swedish kronor for every krona invested, after five years<sup>77</sup>. While these are only pilot studies, they could be expanded to more local governments and municipalities as the result of cost pressures, an emphasis on home care and respect for seniors' autonomy.

#### **Supporting Workers and Quality of Care**

As competition for care workers grows more intense across Europe, policies to attract and support workers could offer some countries an important advantage, and boost the overall quality of care. Denmark is a leader in this regard. Of all European countries, Denmark is one of only two in which institutional care workers earn at least as much as the average national worker<sup>78</sup>. Additionally, Danish care training programmes last several years and focus on practical experience, which minimizes turnover and enables career mobility, while supporting a higher quality of care<sup>79</sup>. Sweden is striving to improve the attractiveness of LTC work, but still faces low levels of training for many care workers<sup>80</sup>. Recruitment will be an increasingly important challenge as the demographic shift begins to place greater stress on both individual care workers, and the overall labour supply. Supporting the LTC workforce is an important driver of care quality, which is a growing concern throughout Europe, even in Sweden. In 2010, it was found that 25 percent of Swedish home care workers lacked professional credentials, and roughly 25 percent of municipalities were not properly handling benefits applications<sup>81</sup>. This created the impetus for reform, and in 2013, a new governmental agency, the Health and Social Care Inspectorate, was tasked with improving the quality of Swedish LTC care<sup>82</sup>. The national government now awards grants to those municipalities that reach certain benchmarks with regard to quality of care, such as reduced hospitalizations<sup>83</sup>. There is also growing concern about the long-term sufficiency of the home-based model for those with severe needs<sup>84</sup>. In Denmark, the local authorities define and oversee quality standards<sup>85</sup>. In both cases, further developing quality control mechanisms, and implementing the training and incentives for an effective LTC work force, will be critical components of an effective, long-term care strategy.

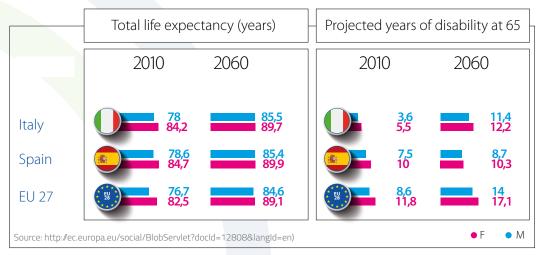
# 4.2 Italy and Spain: Financial Constraints Create Major Gap Between Elder Care Coverage and Need

Italy and Spain, two EU countries that are confronted with significant financial challenges, are also projected to experience some of the most significant elder care burdens in Europe over the next fifty years. Both have implemented national programmes to address these needs, but an overall lack of public funding and organisation have fostered a reliance on cash benefits, family care and migrant care, with significant regional disparities in coverage.



## **National LTC Benefits, Regional Disparities**

Both Italy and Spain have instituted LTC programmes intended to establish a nationwide, minimum level of support for elderly dependents. However, the resulting dependence on minimum levels of cash benefits, supplemented by varying regional services and subsidies, leads to significant disparities, and a reliance on family or migrant care, often provided by undeclared migrant workers. In Italy, the National Institute of Social Security provides a cash benefit to all disabled persons<sup>86</sup>, with over 75 percent of this spending going to elderly dependents<sup>87</sup>. This cash benefit is the largest element of LTC expenditure – roughly 45 percent<sup>88</sup>. However, there is no formal oversight of how the cash benefit is spent, and no variation in the amount based on financial or physical needs<sup>89</sup>. Additional cash benefits or care services are left to the regional authorities, which leads private households in poorer regions to bear the financial and care burden when needs exceed benefits.



Universal LTC coverage is a more pronounced policy objective in Spain, but low levels of public expenditure have created similar limitations. In 2006, a new Dependency Act established universal entitlement to social services for Spanish dependents, delivered (1) through regional networks of public and private providers or, (2) in the form of a cash benefit<sup>90</sup>. However, the implementation of this legal requirement has been uneven and variable. Although the Act was intended to create a network of publically funded service providers, the cash benefit has become the primary provision. 55 percent of beneficiaries receive cash for home care, as opposed to in-kind benefits<sup>91</sup>. As of 2013, 21 percent of those who had qualified for benefits were still waiting to receive them<sup>92</sup>, and those with "moderate dependencies" were not incorporated until nine years after the Act's passage<sup>93</sup>.

Outside of cash benefits, the provision of direct health services is largely the responsibility of regional authorities, which has resulted in significant disparities in care coverage<sup>94</sup>. In those regions where public, formal LTC falls short, dependents often rely on family care or inexpensive migrant workers, or receive no care at all. In Spain, the majority of residential care centres are located in just four regions<sup>95</sup>, and regional home care coverage ratios vary from as low as 1.7 percent to as high as 9.9 percent<sup>96</sup>. Similarly, in Italy, municipal per capita LTC spending varies from €34 to €253 across regions, and rates of those 65+ receiving institutional care vary from 48 per 10,000 to 500 per 10,000<sup>97</sup>.

The low coverage rates of poorer regions are reflected, nationally, in high rates of informal care, provided by family members and migrant workers. In 2006, just 126,000 LTC workers in Italy were in the formal sector, versus 4 million in the informal sector, and in Spain, the ratio was 11,000 to 2.7 million<sup>98</sup>. Over 70 percent of LTC recipients in both countries receive daily care from family<sup>99</sup>, with a disproportionate burden on female caregivers<sup>100</sup>. As a result, many turn to migrant workers: the share of foreign-born workers in the home care labour workforce is over 60 percent in Spain, and over 70 percent in Italy<sup>101</sup>. Overall, the share of those 65+ receiving care is below the EU average, at 7.2 percent in Spain and 4.1 percent in Italy<sup>102</sup>.

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#### Extensive 2060 Elder Care Gaps

Of all European countries, Italy and Spain are facing some of the largest projected increases in their elderly populations. By 2060, the share of those 80+ is projected to more than double in both countries, to 13 percent in Italy<sup>103</sup> and 15 percent in Spain<sup>104</sup>. In both, the share of those 85+ will expand by 2.5-3 times, and the old age dependency ratios will rise to nearly 60 percent<sup>105</sup>. The resulting gaps in coverage could increase just as dramatically. By 2060, the number of elderly Italians receiving informal or no care is projected to approximately double to 4 million<sup>106</sup>. In Spain, the coverage gap may be slightly smaller, but the required resources for LTC will be immense: those receiving institutional care is projected to increase fivefold, and those receiving home care by 300 percent<sup>107</sup>. Further, given high rates of informal care<sup>108</sup>, many elderly dependents may receive low quality care.

#### **Innovations in Regional, Family and Migrant Care**

Given these growing care gaps, especially in certain regions, supporting poorer areas and families requires national programmes that supplement current, minimum levels of public funding. The Italian government passed such a measure in 2007, creating a National Fund for Dependency of €800 million to be distributed to regions on the basis of their elderly population and socio-demographic factors<sup>109</sup>. The Fund's benefits were intended to tie directly to the needs-based provision of care services, and the regional amounts to be calculated on the basis of the region's elderly population and relative wealth<sup>110</sup>. Ideally, these measures would have facilitated more efficient LTC spending, and reduced regional disparities. However, the amount of resources set aside for the Fund were insufficient, and it was ultimately suspended as part of a national austerity measure<sup>111</sup>, highlighting the difficulty of even sustaining current LTC funding in struggling national economies. To that end, Spain's Dependency Act includes some measures that boost cost efficiency, such as adult day care centres - a third of the price of institutional care<sup>112</sup> - and tele-assistance, which allows for the elderly to call for help when needed<sup>113</sup>. However, these services will likely be of limited value once a dependent's needs progress beyond a certain threshold.

As national, regional and municipal governments struggle to fund LTC, a range of policy innovations will be needed to support those who, by default, assume the burden of care. Both countries enable elder care leave for family members: Spain offers the longest period of paid or unpaid care leave in Europe, at 36 months<sup>114</sup>, while a recent Italian judicial ruling allows for up to two years of elder care leave, with some entitled to full pay<sup>115</sup>. Further, both countries have among the most generous short-term leave policies in Europe<sup>116</sup>. Similarly, reliance on migrant care workers is currently central to affordable LTC, and will likely increase with an exponentially growing need. Programmes to legalize, train, and regulate migrant care workers, such as a measure in Italy to "regularize" migrant personal care assistants<sup>117</sup>, could boost the quality of care and improve care coordination<sup>118</sup>.

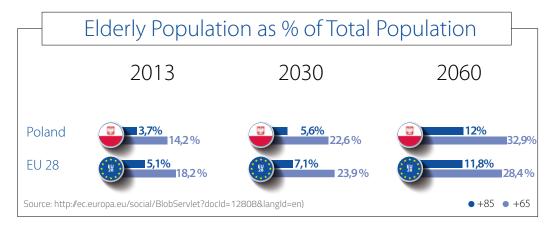
#### Substantial Deficits in Funding and Institutional Care

However, these initiatives still face fundamental gaps in funding, and high levels of need for those with severe limitations. Although Italy and Spain face some of the fastest growing elder care burdens in Europe, their levels of public expenditure on LTC are at, or below, the EU average<sup>119</sup>. Further, tough economic conditions and close scrutiny of spending make it difficult to sustain even current levels of care, as shown by the aforementioned cuts to Spain's Dependency Act and the suspension of Italy's National Fund for Dependency.

While stop-gap measures like day care centres, tele-assistance and informal care are critical for those with moderate limitations, they will likely prove insufficient as the need for more extensive institutional care increases. Family caregivers and migrant care workers will be needed more than ever, but increasing dependency ratios and shifting family patterns may well shrink this source of care<sup>120</sup>. Without a national strategies that significantly address regional disparities and rising needs, this environment could result in extensive care gaps, particularly for intensive care.

# **4.3 Poland:** Over-reliance on Family Caregiving of the Elderly

The Polish long-term care system relies on care by family members, with little outside support. While few policy or care innovations have developed in Poland, measures that enhance or replace the family-based LTC model will be critical, given future demographic and social shifts.

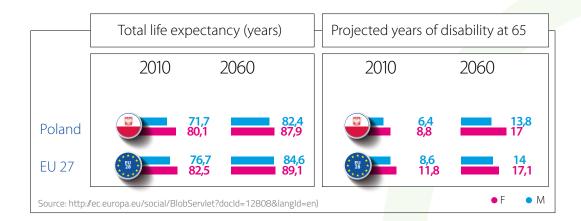


#### The Family's Central Role

The vast majority of long-term care in Poland is provided informally by family members, particularly women, with little public support or private LTC options. Approximately 94 percent of elderly dependents receive care from their family<sup>121</sup>, and only around 2 percent of people aged 80+ use formal long-term care services<sup>122</sup>. A combination of social conventions, traditional practices and living arrangements underpin this family-based model.

Fewer older adults live by themselves in Poland compared to the EU average, and the share living in intergenerational households is among the highest in Europe<sup>123</sup>. Further, approximately 60 percent of Poles said that caring for elderly parents is a moral obligation, compared to an EU average of just 30 percent<sup>124</sup>. This model places a disproportionate burden of care on female family members, who account for 60 percent of informal caregivers<sup>125</sup>.

Further, female working caregivers are more likely to report that providing care interferes with their work<sup>126</sup>. This model of family, especially female, provided care is likely unsustainable given ongoing demographic, social and economic changes, but few other forms of LTC have emerged.



36

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There are limited public programmes and private options to help families and elderly dependents manage long-term care in Poland. Cash benefits are the most common form of public LTC expenditure: in 2007, 96 percent of beneficiaries received cash benefits, compared to 4 percent receiving in-kind benefits<sup>127</sup>. However, the most common public cash benefit, the care allowance, is ten to twenty times less than the cost of commercial LTC<sup>128</sup>. Further, the availability and quality of public and private LTC providers are limited. Public institutional care is only provided to those with dramatic limitations and little income or no relatives<sup>129</sup>. Given the lack of formal care services, nearly half of public spending on LTC funds hospitals, which are cost-inefficient LTC providers<sup>130</sup>.

In the private sector, unregulated care services are common, as the requirements for private providers are often unclear; only half of for-profit care institutions had a legalized status in 2008, and much of private home care is provided by migrant care workers<sup>131</sup>. Additionally, many Polish LTC workers migrate to Western Europe, creating a "care drain" that further depletes the availability of providers<sup>132</sup>.

#### **Demographic and Social Shifts**

Poland has a relatively young population, with an old-age dependency ratio that is the second lowest in Europe<sup>133</sup>. However, the country is expected to undergo a dramatic demographic transformation, and concurrent social shift, which together could result in high levels of need and growing care gaps. From 2013 to 2060, the share of people aged 85+ is expected to grow by more than a factor of four, while the old age dependency ratio will rise from 22 percent to 67 percent<sup>134</sup>. During this same period, the population of those with severe limitations is projected to increase by 60 percent, while the population without limitations will decrease by nearly 30 percent<sup>135</sup>.

Accompanying this demographic transition, there will likely be a transformation of the social structures and conventions that currently lead family members, particularly women, to serve as the de facto, primary caregivers for the elderly. The ratio of women aged 45-65 versus the population aged 75+ will be cut in half over the next 20 years<sup>136</sup>. Simultaneously, more women will be employed<sup>138</sup>, well-educated and retiring later in life. The generation of Polish women who will reach middle age in the near future are better educated and more frequently employed than previous cohorts, increasing the likelihood of sustained employment<sup>137</sup>. Poland's limited labour supply and the recent introduction of a defined benefits pension system will further incentivize later retirement<sup>138</sup>. These changes - critical to gender equity and economic growth - may potentially reduce the supply of full-time family caregivers, which has been the traditional cornerstone of Poland's LTC system.

#### **Supporting Elder Caregivers and Increasing Options**

Despite these demographic and social shifts, family caregivers will likely still shoulder much of the future burden of care; hence, the need to develop policy innovations and care offerings that help families to support elderly dependents<sup>139</sup>, while not sacrificing employment. Currently, most public benefits are not intended for caregivers who provide care to elderly dependents. However, an effective policy framework will need to support caregivers who both work and care for elderly parents. Such measures could include cash benefits, as well as provisions like guaranteed short and long-term family care leave. Employers could also play a crucial role, by introducing scheduling, benefits and leave policies that support caregivers. Finally, increasing the number of adult day care centres – currently there are around 250<sup>140</sup> – could provide a supplementary care option for a growing population of working caregivers. No single tool can bridge the gap between Poland's elderly population and supply of family caregivers, but a mixture of policies and approaches could help reduce care gaps and support working caregivers.

Increasing the availability, affordability and quality of a range of care providers – both public and private – will be critical to transitioning away from Poland's dependence on family caregiving. The Polish Senate has considered two measures that would increase elderly dependents' ability to pay for formal care: the first, proposed in 2009, would have created a system of mandatory insurance for LTC, while the second, proposed in 2011, would have established nursing vouchers to help cover the cost of public or private care. However, both were ultimately abandoned due to financial concerns<sup>141</sup>. Prioritizing similar legislation could both increase the coverage rates for elderly dependents and also encourage the growth of private care providers, who currently struggle to receive reimbursement<sup>142</sup>. Indeed, such measures could realize cost savings by reducing the share of LTC provided through costly hospital stays. In the private providers, and thereby boost the availability and quality of institutional and home care. Further growth and competition in the private sector would increase quality and affordability in an area that is currently underdeveloped or non-existent.

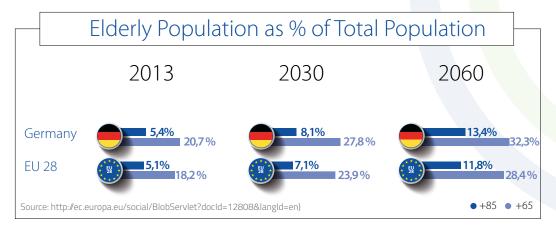
#### Fundamental, Systemic Changes

However, Poland still faces a monumental transition away from the largely informal, familybased model that has defined its LTC system so far. From a policy perspective, greater urgency is needed for LTC reforms and legislation, which have failed in recent years due to concerns about public expenditures<sup>143</sup>. If the political imperative to enact such legislation does not form until a crisis is apparent, it may be difficult to change course in a timely manner and the costs of the current system could increase exponentially<sup>144</sup>.

Indeed, Poland must rapidly develop a sector of its health care system that has been an exclusively family matter so far. Low coverage rates, the loss of care workers to Western Europe and a lack of LTC institutions will likely continue to prevail unless Poland can increase the number of providers of all types. In the meantime, family caregiving will likely remain the default pillar of the LTC system, even as the supply of caregivers declines rapidly.

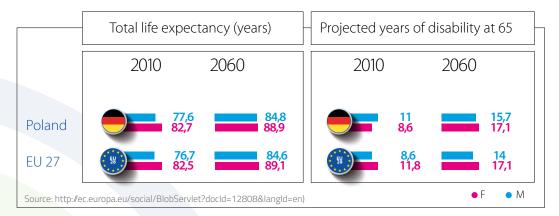
## **4.4 Germany:** One of the Oldest Countries in Europe Still Trying to Strike a Balance

The German LTC system is primarily funded through mandatory LTC insurance, with significant supplementary private spending and caregiving. However, financing, labour and quality challenges will likely be inevitable as the elderly population grows, creating a new and growing need for a range of policy innovations.



#### A Mixed, Balanced System

Germany's long-term care system strikes a balance between a variety of providers and funding mechanisms. It features universal public coverage supplemented by a significant degree of private spending, and a wide range of private providers, but a still significant burden on family caregivers. Elder care has traditionally been provided by family members, until the introduction of the long-term care insurance (LTCI) system in 1995<sup>145</sup>.



Individuals are required to provide roughly 2 percent of their income for LTCI funds<sup>146</sup>, which provide benefits to dependents based on their level of need. Independent review boards perform evaluations with teams of geriatric nurses and physicians, who classify beneficiaries into three levels of need<sup>147</sup>. The system prioritizes home care: of beneficiaries in 2011, 47 percent received a care allowance, 23 percent received benefits for home care and 30 percent received benefits for institutional care<sup>148</sup>. Extra costs beyond LTCI benefits are out-of-pocket, accounting for about 30 percent of LTC expenditure in Germany<sup>149</sup>, with particularly high private costs for institutional care<sup>150</sup>. Family caregivers also play a significant role, as 15 percent of the German population provides informal care<sup>151</sup>; over 70 percent of whom are women<sup>152</sup>. Although there are national

paid and unpaid leave policies<sup>153</sup>, the resulting burden of care is still significant. Roughly 60 percent of informal caregivers are unemployed, and 10 percent of informal caregivers report that they gave up their job to provide care<sup>154</sup>. Therefore, the private arrangements and resources of elderly dependents and families have an important impact on levels of care.

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#### **Strains on Financing and Labour Supply**

Germany is already one of the world's oldest countries, with 20 percent of its population over 65, the greatest share in Europe<sup>155</sup>. Dramatic increases in the elderly population are projected, which will further strain both the financing and workforce of the current LTC system. From 2013 to 2060, the share of those 80+ will more than double, and the old age dependency ratio will grow to~65 percent<sup>156</sup>. This will trigger an increase in LTCI beneficiaries: while just 3 percent of those aged 65-70 receive benefits, the share increases to 20 percent of those 80-85 and 37 percent of those 85-90<sup>157</sup>. Simultaneously, those who need care, but not at the level necessary for LTCI benefits, will also grow. In 2006, this population totalled around 3 million<sup>158</sup>. Without policy changes, resulting public LTC expenditures are projected to double by 2060, and care gaps could emerge, both within the formal LTC system and among those who do not qualify for benefits<sup>159</sup>. Beyond the financing issues, there is growing concern regarding the recruitment of qualified care workers. In 2007, less than 30 percent of the LTC workforce were trained nurses<sup>160</sup>, and in 2014, every region in Germany reported a shortage of elderly care nurses<sup>161</sup>.

It is projected that the demand for LTC workers will increase
 by 70 - 130 percent from 2000 to 2040, but the number of full-time
 LTC workers will decrease by 28 percent during that period<sup>162</sup>.

#### **Recruiting Workers, Integrating Elder Care and Reducing Costs**

Germany is pursuing a variety of measures to increase the supply of qualified LTC workers. In recent years, additional financial incentives have been introduced<sup>163</sup> to correct the imbalance of relatively low wages in LTC<sup>164</sup>, and formal nursing training has been modified to facilitate easier transitions to elder care<sup>165</sup>. Recruiting and training foreign care workers, particularly from within the EU, is a secondary element of Germany's overall LTC workforce strategy. Germany has signed bilateral agreements with Eastern European countries to recruit nursing aides<sup>166</sup>, passed legislation that allows undocumented care workers to attain work permits<sup>167</sup>, and offers language courses to some foreign care workers<sup>168</sup>. However, barriers still remain, as 83 percent of LTC institutions report struggling with complicated regulations for foreigners, and few actively recruit migrant workers<sup>169</sup>. Measures that addressed these barriers could lift the labour supply, while increasing quality of care.

Coordinating LTC and healthcare services, developing preventive policies and implementing innovative home-based approaches could help Germany to lower LTC costs. Preventive and rehabilitative care, particularly hospital rehabilitation<sup>170</sup>, could reduce costs, but a lack of coordination between the LTC and healthcare systems have limited these savings<sup>171</sup>. Currently, such care is the responsibility of the healthcare system, but many of the potential savings would be realized by the LTCI funds<sup>172</sup>. Coordinating care and incentives between the two systems, and introducing more flexible benefits for preventive care, could reduce costs while increasing elderly dependents' quality of life. Similarly, a 2009 reform created a case management system to coordinate care through a network of local case managers and resource centres<sup>173</sup>. Ideally, this system will reduce costs by ensuring that services match a dependent's level of need, while facilitating efficient care provision. Germany is also experimenting with residential groups in which multiple elderly dependents live together and pool their LTCI benefits, generating savings for both beneficiaries and care providers<sup>174</sup>. Further efforts to develop and implement care efficiencies will be critical as costs and needs escalate.

#### **Eligibility Criteria, Care Quality and Family Caregivers**

While there are multiple avenues to improve the LTC system, long-term challenges in funding, the increasing informal caregiving and resulting variability of quality threaten to diminish the effectiveness of German elder care. There is a large, and growing, population of individuals who do not meet the eligibility requirements for LTCI benefits, but still require assistance with everyday activities. It's estimated that this group totalled 3 million in 2006, outnumbering the population of LTCI beneficiaries<sup>175</sup>. Although this population's care requirements are thought to be lower, they will still be the source of a growing care burden, particularly for female family members, both financially and as caregivers. On the opposite end of the care spectrum, the growing population of elderly adults who require institutional care will create mounting costs. Because LTCI benefits only cover about half the cost of institutional care, the amount of private LTC spending will likely increase substantially, as will supplementary public funding for those who cannot afford care<sup>176</sup>. This could test the LTCI pay-as-you-go model<sup>177</sup>, leading to difficult political and public decisions about continuing to raise contribution rates<sup>178</sup>.

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Given these strains on LTC workers, family caregivers and personal finances, it seems likely that the quality of care could erode as needs grow. Almost two-thirds of LTC facilities are already understaffed<sup>179</sup>, and the number of those receiving informal or no care is projected to increase by roughly 750,000 by 2060<sup>180</sup>. In this context, Germany's LTC evaluation system may not be robust enough to ensure a high quality of care. National quality policies are ranked in the midrange of the EU in terms of efficacy<sup>181</sup> and a 2006 study found that approximately 30 percent of home care services did not have adequate quality assurance mechanisms, and roughly 50

percent of nursing homes did not perform audits of care<sup>182</sup>. Although subsequent legislation has since improved quality evaluation and reporting<sup>183</sup>, it may be difficult to adequately determine care quality for those receiving a care allowance, or who do not yet qualify for LTCI benefits. These are by far the largest groups of the German 65+ population, and their growing reliance on informal care from family caregivers and under-trained workers could create care quality issues.

## **4.5 England:** Burden of Elder Care Rests Primarily on Elderly and Their Families

The LTC system in England mostly relies on a high level of private contributions and care, and public funding is limited to those with severe needs and financial limitations. While a series of reforms have improved consistency and efficiency, quality and funding concerns are emerging.

#### Public "Safety Net," Private Elder Caregiving and Financing

The LTC system in England<sup>194</sup> is characterized by public benefits and services for those with the most severe financial and physical needs, and a high private burden for the majority of elderly adults, both financially and through family caregiving. Aside from direct medical services provided by the National Health Service, LTC is the responsibility of local authorities, who assess the needs of elderly dependents and provide benefits, funded by national and local taxes<sup>185</sup>. Most of these benefits pay for care from private providers, who account for 78 percent of institutional care<sup>186</sup> and nearly 90 percent of home care, at 170 million hours in 2012<sup>187</sup>. However, the exact eligibility criteria for LTC benefits are highly complex and opaque, making it difficult for providers or beneficiaries to grasp whether, or how, benefits will be provided<sup>188</sup>. Importantly, local LTC benefits are only awarded to those with high levels of dependency and limited financial resources<sup>189</sup>. Of those individuals aged 80+ with one limitation who received some informal care, just 3 percent received publically funded home help, compared to 70 percent of those with two or more limitations and no informal care<sup>190</sup>. Overall, public funding for LTC in England is primarily focused on the neediest individuals, while the majority of the elderly population receives little public support for LTC services.

Therefore, much of the burden of care and financing rests on elderly adults, their families and informal caregivers. In 2006, private expenditures constituted roughly 40 percent of LTC spending<sup>191</sup>, and 43 percent of elderly dependents in independent institutional facilities funded the entire cost of their care<sup>192</sup>. Family caregiving is also a substantial private burden. Approximately 85 percent of elderly dependents living in a private household received informal care, whether from private providers or family members<sup>193</sup>. There were an estimated 5.4 million family caregivers in England in 2011, a 13 percent increase over 2001<sup>194</sup>, with a particularly significant burden on older adults, as roughly 40 percent of informal care is provided by spouses<sup>195</sup>. This reliance on family caregiving creates a care gap for those living alone, who constitute 66 percent of the 300,000 elderly dependents who do not receive informal care<sup>196</sup>.

Much of the burden of care and financing rests on elderly adults, their families and informal caregivers.
 In 2006, private expenditures constituted roughly
 40 percent of LTC spending<sup>197</sup>, and 43 percent of elderly dependents in independent institutional facilities funded the entire cost of their care.

Nominal public support for caregivers is provided through care allowances for poorer, full-time caregivers, and an "Attendance Allowance" for older adults with disabilities<sup>198</sup>. However, these cash benefits are often insufficient, or do not fund care. Less than one-tenth of family caregivers received a care allowance in 2008<sup>199</sup>, and 29 percent of Attendance Allowance beneficiaries were not receiving care in 2006<sup>200</sup>.

#### **Projected Family and Formal Elder Care Shortages**

Compared to the rest of Europe, England has relatively higher birth rates and immigration, which will help to mitigate the effects of demographic ageing. However, a considerably increased burden of elder care is still expected, as the share of those aged 80+ is projected to double from 2013 to 2060, and the old age dependency ratio is projected to rise from 29 percent to 48 percent<sup>201</sup>. This is likely to create shortages of both formal LTC workers and family caregivers. It is estimated that two million additional LTC workers will be required by 2033<sup>202</sup>. Meeting this demand will be difficult because England is one of the world's largest importers of health care professionals, relying heavily on foreign providers<sup>203</sup>. The burden on family caregivers is even more pressing. The number of those receiving care from children could increase 90 percent by 2041<sup>204</sup>, and a four-fold increase is projected in spousal care for the oldest old<sup>205</sup>. Overall, the demand for informal elder care may have already exceeded supply by as early as 2017, and there could be a gap of nearly 250,000 caregivers by 2041<sup>206</sup>.

#### **A Variety of Reforms**

A vigorous public debate about the current and future state of LTC in England has driven reform efforts in key areas of LTC provision and organisation, such as consistent local care, national eligibility criteria and coordinated healthcare and LTC. While LTC eligibility requirements have been complex and inconsistent, several recent laws have created a national framework for eligibility and needs assessments aimed at decreasing disparities and differences across localities<sup>207</sup>. There is also the opportunity to reduce costs by coordinating or even integrating some elements of locally-run LTC and the healthcare services of the NHS. Initiatives in this area include charges for local authorities when LTC is unnecessarily provided in hospitals<sup>208</sup>, and the merger of health and LTC regulators into a single quality control body, the Quality Care Commission<sup>209</sup>. Currently, most public LTC spending funds those with severe needs, but more consistent and coordinated assessment, care, and regulatory mechanisms could reduce the development of such intense care needs and related costs.

Important opportunities for bolstering national care capacity also exist through support for family caregivers and elderly dependents managing their own care. The U.K. government has extended family LTC caregivers the right to request flexible or reduced working hours<sup>210</sup> and is developing a caregiver assessment tool to identify their needs and guide the design and development of adequate solutions<sup>211</sup>. Further, the government recently passed legislation which would cap private LTC spending at a set limit<sup>212</sup>, thereby lowering the financial burden of care and encouraging a market for private LTC insurance<sup>213</sup>. These measures could help to reduce the burden on private individuals and finances, while enabling older adults and families to manage their later life care with a high degree of autonomy.

#### **Quality Scandals and Funding Cuts**

Unfortunately, a series of high-profile elder abuse scandals have driven much of the public attention surrounding LTC in recent years, and quality control issues continue to be a central concern for England<sup>214</sup>. 41 percent of LTC institutions were rated inadequate in 2015, according to a report by the Care Quality Commission<sup>215</sup>, which may be receiving more than 150 allegations of elder abuse every day<sup>216</sup>. Further, the number of those 90+ arriving at hospitals via ambulance has spiked by 61 percent over the last five years, highlighting the need for greater preventive care to reduce both safety risks and costs<sup>217</sup>. High staff turnover of around 20 percent in the UK's LTC sector also indicates potential quality concerns<sup>218</sup>, as do the low wages of care workers, who earn just 67 percent of the average national worker<sup>219</sup>. These difficulties have occurred despite the oversight of the newly formed Care Quality Commission, and any future quality measures may struggle with the fundamental demographic reality of an ageing population and decreasing base of potential care workers and caregivers.

Finally, recent cuts indicate waning political and public support for increasing, or even maintaining, current LTC funding levels. In general, long-term trends indicate a shift towards increased private funding<sup>220</sup> and recent budget cuts could exacerbate this burden. Since 2010, cuts in local funding for LTC have totalled £4.6 billion, or 31 percent in real terms of net budgets, even though funding for health services has increased 20 percent over the same period<sup>221</sup>. Developing more efficient ways to provide and fund healthcare and LTC-related services, and implementing these policies on a national scale, could be the deciding factor for the long-term viability of both private and public LTC funding and care.





# 5. Innovations in Elder Caregiving:

### Promising Models for Future Responses to Growing Caregiving Needs

The challenges posed by population ageing in Europe provide the impetus and a real opportunity for innovative approaches to elder caregiving models, technologies and education programmes. Governments, policy advocates, entrepreneurs and companies willing to take up this challenge will help drive elder caregiving and Europe's healthcare system into the 21st century. Though we are only at the beginning of this wave of innovation, several efforts are underway in Europe that could provide promising models for wide-scale change.

# INNOVATIONS IN ELDER CAREGIVING

#### Professional Homecare

Professional caregivers are able to identify and respond to health problems before they escalate into more serious conditions that necessitate doctor visits or hospital admission. This ultimately cuts unnecessary costs to public health systems and the national economy.

## Training

Standardized training is critical to boosting the quality of care, making careers in LTC more attractive and bolstering the efficacy and efficiency of the LTC workforce

Tele-medicine and other related emerging technologies may effectively enhance care provision, realize savings and support care workers and families

Tele Homecar

# 5.1 Professional Home Care Improves Care and Enables Ageing in Place

A new approach to elder care has emerged in a number of countries around the world that emphasizes the value of professional elder home care. This is a shift away from the long-term care models that promote institutional care or reliance on informal caregivers in the home. The professional home care model has proven to reduce caregiver stress, improve health outcomes for both the caregiver and care recipient and create efficiencies in the health care system.

In addition to affording older adults the ability to age in place and remain independent longer, professional home care reduces the care burden on family caregivers. In a study completed in the U.S., caregivers who used paid in-home non-medical care reported having higher quality of life than those who did not: 78 percent of those receiving help from professional caregivers reported having "good" or "very good" health compared to 72 percent of family caregivers who did not receive professional caregiving help<sup>222</sup>.

Standardized training provided to professional in-home caregivers leads to improved quality of care and health outcomes. Professional caregivers are able to identify and respond to health problems before they escalate into more serious conditions that necessitate doctor visits or hospital admission. This ultimately cuts unnecessary costs to public health systems and the national economy. For example, in the U.S., seniors receiving professional home care saw several benefits, for example the length of hospital stays decreased by four percent between 1998 and 2008, which is attributed to the number of individuals discharged from the hospital to professional home health workers rising from 6 percent to 10 percent over this same period<sup>223</sup>.

Both the public and private sectors have acknowledged the benefits of professional home care and are bringing new opportunities to the caregiving market.

- Several regional government agencies have begun to provide partially subsidized funding for professional care in the home. For example, the Exceptional Medical Expenses Act (AWBZ) in the Netherlands has created the "personal budget" option, providing public funding for professional home care<sup>224</sup>.
- In response to policy shifts and growing customer demand, professional home care companies have expanded in Europe. For example, one professional home care company,
   Home Instead Senior Care, offers services in the U.K., Ireland, Germany, the Netherlands, Switzerland, Austria and Finland. These companies are managed as franchises and adapt to local policy regulations and market needs<sup>225</sup>. They are based on a unique form of "relationship-building" to support high quality consistent elder care as contrasted with the more traditional "task oriented" version of elder care. Moreover, there is significant experience in training, education, skill development and monitoring in this private sector innovation model which will inform the core curriculum CARE will be able to develop<sup>226</sup>.

# **5.2 Technological Innovations in Care**

Mounting investment and a range of innovative pilot projects indicate growing public and private interest in tele-medicine and other related emerging technologies as tools that may effectively enhance care provision, realize savings and support care workers and families, for example:

- The European Commission has invested over €10 million in innovative projects for robotics and healthy ageing, including devices to help with everyday tasks, improve the elderly's mobility and aid those with dementia<sup>227</sup>.
- The United Kingdom has undertaken major initiatives to drive innovation in telehealth, including the Preventative Technologies Grant and the Whole System Demonstrators Programme<sup>228</sup>, helping between 300,000 and 350,000 people to use some form of remote care<sup>229</sup>.
- Studies conducted by the Swedish Institute of Assistive Technology indicated the
  potential for some types of care technology to return as much as 400 percent on
  investment<sup>230</sup>, and the Danish Digitization Authority has invested over €3 million in
  technology to help with home health monitoring for those with chronic conditions<sup>231</sup>.

Further, the vast majority of older adults and care workers support the introduction of telehealth and other technologies<sup>232</sup>, viewing them as innovative solutions to better coordinate care management and supplement existing services. Such technologies can connect patients with healthcare providers and home health workers, while reducing costly interventions like hospitalization<sup>233</sup>.

Given these findings, further developing and expanding efficient models of elder care technologies represents an important opportunity for LTC systems throughout Europe. Ranging widely in applications and intended users, such technologies can be tailored to the populations, situations and systems where it will provide the greatest benefits to safety and efficiency. New technologies could be particularly useful for the growing population of older adults who continue to live alone and manage their own care, as they can facilitate increased access to healthcare when needed and provide assistance in case of emergencies.

Pilot programmes indicate that technology is most effective when staff are specifically trained for its use, and it is integrated throughout medical and LTC organisations<sup>234</sup>. Intergovernmental organisations, national governments and LTC systems that embrace these imperatives and prioritize technology for care could reduce costs and increase the efficacy of services, thereby helping to address potential care gaps.

# 5.3 Growing Emphasis on Formal Training and Oversight

Training for all individuals who care for older adults, from those with professional qualifications to family caregivers, will become increasingly important as the growing elderly population results in increased demand for Long Term Case workers, and possible labour shortages. Standardized training is critical to boosting the quality of care, making careers in LTC more attractive and bolstering the efficacy and efficiency of the LTC workforce. Realizing this potential, countries and employers across Europe have launched new and enhanced training mechanisms, including measures that encourage attendance in training courses, institute national training requirements and incorporate leading-edge LTC practices<sup>235</sup>.

Training programmes that put emphasis on practical experience can help to reduce turnover and career mobility, while increasing the attractiveness of LTC positions<sup>236</sup>. Programmes specifically targeted at migrant care workers include those, such as in Sweden and Germany, which provide language courses to foreign LTC workers<sup>237</sup>, or create partnerships to recruit and train workers from specific foreign countries<sup>238</sup>. Training for family caregivers, such as those provided to people receiving a home care allowance in Spain<sup>239</sup>, can help to boost the quality of informal care and relieve caregivers' stress. This wide range of measures reflects the diversity of those who provide care, highlighting the need for a broad-based approach to the growing demand for care.

Further additions and improvements to training programmes and requirements, by both public and private entities, will be needed to prevent or minimize care gaps. As the supply of potential care providers comes under increasing pressure, training will be critical to bolstering the number of effective, potential care workers and caregivers. Training programmes can also help develop the recognition of LTC as a respected and worthwhile career choice, and improve the ability of care workers to receive adequate pay. As Europe's ageing workforce creates the need for more foreign-born care workers, training will be necessary to standardize qualifications and provide language proficiency. Finally, family caregivers can also benefit from training programmes that develop proficiency with common care tasks, and provide education about available resources.

A 21st century European elder care strategy will need to incorporate these kinds of new approaches, with emphasis placed on how they interact to create better and more care. Adopting the necessary educational support systems, oversight mechanisms and technological platforms will be critical to scale these solutions, while customizing them to local customs, challenges and policy environments.





# Conclusion

Across Europe, countries face an unprecedented demographic shift that will result in rapidly growing elderly populations. In most European countries, the old-age dependency ratio will rise to 50 percent or more, while the population of those 80+ will double or even triple<sup>240</sup>. Better and more efficient elder caregiving emerges as one of the truly strategic needs for 21st century Europe if it is to:

- Manage fiscal sustainability of its health care systems;
- Create jobs and achieve reasonable economic growth goals;
- Maintain and strengthen core societal values of solidarity and human dignity for all Europeans; and
- Prepare future generations to realize a healthier and more active ageing.

This landscape analysis underscores that the gap between the demand for elder caregiving needs and the supply of elder caregivers is substantial and growing. It also shows us where 20th century models have provided substantial and valuable service and where they are falling short given 21st century demographic realities. Finally, it sheds light on potential pathways to align 21st century longevity and elder caregiving solutions.

CARE is a first step on the path to a Europe-wide long-term solution as it envisions education and training that will supplement current elder caregiving skills and capabilities and create opportunities for the development of thousands of new elder caregivers. It will also provide the guidance and tools for current and emerging institutions in education, healthcare and caregiving itself. Based on this analysis, there are seven takeaways to inform how we implement CARE:

**1. Build on Traditional Approaches to Create New, Better Quality Elder Care.** CARE should aim at enhancing and supplementing caregiving skills for the elderly to address new home care needs arising from longevity and other health trends.

For example, caring for conditions that erode quality of life will become more important with increasing longevity. These include critical areas such as skin health, vision loss or related emotional and mental health deterioration. Skin health is a particularly important area that to date is largely overlooked but can have huge impact on quality of life, health costs and health conditions of seniors as reflected in the new WHO Health and Ageing Strategy<sup>241</sup>. Moreover, the growth in non-communicable diseases, including cancers, Alzheimer's and other dementias suggests that a new and different set of knowledge is required for better and more effective elder caregiving.

**2. Identify and Respond to the Needs of Older People and Caregivers**. CARE should improve knowledge amongst informal and formal caregivers to identify and respond to the needs that are important to the older person. It should improve knowledge amongst formal caregivers to identify and respond to the needs of informal caregivers in their caregiving roles.

**3. Support Ageing in Place with Professional Home Care.** While European 20th century elder care has primarily focused on supporting long-term care in institutional settings, 21st century longevity demands elder care that supports ageing in place. CARE must define how the needs for care recipients and caregivers differ in the home vs. an institution and map training strategies to ensure a positive, efficient caregiving environment.

**4. Integrate Elder Care Technologies.** Opportunities abound for integrating technologies into elder care education. They should be seen as an enabler of elder care – not a replacement for caregivers. The goal should be to create technologies to enable caregivers to access information about locally available resources to respond to the needs of the older people and their informal caregivers for support. New technologies can also serve to disseminate standardized training at an accelerated pace and on a more expansive scale, improving care quality and increasing access.

**5. Provide Education and Skill Development Through CARE CAMPUS.** Education can be the critical and normalizing pathway through which to elevate the standard of elder care across all of Europe. CARE will enable the creation of a body of knowledge to inform and itself provide the strategic support for higher quality, more effective elder care across all Europe. CARE standards will be the basis for professionalizing and standardizing high quality, cost effective and better managed elder caregiving.

**6. Drive Toward Sustainability.** Elder care in the 20th century was manageable and affordable because (a) the need was much smaller as the proportion of seniors was smaller; and (b) the proportion of working-to-retired persons provided a tax base to fund elder care. Our analysis is clear that the burden is already challenging and will become unsustainable without strategic and systemic reforms. Public systems will be unable to continue taking care of elders with any degree of quality, which will mean new roles will need to be carved out for public-private partnerships in implementation of training programmes, support and oversight.

**7. Pursue Innovative Approaches to Education.** Harnessing cutting-edge educational tools and applying them as never before to elder care is critical to a rapid uptick in training across Europe. On-line education will be an important enabler as will be integrating businesses and other stakeholders who have an interest in solving 21st century elder care challenges into the educational process. Use should be made of technologies that provide assured open access massive on-line learning. Caregiving education platforms should not only focus on teaching, but also on measuring progress in ways that reflect better and more efficient caregiving systems. References

# EU CARE: How We Must Implement CARE





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EIT Health partners in this project





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Global Coalition on Aging









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