

BAY OF BISCAY BAY OF CARE REPORT

DEVELOPING THE LONG-TERM CARE EMPOWERMENT MODEL



JUNE 2022

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FOREWORD BY **UNAI REMENTERIA MAIZ** DEPUTY GENERAL. GOVERNMENT OF BISCAY

Life expectancy at birth in Europe rose rapidly during the second half of the last century, reaching eighty years on average. This can be considered the outcome of an array of common welfare policies applied in Europe during this period, resulting in a rise of living standards, improved lifestyles and better education, as well as advances in social services and *healthcare*.

Longevity is not an exception for us in Biscay, a small region washed by the Bay of Biscay, in the Basque Country. Our life expectancy is 86.3 years for women and 80.7 years for men. As a matter of fact, our society is ageing, and 23% of us are over 65 years old. All those figures stand slightly above the European average, which makes us feel specially proud insofar as they reflect the achievements of a society that came out of a dictatorship and underwent a great industrial crisis in the early 1980s.

These extra years of life have great implications for each of us; there is little doubt about it. Furthermore, such a demographic change means a whole change in the policy framework of the society we live in. A focus on the quality of life spent in a healthy state, rather than the quantity of life, warns of a need of action in Long Term Care to support fulfilling lives for all. This need for new efforts is not just a hunch but is borne out by facts and data.

Some lessons can be learnt from the leadership and the policy responses that have led us to the present situation; determination and cooperation played a key role. They will be necessary, but not enough. Systemic change is needed. Biscay and Europe, we need precise intervention and comprehensive overview; local individual commitment and common European involvement.

In the Government of Biscay, we believe that local governments have a significant leadership role to play in this issue and by mobilizing the public and private sector, employers, workforce, academia and the voluntary and community sector we can become longevity just one contextual element of new inclusive prosperity.

Some of our efforts at local level are driven by a Transition Plan in Long Term Care. The EU Care Strategy will drive common efforts. Far from believing that the answer will be built at once or according to a single plan, we are involved in developing tools for common action of mutual interest. This report *Bay of Biscay, Bay of Care* is a genuine piece of work devoted to ensure that the opportunities of an ageing population are seized and the challenges faced.



FOREWORD BY PROFESSOR **SARAH HARPER CBE**
CLORE PROFESSOR OF GERONTOLOGY, UNIVERSITY OF OXFORD,
AND CHAIR OF EXPERT GROUP

European countries have aged continuously over recent decades, seeing an increase in the percentage of those aged over 60 years, and a decrease in those under 15. By 2030 Europe will have 43% of its population aged over 50, around one quarter over 65, and over 10% per cent over 75. This has arisen though both falling mortality and childbearing rates. Life expectancy at birth is now over age 80, with women at 83.2 years, and men at 77.5 years. However, healthy life expectancy remains well below, with women experiencing 64.5 years of healthy life, and men 63.5. Falling mortality, and in particular falling late life-mortality, results in the growth in the number and proportion of oldest-old, increasing demands for health and social care. By the middle of the century, there will be over 30 million people aged over 85 within the region.

This increase in longevity is occurring alongside below replacement child bearing, which is reducing the numbers of workers, and professional and family carers needed to provide financial and practical support and care to the increasing number and percentage of older dependents. At the same time, migration patterns, female employment rates, and the increase in individuals living alone, are also challenging the availability of European societies to provide care.

These demographic and social changes have thus led to three major challenges for European health and social care systems. There is an increase in the proportion of illness in the population and a change in the predominant type of illness towards non-communicable chronic diseases and co-morbidities, both of which are coinciding with a reduction in the availability of carers, both family and non-kin, so that many countries are increasing reliant on migrant carers and workers.

As Europe emerges from the Covid pandemic, and addresses the new health and care needs of our societies, we have a real opportunity to create new frameworks for inclusive, empowering long term care for our older population.



FOREWORD BY MACIEJ KUCHARCZYK SECRETARY GENERAL, AGE PLATFORM EUROPE

Long-term care systems in the EU have strengths, but also weaknesses, particularly about the realisation of the rights of persons in need for care: ageism, linked to poor quality of care; lack of or insufficient access to care; as well as problems in the organisation of care; lack of coordination between health and social care, staff shortages, insufficient funding, administrative barriers.

Back in 2021, we conducted a series of discussions with our members to renew our vision of long-term care. This resulted in a broader and more positive vision where the purpose of long-term care is to ensure autonomy and independence of people of all ages. Long-term care systems must enable everyone to continue to be part of society as equal citizens. We must combat the idea that the persons in need of care are burdens on society. Finally, in our vision, care services are not the goal in themselves, but the means to preserve or achieve a good quality of life.

“We want care that supports individuals to remain included and participate in society at all stages of life. Services should not be the end goal, but the means to achieve integration and inclusion”.

The Provincial Council of Bizkaia has courageously initiated a process of reflection together with us and various European experts, agreeing to question their existing long-term care system. This reflection has led to the design of reforms, refocusing the purpose of care, which is necessary to remedy the shortcomings of the current systems and make sure that the dramatic experience of the COVID-19 pandemic cannot be repeated in the future.

While reforms and initiatives on long-term care are being developed at local, regional, and national level, the release of an EU Care Strategy can be a turning point to materialise a shift from care as a problem to care as a solution, enabling people of all ages to participate, contribute and remain integrated in society. With the support of the EU, all our governments must bring this renewed and positive vision of care to life, and to trigger more ambitious action across the continent.

On the eve of the publication of the EU Care Strategy, this a unique moment to influence policy makers, services providers and us, the societies and local communities to implement a new, empowering, accessible and quality care that respects our human rights – the kind of care we all would like to receive at any moment of our lives when we may need it. Let’s make it happen, together!



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FOREWORD

In March 2020, before the COVID-19 pandemic, the Government of Biscay approved a collaboration agreement with Age Platform Europe to set up a group of European experts to prepare a report on long-term care. As a result of this agreement, a group of six experts was formed, made up of the following people:

- **Sarah Harper, Chair.** Professor of Gerontology, University of Oxford and Director of the Oxford Institute of Population Ageing. Advisor on demography and ageing to the UK Government, as a member of the Prime Minister's Council for Science and Technology, and the Chair of the UK Government Review on Ageing.
- **Liesbeth De Donder.** Professor at the VUB (Vrije Universiteit Brussel), with expertise in community participation and development, elder abuse and quality of care.
- **Anne Hendry.** Geriatrician and Senior Associate at the International Foundation for Integrated Care, Professor at the University of the West of Scotland (UK), with more than 30 years of experience in the transformation of the social and health care model of care in Scotland.
- **Stefania Ilinca.** Phd. Technical advisor for long-term care, WHO European Office. Researcher, European Centre for Social Welfare Policy and Research. Senior Atlantic Fellow for Equity in Brain Health, Global Brain Health Institute, Trinity College Dublin
- **Giovanni Lamura.** Director of the Centre for Socio-Economic Research on Ageing at INRCA IRCCS (the National Institute of Health and Science of Aging) in Ancona, Italy. Vice-President for Research between 2009-2014 of Eurocarers, a European association working on behalf of unpaid caregivers.
- **Tine Rostgaard.** Professor at Roskilde University, Denmark and Professor, Stockholm University, Sweden. Expert in long-term care and child care policies and practices. Chair of the Transforming Care Network.

Mission of the group: define the broad guidelines for a quality model, including the current needs of older adults who require long-term care and assistance and, therefore, taking into account current social and demographic changes.



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EXECUTIVE SUMMARY

21st century long-term care is a human right and refers to support that is needed by persons with limited ability to care for themselves due to disability, physical or mental, associated with frailty or multi-morbidity. The needed support can be provided at home, in the community or in residential care facilities and includes for example assistance with daily living activities such as dressing, preparing meals, medication management but also basic healthcare services. Such services are usually provided by formal or informal caregivers, paid or unpaid. Formal care workers might be skilled health or social care workers that are employed, for example by home care providers or in residential care facilities. Informal care workers include unpaid family, friends or community members and paid caregivers who often work outside formal employment regulations or on the basis of unregulated agreements with families.

Definition of long-term care

Our report is aligned with the definition included into the WHO Europe policy brief “Rebuilding for sustainability and resilience: strengthening the integrated delivery of long-term care in the European Region”, 2022:

Long-term care refers to a broad range of personal, social and medical services and support that ensure people, with or at risk of a significant loss of intrinsic capacity (due to mental or physical illness and disability), can maintain a level of functional ability consistent with their basic rights and human dignity

The World Health Organisation (WHO) defines this as a means to ensure that older adults with a significant loss of capacity can still experience *healthy ageing*¹. In particular, they argue that it is essential to realign health systems to the needs of older adults, requiring a shift from systems designed around curing acute disease, to systems that can provide ongoing care for the chronic conditions that are more prevalent in older age. Governments, it argues, also need to develop long-term care systems to ensure people live their last years with good quality of life and *dignity*. Other framings call for *person-centred orientation*, *rights-based approaches*, and most recently *empowerment* of through long-term care.

We also note that the question of appropriate long-term care for ageing populations has become more pressing in the light of the overwhelming morbidity and mortality rates among older adults caused by the SARS-CoV-2 virus. The deaths in 2020 in residential

1 WHO 2015, World Report on Ageing and Health, <https://www.who.int/publications/i/item/9789241565042>



long-term care settings was particularly devastating. The WHO estimates that around half of all European COVID-19 deaths by mid-2020 occurred among care home residents, hundreds of care workers died and tens of thousands of older adults and their carers were affected by coronavirus and by related restrictions. A review of care home mortality in 20 countries reported that while the average share of the population in care homes is 0.73%, the average share of all COVID-19 related deaths that were care home residents was 46%. In addition, disruptions of primary health care and community-based care services have disproportionately affected older adults and other vulnerable groups, limiting access to essential care services and significantly increasing the pressure on informal caregivers.

At the same time, the pandemic and subsequent containment measures brought into sharper focus persistent gaps and the vulnerabilities embedded in long-term care systems. There is now widespread public and political interest across Europe to reshape and reform long-term care systems with a view to promoting sustainability, resilience and equity.

Chapter 1. Developing a vision for long-term care: This chapter introduces the report, highlighting the main themes and structures. Throughout we take a Human Rights approach and draw on vision building for a new concept and framework for long-term care based around empowerment.

Chapter 2. The need for long-term care: Individuals and Communities: This chapter explores the main demographic, epidemiological and socio-economic trends of an ageing population in Europe, while acknowledging marked differences both within and between countries. We also consider indicators for two important goals of long-term care systems – quality of life and social participation.

Chapter 3. Provision: This chapter explores how long-term care systems may be organized to provide the required networks of care and support services required for full empowerment of older adults. It outlines the various places in which care and support are delivered and the variety of professionals and partner organisations involved. It considers the procedures for assessing needs and ensuring continuity and coordinated care for individuals.

Chapter 4. Enabling: This chapter delves into the key components essential for an effective and sustainable long-term care system: what key conditions (enablers) should be in place in order to deliver high quality, timely and sufficient care? It reflects on system financing and governance, workforce, innovation and technology.

Chapter 5. Long-term care system performance: This chapter provides an overview of how the performance of long-term care systems can be assessed, by evaluating how the four goals of care are achieved. We attempt to assess whether the supply and demand for care services and cash-for-care benefits for older adults and their informal carers are well aligned both in terms of coverage and care quality. We look at how care resources respond to the preferences of people who receive long-term care and how they leverage existing strengths or exacerbate existing inequalities, for individuals, informal carers and communities.

Chapter 6. Rethinking: long-term care post-pandemic: This chapter covers the key challenges long-term care shall address and which have been made even more urgent with the implications of COVID-19. It highlights how critical the narrative on ageing and care to change the “way we think, feel and act towards care and caring”.

Chapter 7. Long Term Care Empowerment Model and recommendations: The Long-Term Care Empowerment Model aims to realise our vision and the subsequent principles address the identified challenges, delivering quality care and ensuring human rights and dignity for all. The model emphasises integrated person-centred care, which is proactive, holistic, anticipatory, preventive and, importantly, empowering.



: DARIO VALENZUELA – UNSPLASH



CHAPTER 1. DEVELOPING A VISION FOR LONG-TERM CARE

As life expectancy continues to increase, people in older age groups represent a growing share of the population in many European countries. Ensuring that all older adults have the opportunity to live meaningful lives and continue to actively participate in society is therefore an important issue facing governments. Despite increases in life expectancy, not all life years gained will be lived in good health, especially for the very old. A significant proportion of older adults will be living with disease and disability. For them, wellbeing and participation are closely linked to access to affordable, quality long-term care.

The question of appropriate long-term care for Europe's ageing population has become more pressing in the light of the devastating mortality rates in 2020 caused by the SARS-CoV-2 virus, which led to the coronavirus disease pandemic – COVID-19. The situation in residential long-term care settings is perhaps the most telling example. The World Health Organisation (WHO) estimates that up to 50% of all European COVID-19 deaths by mid-2020 occurred among care home residents. As of June 30, cases in Europe rose above 2 million (2,004,226) and 173,280 deaths have been reported by authorities across the European Union (EU) and the European Economic Area (EEA), according to the European Centre for Disease Prevention and Control (ECDC). Around 100,000 older adults died in care homes, hundreds of care workers have also died, and tens of thousands of older adults and their carers have been infected. There is now widespread acknowledgement that despite predisposing risks (such as physical frailty or multi-morbidity), long-term care homes were both underprepared and under-equipped to protect their residents.

The pandemic and subsequent containment measures implemented in all European countries have brought into sharper focus persistent gaps and the vulnerabilities embedded in long-term care systems. Among them, overreliance on residential care services and the parallel under-development, under-recognition and under-valuing of community-based care alternatives, lack of informal carer support programs, dominant focus on physical health, and the difficulties of ensuring safe working conditions for a strained long-term care workforce. The pandemic has also highlighted and contributed to the deepening of both gender and socio-economic inequalities². Women, low-income individuals and marginalised groups have been both more exposed to the risk of contracting the virus and more vulnerable to the negative economic and mental health consequences of the subsequent containment measures.

2 WHO 2021, Drawing light from the pandemic: A new strategy for health and sustainable development A review of the evidence, Edited by Professor Martin McKee - <https://apps.who.int/iris/handle/10665/345027>
Preventing and managing COVID-19 across long-term care services : policy brief. Geneva: World Health Organization; 2020 - https://apps.who.int/iris/bitstream/handle/10665/333074/WHO-2019-nCoV-Policy_Brief-Long-term_Care-2020.1-eng.pdf?sequence=1&isAllowed=y



The ability of older adults to maintain good health, and a high quality of life and independence is often predicated on an enabling environment and access to support, be it from families and communities (often referred to as informal care) or from formal care services. However, the extent to which European countries manage to respond to growing needs for support by ensuring sufficient provision of in-kind care services or cash benefits varies widely. Moreover, the policy discourse surrounding population ageing and the development of adequate support infrastructures has overwhelmingly focused on issues related to the financing, organisation and sustainability of long-term care systems. While these topics are essential, they have shifted focus away from the goals and principles that underpin societal efforts to support an ageing population and that should guide the development of policies and services addressing their needs.

We propose long-term care systems should pursue the following core goals:

- To support older adults to lead meaningful lives, to promote quality of life; and to empower older adults until the end of their lives;
- To ensure dignity, autonomy and self-determination, as well as equality and non-discrimination, for all older adults;
- To promote healthy ageing, defined as the process of developing and maintaining the functional ability that enables wellbeing in older age³;
- To enable the inclusion and social participation of older adults, allowing them to remain active and engaged members of their communities should they so desire.

These goals reflect a **rights-based approach to the development and delivery of long-term care** and are aligned with calls from international and national advocacy organizations calling for changing the way we think about and approach ageing, to emphasize the societal responsibility to protect and work towards realizing older peoples' human rights.

Our report aligns itself with and argues for strengthening commitment to a rights-based approach to care in Europe, calling for a **Long-Term Care Empowerment Model, which brings long-term care for older adults in line with the recognized health care empowerment approach**. We believe that a human rights-based approach and respect for diversity of needs should be central to the design of any model of long-term care. Long-term care services should take a broader, more holistic view in which older people's well-being and quality of life and their preferences regarding care and support are central to the design of services in line with

3 WHO, 2020 – Decade of Healthy Ageing baseline report - <https://www.who.int/publications/i/item/9789240017900>



existing human rights standards⁴. To this end, our report and recommendations are informed by the principles of systems thinking, person-centered and integrated care, and take **a life-course approach which reflects concern with promoting healthy ageing, gender and social equity**. Our work builds on and extends the thinking in the WHO Europe Country assessment framework⁵ for the integrated delivery of long-term care and in the ICOPE implementation framework for integrated care for older people.

Definition of long-term care

Our report is aligned with the definition included into the WHO Europe policy brief “Rebuilding for sustainability and resilience: strengthening the integrated delivery of long-term care in the European Region”, 2022:

Long-term care refers to a broad range of personal, social and medical services and support that ensure people, with or at risk of a significant loss of intrinsic capacity (due to mental or physical illness and disability), can maintain a level of functional ability consistent with their basic rights and human dignity

There is increasing recognition among policy makers and the public that long-term care requires a radical re-design, that moves away from the ‘top down’ perspective of organisations and governments towards emphasizing a service configuration that supports older people, their families and communities to play a central role in the planning and management of their care and wellbeing. In doing this we call for a new **Long-term Care Empowerment Model**. Drawing on the established thinking around empowerment and healthcare, we suggest this involves a dynamic interplay of cultural, social, and environmental factors; personal resources; and intrapersonal factors.

Throughout the report, we highlight how these aspects can be addressed in order to improve the resilience of long-term care systems and the wellbeing of individuals and communities throughout Europe. We need, for instance, to better understand the relative importance of the built environment, the nature and intensity of staff–resident and resident–resident interactions, investment in staff training and infection control procedures, and an increased attention for older people’s agency and mastery.

4 Birtha, M., Rodrigues, R., Zólyomi, E., Sandu, V. & Schulmann, K. (2019). *From disability rights towards a rights-based approach to long-term care in Europe: Building an index of rights-based policies for older people*. Vienna: European Centre for Social Welfare Policy and Research.

5 WHO Europe, 2019, Country assessment-framework for the integrated delivery of long term care - <https://www.who.int/europe/publications/i/item/WHO-EURO-2019-3522-43281-60659>



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CHAPTER 2. THE NEED FOR LONG TERM CARE: INDIVIDUALS AND COMMUNITIES

THE DEMOGRAPHIC LANDSCAPE: POPULATION STRUCTURE

For several decades, the population of Europe has been progressively ageing, through a demographic process that is project to peak by 2050, when an estimated 149 million Europeans (the equivalent of 28% of the total population) will be aged 65 or older. In addition, is the progressive ageing of the older population itself. The oldest-old (i.e. those aged 85 and over) are the fastest growing age group in Europe, and their numbers are expected to more than double, reaching 31.8 million, in the next three decades⁶. While different countries find themselves at different points on the population ageing spectrum, a trend towards convergence is also evident. Eastern European countries experience ageing at considerably faster rates than Western and Southern countries, where older population groups already represent a large share of the population⁷. While only one fifth of the older European population lives in rural environments, internal migrations patterns (i.e. exodus of working age population from primarily rural regions) conspire with demographic ageing to ensure less urbanised areas are also the ones with the highest share of older people, in comparison to their total population⁸. This has been particularly the case of Eastern and Southern European countries, where the rural population, which faces higher rates of poverty, has been declining over the last decade⁹. The two issues can compound, leaving rural environments in the most rapidly ageing European countries to face the challenges of addressing the needs of a very old local population, without having the time for social support structures and public infrastructure to adequately adapt to the fast-changing circumstances.

6 Eurostat, Ageing Europe – Looking at the lives of older people in the EU, 2019 Edition - <https://ec.europa.eu/eurostat/documents/3217494/10166544/KS-02-19-681-EN-N.pdf/c701972f-6b4e-b432-57d2-91898ca94893?t=1631631350686>

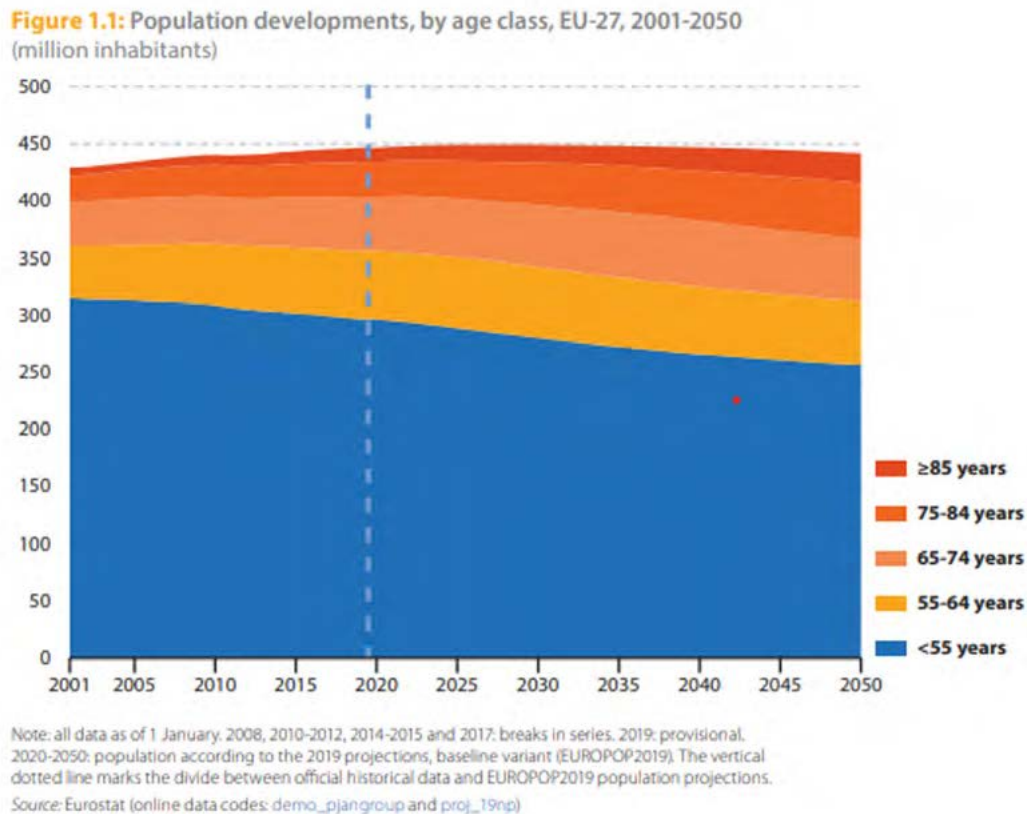
7 Antczak, R., & Zaidi, A. (2018). Well-Being of Older Persons in Central and Eastern European Countries. *Research on Ageing and Social Policy*, 6(1), 26 - 52. doi: 10.4471/rasp.2018.3109

8 UNECE 20017, Older persons in rural and remote areas, Policy Brief - https://unece.org/DAM/pau/age/Policy_briefs/ECE-WG1-25-E.pdf

9 Eurostat, 2020 - <https://ec.europa.eu/eurostat/web/population-demography/demography/publications/demography-report>



FIGURE 1- POPULATION DEVELOPMENTS, BY AGE CLASS, EU-27, 2001-2050 (EUROSTAT, 2020)



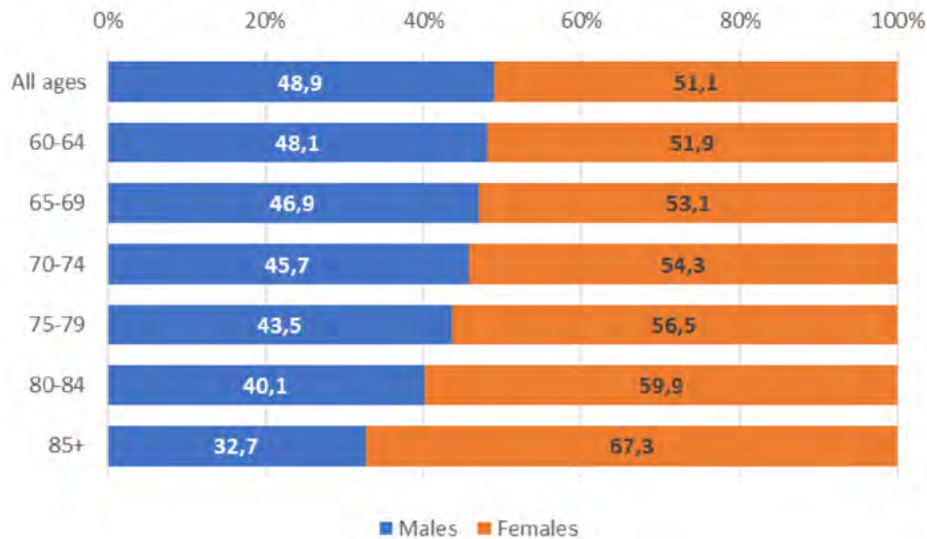
Another demographically crucial aspect of the ageing process is the marked gender imbalance in the older population, particularly among the oldest-old, reaching 2.1 women for every man among the very old (85+)¹⁰. In addition, older women report stronger cumulative effects of gender disparities throughout their (longer) life course, in terms of higher risks of vulnerability to poor health, poverty, marginalization, social isolation and violence¹¹.

10 Eurostat, Ageing Europe – Looking at the lives of older people in the EU, 2019 Edition - <https://ec.europa.eu/eurostat/documents/3217494/10166544/KS-02-19-681-EN-N.pdf/c701972f-6b4e-b432-57d2-91898ca94893?t=1631631350686>

11 Davidson, P. M., DiGiacomo, M., & McGrath, S. (2011). The feminization of aging: How will this impact on health outcomes and services? *Health Care for Women International*, 32, 1031-1045.
ROSEnet 2020 - <http://rosenetcost.com/>
UN Women, 2017, Policy Brief, "Long-term care for older people: A new global gender priority", <https://www.unwomen.org/en/digital-library/publications/2017/12/long-term-care-for-older-people>



FIGURE 2 SHARE OF POPULATION BY SEX IN THE EU-27 (IN %), 2019



Source: Eurostat (DEMO_PJANGROUP)

THE EPIDEMIOLOGICAL LANDSCAPE

While both life expectancy and healthy life expectancy are increasing in Europe, the prevalence of chronic conditions, functional limitations and cognitive impairment are also growing

Life expectancy and healthy life expectancy

Life expectancy at birth averaged 81 years across the EU in 2016, marking a decade of small albeit sustained gains in most member states, and stagnation or marginal decreases in some Western European countries (albeit first signs of drops in life expectancy due to the impact of the pandemic are now emerging). Life expectancy was in 2016 on average 5.5 years longer for women than for men. Conversely, there is virtually no difference between men and women in healthy life expectancy, i.e. without irreversible limitations of activity in daily life due to disabling illnesses at age 65 both women and men can expect to live an additional 10 healthy years, free of disability, although women of this age live on average an additional 21.6 years, compared to 18.2 years for men¹². Thus women are more vulnerable to spending a portion of their older years in dependency

12 Eurostat 2018 - <https://ec.europa.eu/eurostat/web/products-eurostat-news/-/EDN-20200407-1>



Prevalence of chronic conditions and long-term illness

Gender differences in healthy life expectancy are closely linked to the higher prevalence of chronic conditions and illness among women. In 2018, 34.4% of women in the EU-28 reported long-standing chronic illness or longstanding health problems, compared to 30% of men in all age groups¹³. As the prevalence of chronic conditions increases with age for both sexes, so does usually the gender gap, although among the very old (85+) the gender gap narrows.

FIGURE 3- PREVALENCE OF LONG-STANDING ILLNESS OR HEALTH PROBLEM, BY SEX AND AGE IN THE EU-28 (2018)

	16+	65-74	75-84	85+
Males	35.1	56.0	64.2	72.7
Females	38.7	57.3	68.6	73.8
Gender Gap	3.6	1.3	4.4	1.1

Own elaboration based on data from Eurostat - hlth_silc_19

The higher prevalence of morbidity in older age groups is also reflected in people's own perceptions of their general health. Across European countries, the share of people reporting good or very good health drops sharply with age, from half (49.7%) of those in the age group 65-74, to a third (34.1%) among the 75 to 84 year-olds, down to a quarter (25%) of those aged 85 and above¹⁴.

Functional limitations

As individuals age, their quality of life is to a large extent tied to achieving a general level of health that, while not perfect, can still allow them to preserve functional ability and an acceptable level of independence in daily life. Surveyed in 2014, one quarter of older Europeans reported difficulties in performing personal care tasks, 48% reported difficulties in carrying out common household activities, while 20% considered themselves severely limited in this respect¹⁵. Similarly to morbidity, functional limitations more commonly affect older women than men, with sex differences increasingly more visible in age groups¹⁶.

- 13 European Core Health Indicators, 2018 - https://ec.europa.eu/health/indicators-and-data/european-core-health-indicators-echi_en
- 14 Eurostat, Ageing Europe – Looking at the lives of older people in the EU, 2019 Edition - <https://ec.europa.eu/eurostat/documents/3217494/10166544/KS-02-19-681-EN-N.pdf/c701972f-6b4e-b432-57d2-91898ca94893?t=1631631350686>
- 15 Eurostat 2014, https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Functional_and_activity_limitations_statistics
- 16 Scheel-Hincke, Lasse & Möller, Sören & Lindahl-Jacobsen, Rune & Jeune, Bernard & Ahrenfeldt, Linda. (2020). Cross-national comparison of sex differences in ADL and IADL in Europe: findings from SHARE. *European Journal of Ageing*. 17. 10.1007/s10433-019-00524-y.



Loss of functional ability can usually be traced back to sensory and physical impairments, which increase with age and are significantly more prevalent among women and lower socio-economic status groups. One out of four older women (65+) reports severe mobility limitations in walking, but this share increases to almost 40% among those aged 75 and over, compared to only one quarter of men in the same age group. A similar trend can be observed for sensory impairments: both seeing and hearing difficulties become more common as people age, although differences between sexes are less marked.

FIGURE 4 - PREVALENCE OF SEVERE PHYSICAL AND SENSORY FUNCTIONAL LIMITATIONS BY SEX AND AGE IN THE EU-28 (% , 2014)

	Age group	Seeing	Hearing	Walking	Total
Males	All ages	1.6	4.1	5.0	8.6
	65+	4.0	12.4	15.7	24.3
	75+	6.4	18.4	24.3	35.3
Females	All ages	2.6	4.2	8.2	11.6
	65+	6.8	12.0	25.3	32.1
	75+	10.2	18.1	37.8	46.1

Own elaboration based on data from Eurostat - hlth_ehis_pl1e

Mental health and cognitive decline

Depressive disorders, which affected more than 20 million Europeans in 2016, are the single largest contributor to global disability¹⁷. Their prevalence increases with age, reaching the highest values among older women: in 2014, 12.4% of women aged 75+ in Europe reported chronic depression, compared with 8.8% of women of all ages and 6.5% of older men¹⁸. Lower income and education are strongly associated with higher rates of depression, particularly for older women who can be more vulnerable to the detrimental mental health effects of deprivation and exclusion¹⁹. Poor health, functional decline, bereavement, social isolation and loneliness, all act as predisposing factors for late-life depression. Loneliness, in particular, has recently received much public attention as it becomes increasingly apparent in older adults who lack close social connections, companionship and strong ties to their communities and are vulnerable to adverse mental and physical health outcomes²⁰.

17 WHO, Mental Health ATLAS, 2017 - <https://www.who.int/publications/i/item/9789241514019>

18 Eurostat, 2014 - https://ec.europa.eu/eurostat/statistics-explained/index.php?oldid=412722#Prevalence_of_chronic_depression

19 Hansen, Thomas, and Britt Slagsvold. "The East–West divide in late-life depression in Europe: results from the Generations and Gender Survey." *Scandinavian Psychologist* 4 (2017).

20 Courtin, E., & Knapp, M. (2017). Social Isolation, Loneliness and Health in Old Age: A Scoping Review. *Health & Social Care in the Community*, 25, 799-812 - <https://doi.org/10.1111/hsc.12311>



2019 estimates place the number of people living with dementia in Europe at 8.8 million (6 million of whom were women), and this number is expected to double by 2050²¹. Dementia prevalence increases very rapidly with age, from only 0.6% for people aged 60 to 64, to 8% in the 75 to 79 age group and finally to 40.8% among the oldest old (90+). As the European population ages, the share of older adults living with dementia will also continue to increase, most pronouncedly in those countries who will experience a more rapid growth of the 85+ population group²². Specific attention has to be paid to protect the rights of older adults with cognitive impairment within the social and legal context. These may impact on their right to self-determination or allow limits to the person's right to free movement.

THE SOCIO-ECONOMIC LANDSCAPE

Older adults contribute significantly to local communities through volunteering and the provision of the majority of community-based care. However, old-age poverty and material deprivation remain important concerns that hinder healthy ageing and social participation, particularly for older women. Changing living arrangements are leading to significant numbers of older adults who are socially isolated, despite more regular use of new technologies among older people.

Income and wealth

Material deprivation and poverty are key determinants of wellbeing, and can expose older adults to insecurity, distress and increased risk of poor health outcomes²³. In the EU, poverty rates are on average lower for older adults (65+) than for the general population, although the opposite is true in all Baltic states and several Eastern European EU member states²⁴. However, such general statistics often hide the heterogeneity of the population within older age groups. In fact, poverty rates tend to increase in later life, leading to a situation where the risk of poverty among those aged 75 and over is higher than in the general population for the vast majority of EU countries. A further crucial disaggregation reflects the large gender gap in old-age poverty, with higher shares of older women exposed to poverty risk both compared to the general population and to older men.

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- 21 Alzheimer's Europe Yearbook, 2019 - https://www.alzheimer-europe.org/sites/default/files/alzheimer_europe_dementia_in_europe_yearbook_2019.pdf
 - 22 Eurostat, 2019 - https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Mental_health_and_related_issues_statistics#Deaths_from_mental_and_behavioural_disorders.2C_Alzheimer.E2.80.99s_disease_and_intentional_self-harm
 - 23 Eurostat, 2019 - https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Material_deprivation_statistics_-_early_results#Severe_material_deprivation_by_age
 - 24 Eurostat, 2019 - https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Material_deprivation_statistics_-_early_results#Severe_material_deprivation_by_age



Almost three quarters of all Europeans lived in owner-occupied housing in 2018, suggesting that many households enjoy economic stability and wellbeing, although variability between countries is extremely large. Whereas home ownership approaches 100% in some Eastern European countries, and is also high in the UK, rates are considerably lower in Northern, Western and Southern Europe²⁵. However, the rise in home-ownership, that has been one of the hallmarks of economic and social development in Europe over the last century, has slowed down considerably in more recent times.

Housing and Age-friendly environments

Functioning and wellbeing of older adults depends not only on access to housing but also on the quality of private dwellings and accessibility of public spaces, a problem that primarily affects urban communities. The WHO describes age-friendly environments as spaces that promote the maintenance of intrinsic capacity across the life-course and enable greater functional ability²⁶. They support older adults to remain mobile, access key support services, build and maintain social relationship and contribute to their communities.

Home ownership patterns are also reflected in age-based gaps in housing conditions and quality. As older adults who own their house tend to continue living in the same dwelling long after their children have left the household, almost half of all older Europeans live in under-occupied houses²⁷. Though over-crowding is a considerable issue in many Eastern European countries, even here, older adults living alone or in nuclear families occupy housing with an average of two rooms per person (an average that reaches four rooms per person in Belgium, Malta and Ireland).

Despite this apparent advantage in housing conditions, it is important to underline that many older adults require much more than decent living standards in order to be able to continue living independently in the community. Particularly among the very old, who often experience considerable functional limitations and declining health, thermal comfort and home adaptations to facilitate independent mobility are crucial to facilitate ageing in place²⁸.

Age-friendly cities and communities are receiving growing attention, both at regional and European level, with promising local initiatives growing across European countries. Their

25 Eurostat, 2018 - <https://ec.europa.eu/eurostat/statistics-explained/index.php?oldid=497245>

26 Eurostat, 2018 - <https://ec.europa.eu/eurostat/statistics-explained/index.php?oldid=497245>

27 Eurostat, Ageing Europe – Looking at the lives of older people in the EU, 2019 Edition - <https://ec.europa.eu/eurostat/documents/3217494/10166544/KS-02-19-681-EN-N.pdf/c701972f-6b4e-b432-57d2-91898ca94893?t=1631631350686>

28 Mulliner, Emma & Riley, Mike & Maliene, Vida. (2020). Older People's Preferences for Housing and Environment Characteristics. Sustainability. 12. 5723. 10.3390/su12145723.
Braubach, Matthias, Jacobs, David E & Ormandy, David (2011). Environmental burden of disease associated with inadequate housing: a method guide to the quantification of health effects of selected housing risks in the WHO European Region: summary report. World Health Organization. Regional Office for Europe - <https://apps.who.int/iris/handle/10665/344853>



efforts focus on developing accessible outdoor environments and transportation systems, as well as promoting social connectedness and engagement of older people²⁹.

Housing Europe (European Federation of Public, Cooperative and Social Housing): **“Ageing Well at Home” – Research Briefing (May 2021)**: This document highlights concrete examples and practices developed by public, cooperative and social housing providers to address the need and wishes of older people. It also brings to the surface the lessons learnt for policymakers, as well as what the EU could do to ensure that people are allowed to age well at home.

Homes4Life (EU Project, H2020, 2018-2020)

Homes4Life addresses the challenges brought by Europe’s ageing demographics by contributing to the development of a new European certification scheme. The scheme is based on an inspirational and realistic long-term vision of people’s needs and requirements in a holistic life-course approach, and helpshelps develop better living environments, integrating construction and digital solutions where this is beneficial.

Living arrangements and social connectedness

European countries have experienced a significant increase in the share of nuclear families and individuals living alone, particularly among older age groups³⁰. Even though such patterns differ across countries and regions, older adults in Northern and Western Europe are more likely to live alone³¹, while co-residence with adult children remains a common household living arrangement for older adults in Southern and Eastern Europe³². While poorer individuals (more likely represented by women) tend to live alone in old age across European

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- 29 ESPON led project: ACPA – Adapting European Cities to Population Ageing: Policy Challenges and Best Practices, 2019-2020 - <https://www.espon.eu/ACPA>
- 30 United Nations, Department of Economic and Social Affairs, Population Division. (2017). World Population Prospects: The 2017 Revision. Retrieved from <https://esa.un.org/unpd/wpp/Download/Standard/Population/>
- 31 David Reher, Miguel Requena (2018), Living Alone in Later Life: A Global Perspective, 2018 - <https://onlinelibrary.wiley.com/doi/full/10.1111/padr.12149>
OECD 2019, Living arrangements by age groups, <https://www.oecd.org/els/family/HM1-4-Living-arrangements-age-groups.pdf>
- 32 Eurostat, Ageing Europe – Looking at the lives of older people in the EU, 2019 Edition - <https://ec.europa.eu/eurostat/documents/3217494/10166544/KS-02-19-681-EN-N.pdf/c701972f-6b4e-b432-57d2-91898ca94893?t=1631631350686>



countries, richer households are more frequently also larger³³. A similarly pronounced gender gap can be observed in the likelihood to reside in an institutional care setting: across the EU-28, almost 4% of women aged 65 or older lived in residential care in 2011, a share that is twice as large as that of older men (1.9%)³⁴.

De Weister, Aalbeke (Belgium)

This care facility host around 45 residents – part of them being older adults with dementia. The building is located in the center of the town and its cafeteria mainly run by the residents is open to the public. A “reminiscence promenade” has been developed around the care facility and through the town: 4 walks have been designed with and for residents, in collaboration with inhabitants and tourists. The project has been an opportunity to develop an educational programme to overcome the taboo of dementia. The walks have also been an opportunity to improve the accessibility of the town and enable intergenerational contacts.

Independent living arrangements in older age are no doubt a reflection of changing cultural values and social dynamics, but they might also be interpreted as indicative of higher accessibility of financial and community-based support systems in countries that are economically more developed and have set up more robust welfare systems³⁵. Notwithstanding these gains in social support and opportunities for independent living at every age, the prevalent changes in living arrangements leave many older adults exposed to isolation and loneliness³⁶.

In counterbalance, developments in communication technology and increases in its uptake have expanded opportunities for social connectedness among older Europeans. By

33 United Nations, Department of Economic and Social Affairs, Population Division. (2017). World Population Prospects: The 2017 Revision. Retrieved from <https://esa.un.org/unpd/wpp/Download/Standard/Population/>

34 Eurostat, Ageing Europe – Looking at the lives of older people in the EU, 2019 Edition - <https://ec.europa.eu/eurostat/documents/3217494/10166544/KS-02-19-681-EN-N.pdf/c701972f-6b4e-b432-57d2-91898ca94893?t=1631631350686>

35 S. Mudrazija, J.L. Angel, I. Čipin, Š. Smolić, “Living Alone in the United States and Europe: The Impact of Public Support on the Independence of Older Adults”, March 2020, Research on Aging 42(5-6), DOI:10.1177/0164027520907332
United Nations, Department of Economic and Social Affairs, Population Division. (2017). World Population Prospects: The 2017 Revision. Retrieved from <https://esa.un.org/unpd/wpp/Download/Standard/Population/>

36 WHO 2021, Social isolation and loneliness among older people: advocacy brief- <https://www.who.int/teams/social-determinants-of-health/demographic-change-and-healthy-ageing/social-isolation-and-loneliness>



2018, 9 in 10 European households had internet access, an increase of one third over the last decade. While Information and Communication Technologies (ICT) use remains much lower among older adults as compared to the general population, the shares of computer users in the 55-64 and 65-74 age groups have increased by 20 and 28 percentage points respectively since 2008. In 2018, 60% of people aged 65 to 74 used a computer, although significantly lower shares used it regularly, to connect to social networks or to make telephone and video calls³⁷. As current adult cohorts progress into older age, these rates are expected to increase very rapidly in the coming years, although much more should be done to encourage and support current old age cohorts to access ICT, especially among those characterised by a lower socio-economic status, who are less digitally skilled and therefore less likely to benefit from these digital developments³⁸.

Social Participation and Quality of life in later life

Promoting quality of life and ensuring older adults can remain engaged in their communities for as long as possible are key goals of long-term care systems. The two concepts are closely linked to each other as well as with perceptions of one's health, relationships, living standards and financial insecurity³⁹. The social, economic and familial factors reviewed in previous sections are therefore key to improving the lives of older people.

Commonly described as the U-shape curve of life satisfaction⁴⁰, numerous studies have pointed to a tendency of individuals to report lower satisfaction with life during mid-life, as compared to younger and older ages. This is confirmed by recent surveys, highlighting that, on average, life satisfaction in Europe is slightly higher among older age groups (65+) than in middle life. However, a global 'old age' category masks important variation. Previous research has shown that life satisfaction declines after 75 and its levels are very closely related to perceived health status as individuals progress into old or very old age⁴¹. Pan-European

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- 37 Eurostat, Ageing Europe – Looking at the lives of older people in the EU – 2020 edition, <https://ec.europa.eu/eurostat/en/web/products-statistical-books/-/ks-02-20-655>
- 38 König, R., Seifert, A. & Doh, M. Internet use among older Europeans: an analysis based on SHARE data. *Univ Access Inf Soc* 17, 621–633 (2018). <https://doi.org/10.1007/s10209-018-0609-5>
- 39 van Leeuwen KM, van Loon MS, van Nes FA, et al. What does quality of life mean to older adults? A thematic synthesis. *PLoS One*. 2019;14(3):e0213263. Published 2019 Mar 8. doi:10.1371/journal.pone.0213263
- 40 Easterlin, Richard. (2006). Life Cycle Happiness and Its Sources. *Journal of Economic Psychology*. 27. 10.1016/j.joep.2006.05.002.
- 41 Gwozdz, Wencke, and Alfonso Sousa-Poza. "Ageing, Health and Life Satisfaction of the Oldest Old: An Analysis for Germany." *Social Indicators Research*, vol. 97, no. 3, 2010
Angelini V, Cavapozzi D, Corazzini L, Paccagnella O. Age, Health and Life Satisfaction Among Older Europeans. *Soc Indic Res*. 2012;105(2):293-308. doi:10.1007/s11205-011-9882-x



data collected in 2018 point to the same trend: the share of individuals reporting higher life satisfaction declines from 25.5% in the general population (16 and over), to 24% in the 65-74 year old group, and further to 20.3% for those aged 75+⁴².

The wellbeing and quality of life in older age are associated with the possibility of being and feeling involved in the community and broader society. This societal participation can take place in different ways, the most important of them being paid work, volunteering and informal care. As for the first, in recent years retirement across Europe has been postponed, via different measures such as raising the minimum retirement age, aligning it to changes in life expectancy, or restricting early retirement options. As a consequence, employment rates of workers aged 55 and over – which are generally lower than in younger age cohorts – have been increasing recently in most EU countries⁴³.

The societal contribution provided by older adults in the form of organized voluntary work follows a different pattern than that observed for paid employment, since it usually increases in older age groups compared to the general population⁴⁴. This is not surprising, given the larger availability of paid work-free time in later life, but it should also be welcomed and promoted more systematically, given the well-established positive association existing between volunteering and health, a phenomenon that is not restricted to high-income countries only⁴⁵. The provision of informal care represents another, maybe even more fundamental area of contribution by older adults to the community. This care can take different forms, intergenerational – such as that provided to children and grandchildren (e.g. grandparenting) – as well as intra-generational, when granted to other older adults (both inside and outside the household)⁴⁶.

42 Eurostat, 2018 - <https://ec.europa.eu/eurostat/documents/2995521/10207020/3-07112019-AP-EN.pdf/f4523b83-f16b-251c-2c44-60bd5c0de76d>

43 Eurostat 2021 - https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Employment_rates_%E2%80%93_annual_statistics&oldid=549029#More_persons_aged_55-64_in_employment

44 Eurofound, European Quality of Life Survey, 2016 - <https://www.eurofound.europa.eu/surveys/european-quality-of-life-surveys/european-quality-of-life-survey-2016>

45 Kumar, S., Calvo, R., Avendano, M., Sivaramakrishnan, K., & Berkman, L. F. (2012). Social support, volunteering and health around the world: Cross-national evidence from 139 countries. *Social Science & Medicine*, 74(5), 696–706. <https://doi.org/10.1016/j.socscimed.2011.11.017>

46 Eurofound, European Quality of Life Survey, 2016 - <https://www.eurofound.europa.eu/surveys/european-quality-of-life-surveys/european-quality-of-life-survey-2016>



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CHAPTER 3. PROVISION: HOW WE DELIVER LONG-TERM CARE

INFORMAL CARE

Informal care remains the main source of support for older adults across Europe. Estimates place the contribution of families, friends and communities at 80% of all long-term care provided⁴⁷, with an expected monetary value that far exceeds public expenditure on long-term care services and cash benefits combined⁴⁸.

Informal care provision rates vary significantly across countries. According to recent data from the European Quality of Life Survey (EQLS, 2016), approximately 10% of the total population is providing informal care in Romania, Austria, Ireland and Sweden, while the share reaches over 25% in Malta, Belgium or Greece. A disaggregation by gender and age reveals a well-established, common European pattern: women are significantly more likely to provide informal care and particularly among them middle-aged and older women⁴⁹. Recent and projected changes in population structure, workforce mobility and migration patterns, labour market attachment of women, further increases of retirement age, as well as changes in cultural norms are all conspiring to create what is described as a crisis of familial care availability in the future⁵⁰.

It should be underlined that, while informal care represents an essential component of the overall care provided within our ageing societies, it might also imply, at individual level,

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- 47 Hoffmann, F., & Rodrigues, R. (2010). *Informal Carers: Who Takes Care of Them?* Policy Brief 4/2010, Vienna: European Centre - [https://www.scirp.org/\(S\(351jmbntv-nsjt1aadkposzje\)\)/reference/referencespapers.aspx?referenceid=2910964](https://www.scirp.org/(S(351jmbntv-nsjt1aadkposzje))/reference/referencespapers.aspx?referenceid=2910964)
- 48 Chari AV, Engberg J, Ray K, Mehrotra A. The opportunity costs of informal elder-care in the United States: new estimates from the American Time Use Survey. 2014. *Health Serv Res.* doi:10.1111/1475-6773.12238. Paraponaris A, Davin B, Verger P. Formal and informal care for disabled elderly living in the community: an appraisal of French care composition and costs. *Eur J Health Econ.* 2012 Jun;13(3):327-36. doi: 10.1007/s10198-011-0305-3. Epub 2011 Mar 13. PMID: 21400197
- Rothgang, Heinz & Obinger, Herbert & Leibfried, Stephan. (2006). *The State and Its Welfare State: How Do Welfare State Changes Affect the Make-Up of the Nation State?*. *Social Policy & Administration.* 40. 250 - 266. 10.1111/j.1467-9515.2006.00488.x.
- 49 Zigante, V. (2018). *Informal care in Europe: Exploring Formalisation, Availability and Quality*, Brussels, European Commission: Directorate-General for Employment, Social Affairs and Inclusion - <https://op.europa.eu/en/publication-detail/-/publication/96d27995-6dee-11e8-9483-01aa75ed71a1>
- 50 Spasova, S., Baeten, R., Coster, S., Ghailani, D., Peña-Casas, R. and Vanhercke, B. (2018). *Challenges in long-term care in Europe. A study of national policies*, European Social Policy Network (ESPN), Brussels: European Commission - <https://op.europa.eu/en/publication-detail/-/publication/c12c65f9-c6b6-11e8-9424-01aa75ed71a1/language-en>
- Pickard, L. (2015). A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032. *Ageing and Society*, 35: 96-123



a significant burden for those who provide it when no adequate support is granted to them. Therefore, appropriate supports are needed, especially in countries with a less developed infrastructure of in-kind care services, and particularly in these COVID-19 pandemic times, that have often implied an increase in the responsibility lying on informal carers' shoulders⁵¹. As older adults themselves account for a significant share of informal caregivers it is essential they are supported to remain engaged in meaningful care activities without suffering ill-effects to their health and wellbeing.

Volunteers and community partners

Involvement of volunteers, local faith communities, schools and community organisations provides valuable befriending and practical support to enable older adults and their carers to stay well at home and connected to community networks. Caring cities or compassionate communities⁵² mobilise the collective strengths and 'assets' of citizens to support older adults and their carers.

Eligibility, Assessment and Care Planning

Eligibility for publicly funded long-term care is generally based on care dependency and inability to perform basic and instrumental activities of daily living⁵³. The precise assessment tool is less important than how, when and where the assessment is undertaken. Decisions about long-term care should follow a process of holistic assessment that includes the opportunity for rehabilitation to enable the older person to regain confidence and independence, particularly if they have experienced a recent illness or bereavement. Comprehensive multi-dimensional assessment should consider physical, psychological, social and cognitive health needs, functional ability and requirement for nutritional, sensory, communication, pharmaceutical care, housing, transport and social support; moreover, they should also materialise a goal-oriented approach to care by considering older people's strengths, resources, purpose and life goals.

Following assessment, a personalised care plan is developed through a process of shared decision making with the older person about what matters to them and their family and informal carers. The plan identifies personalised care goals and any specific

- 51 Lorenz-Dant, K. and Comas-Herrera, A., 2021. The Impacts of COVID-19 on Unpaid Carers of Adults with Long-Term Care Needs and Measures to Address these Impacts: A Rapid Review of Evidence up to November 2020. *Journal of Long-Term Care*, (2021), pp.124–153. DOI: <http://doi.org/10.31389/jltc.76>
- 52 Librada Flores, S. (2018). All with You: a new method for developing compassionate communities - experiences in Spain and Latin-America. *Ann Palliat Med*. 2018 Apr;7(Suppl 2):S15-S31
- 53 Spasova, S., Baeten, R., Coster, S., Ghailani, D., Peña-Casas, R. and Vanhercke, B. (2018). Challenges in long-term care in Europe. A study of national policies, European Social Policy Network (ESPN), Brussels: European Commission - <https://op.europa.eu/en/publication-detail/-/publication/c12c65f9-c6b6-11e8-9424-01aa75ed71a1/language-en>



needs relating to gender, culture, ethnicity and support for family carers. It considers how these goals can be met by coordinating a range of services that enable the older person to maintain intrinsic capacity and functional ability⁵⁴ so that they, and their carer, are able to live the lives they want to lead. As care and support needs will change over time, the care plan should be reviewed regularly and as health, carer support and circumstances change. Advance care planning documents the individual's wishes and care preferences in the event of a future deterioration in health or a sudden change in circumstances for their carer, and has been an important component of person centred planning in the context of COVID-19⁵⁵.

HOME CARE AND REABLEMENT

Home care services are provided for older adults in their own home by care assistants who may provide help with personal hygiene, at mealtimes, help with medication, assistance with immobility or in maintaining general wellbeing. Domestic services such as help with housework, laundry, shopping may also be included. Home care usually excludes tasks that require the knowledge or skills of a qualified nurse but trained care workers are increasingly undertaking some tasks that were previously done by clinical staff. Building on the principles of a rights-based approach to care and a focus on promoting healthy ageing and independence, home care should be delivered with a focus on prevention and reablement. This implies promoting physical activity and helping older adults maintain their social networks to enhance wellbeing, independence and reduce isolation, depression and anxiety. Reablement is a time-limited, person-centred intervention that aims to restore self-care and daily living skills and restore social connections and activities⁵⁶. This approach supports older adults to resume activity after illness to reduce their risk of deconditioning, social isolation and associated demand for services.

Fredericia “Lifelong living: ambient assisted living” (Denmark)

The city of Fredericia started this reablement initiative in 2007 with a projection of the need for support services for older people: these projections made clear

- 54 WHO 2019, Integrated care for older people: guidance on person-centred assessment and pathways in primary care - <https://www.who.int/ageing/publications/guidelines-icope/en/>
- 55 Combes S, Nicholson CJ, Gillett K, Norton C. Implementing advance care planning with community-dwelling frail elders requires a system-wide approach: An integrative review applying a behaviour change model. *Palliat Med* 2019;33:743-56. [10.1177/0269216319845804](https://doi.org/10.1177/0269216319845804) 31057042
- 56 Aspinal, F., Glasby, J., Rostgaard, T., Tuntland, H., & Westendorp, R. G. J. (2016). New horizons: Reablement – Supporting older people towards independence. *Age and Ageing*, 45, 574–578. <https://doi.org/10.1093/agein g/afw094>



that the former model was not sustainable financially and in terms of staff resources. The city decided therefore to launch a new initiative to develop a model for a new form of interaction between older adults and the municipality involving rehabilitation and prevention rather than traditional and expensive compensatory initiatives. The overall goals were to ensure:

- that the individual users of the local welfare services experience a high level of satisfaction;
- that local employees thrive and develop their skills to the benefit of the users;
- and that the local financial performance is improved, enabling us to provide more welfare for the same amount of money.

The initiative has been positively assessed and reablement is now part of the legislation and mandatory in all Danish municipalities.

HOUSING AND ASSISTIVE TECHNOLOGY

Older adults welcome opportunities to age ‘in place’ in housing that enables them to stay connected with their social networks and to remain active⁵⁷. Accessible or dementia friendly design enables independence through equipment, adaptations and assistive technology designed to monitor safety and secure an immediate response in an emergency. Assistive technology may increase choice, improve quality of life, reduce physical and emotional burden on carers, make the provision of care less intrusive, and can reduce demand for 24 hour care⁵⁸. Examples include personal alarms; medication dispensers; motion sensors; fall detectors; temperature, smoke and flood detectors; and GPS monitoring devices. Preventative health and wellbeing support in assisted living facilities or housing with care units can help older adults stay well at home for longer⁵⁹.

“Die Mitalternde Wohnung” in Saxony (Germany)

The Association of Saxony Housing Cooperatives (VSWG) has developed a key concept namely “Die Mitalternde Wohnung”. This is basically a dwelling that will adapt to the need of the inhabitant step by step thanks to a Universal Design Approach. The basis is

57 WHO 2018, The Global Network for Age-friendly Cities and Communities: Looking back over the last decade, looking forward to the next - <https://www.who.int/ageing/publications/gnafcc-report-2018/en/>

58 NIHR Themed Review 2018. Help at Home. Use of assistive technology for older people - <https://www.mis.dc.nihr.ac.uk/content/themedreview-03385/help-at-home-use-of-assistive-technology-for-older-people/3310/t/emedreview-03345>

59 The Extracare Charitable Trust. Research report by Aston and Lancaster Universities. Accessed from www.extracare.org.uk/research/findings/ Last accessed April 27, 2019



an apartment that has been structurally upgraded and equipped with sufficient connection options (basic equipment) and includes the necessary technicalities (e.g. laying cables and connections) to create the technical prerequisites for further expansion stages.

The concept is based on a combined approach, consisting of economically justifiable structural measures in the apartment to reduce barriers in the housing stock, the integration of technical support systems for assistance in everyday living and coupled services for the tenants.

DAY CENTRES OR DAY CARE SERVICES

Day centres may be operated by a range of voluntary, community and statutory providers and offer preventive and recreational activities for older adults who are socially isolated, ambulatory assessment and monitoring, and planned respite for family caregivers.

Age UK Day Centres

Age UK supports a network of day centres providing older adults with both practical assistance and a chance to socialise, with support from trained staff and volunteers. There is a wide variety of activities including singing, dance and music, quizzes, exercise, arts and crafts, and day trips. Older adults are served a hot lunch and refreshments throughout the day. Some of the day centres also offer other services, such as mobile supermarkets, assisted bathing, hairdressing and foot care.

CARE HOMES

Older adults who have severe care needs and have cognitive impairment and multiple health conditions may require more intensive support in a residential or nursing home. Most care is provided by care assistants who may have variable training but have valuable skills and experience in managing the needs of this care group and their families. However, many older adults in care homes will be approaching the end of their life and will benefit from support from skilled nurses, primary care physicians, pharmacists and allied health professionals (e.g., physio- and occupational therapists) with expertise in managing dementia, frailty, pharmaceutical care and palliative care⁶⁰. Here again, professionals can aim to become “competence-trainers” that support older adults in accomplishing their life goals and wishes.

60 Evans, C.J., Ison, L., Ellis-smith, C., Nicholson, C., Costa, A., Oluyase, A.O., Namisango, E., Bone, A.E., Brighton, L.J., Yi, D., Combes, S., Bajwah, S., Gao, W., Harding, R., Ong, P., Higginson, I.J., and Maddocks, M. (2019). Service Delivery Models to Maximize Quality of Life for Older People at the End of Life: A Rapid Review. *The Milbank Quarterly*, Vol. 97 (1): pp.113-175.



Care homes in Denmark focus on high-quality nursing care, assistive technologies, architecture, and design to improve residents' quality of life and overall well-being. All nursing homes in Denmark aim to enhance the quality of practice in care. When Danish municipalities build new nursing homes, they are built to support quality care practice and a socially active life, while also acknowledging the wide range of residents' needs. Designed as real homes, with private bathroom and kitchenette, they aim to give the older person a sense of living an ordinary everyday life. Parks and gardens often invite them to engage in outdoor activities, while a range of individual and social activities stimulate the senses, support mobility and encourage social inclusion.

The Nursing Home of the Future in Aalborg, in the North Denmark Region, has implemented innovative assisted-living technologies and sensory stimulation, which can improve older adults' overall well-being and quality of life. The apartments are equipped with pressure-sensitive flooring that – if the resident permits it – can alert the nursing staff automatically in the case of fall accidents. Flush/dry toilets make it possible for some of the residents to go to the bathroom without assistance, while electronic information boards in the hallways keep the residents updated with important information.

CASH BENEFITS AND SERVICES TO SUPPORT INFORMAL CARERS

Countries offer varying levels of cash benefits and in-kind support for informal carers to mitigate the potential negative impacts of caring. Supports may include flexible working arrangements for those in employment including paid and/or unpaid carer leave; day and residential respite care; information, advice and training; peer to peer and professional emotional and psychological support; and cash benefits or carer allowances. A lack of these supports increases the risk of mental health problems, violence and abuse in caring situations.

Support to Informal carers

[InformCare](#) is an information hub for Informal Care in the EU. It supports informal caregivers by providing information on caring for older people, support from their specific state, and the needs of carers. They also provide interactive services which are a virtual meeting place for carers to connect (for some countries). The project is led by Eurocarers and the Italian National Institute of Health and Science on Ageing and co-funded by the European Union.

The Eurocarers Erasmus+ project [CARE4DEM](#) is a mutual aid platform designed to support caregivers who care for people living with dementia.



INTEGRATED CARE PATHWAYS

This range of long-term care services is a complex landscape that is often difficult for older persons, families and professionals to navigate⁶¹. Fragmented services delivered by different providers often result in delays, waste, harm and a poor care experience through failures of communication, inadequate sharing of information and missed or duplication of assessments or investigations. Many individuals in receipt of long-term care will have complex or frequently changing needs that benefit greatly from proactive assessment and care pathways that ensure continuity and coordination of care⁶². Some people will experience frequent exacerbations of their chronic conditions and may require rapid access to quality intermediate care services as an alternative to urgent hospital care. Similarly, it is important that those who have advanced dementia or frailty or are approaching a palliative or end of life care stage are able to access the appropriate specialist services. Therefore, it is crucial that local care pathways ensure these specialist services are well integrated with the provision of long-term care.

The ADVANTAGE Joint Action Framework for a Frailty Prevention Approach in Europe

ADVANTAGE is a Joint Action funded by the EU and 22 Member States. It has delivered a “Frailty prevention approach”, a common European model to tackle frailty and indicate what should be prioritized in the next years at European, National and Regional level and on which to base a common management approach of older adults who are frail or at risk of developing frailty in the EU.

The care and support services approach developed by ADVANTAGE is ‘wrapped around’ the individual, their family, friends and social network within an age friendly community (see Figure 2 in the Frailty Prevention Approach).

INTERMEDIATE CARE

Older adults often want to remain at home or in their care home in the event of an acute illness. Intermediate care, including transitional care and hospital at home, are time-limited services at the interface between home and acute services, that ensure continuity

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- 61 Spasova, S., Baeten, R., Coster, S., Ghailani, D., Peña-Casas, R. and Vanhercke, B. (2018). Challenges in long-term care in Europe. A study of national policies, European Social Policy Network (ESPN), Brussels: European Commission - <https://op.europa.eu/en/publication-detail/-/publication/c12c65f9-c6b6-11e8-9424-01aa75ed71a1/language-en>
- 62 WHO 2018, Continuity and coordination of care - A practice brief to support implementation of the WHO Framework on integrated people-centred health services - <https://apps.who.int/iris/bitstream/handle/10665/274628/9789241514033-eng.pdf?sequence=1&isAllowed=y>



and quality of care, promote recovery and restore independence and confidence⁶³. Hospital at Home provides short-term acute care, equivalent to the level that would be provided in hospital, within the person's own home. Some people benefit from a period of bed based Intermediate care in a care home, community hospital or housing facility to recover confidence and independence, and avoid making premature life changing decisions about future care. These models work best as part of an integrated service led by risk tolerant experienced clinical decision makers in a multidisciplinary team of doctors, nurses, allied health professionals, social workers and pharmacists who have excellent links with primary care, community and rehabilitation services.

PALLIATIVE AND END OF LIFE CARE

“An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO 2002).

The mid to late stages of dementia and frailty for older adults is seen to mark the start of an extended palliative phase of progressive disability at the end of life⁶⁴. Community palliative care is increasingly shared care or ‘hospice influenced care’. Technology enabled education may increase the skills and confidence of the community workforce. This may be supported by specialist practitioners providing outreach assessment and advice at home or in care homes. Pharmacists have a key role for people who are moving to a palliative phase and for those who are prescribed multiple medicines. One key issue is that using medicines which are either inappropriate or are no longer indicated, increases adverse drug reactions, hospitalisation, costs of care, and may exacerbate frailty or cause delirium. Patients, carers and care providers should have access to tools and support that enable them to make informed choices about the benefits or burden of medicines⁶⁵.

WHO Europe, Palliative care for older people: better practices, 2011

This publication aims to provide examples of better palliative care practices for older adults to help those involved in planning and supporting care-oriented services most appropriately and effectively. Examples have been identified from literature searches

- 63 Sezgin, D. et al. Defining the characteristics of intermediate care models including transitional care: An International Delphi Study. *Aging Clinical and Experimental Research*. 2020 <https://doi.org/10.1007/s40520-020-01579-z>
- 64 Gill TM, Gahbauer EA, Han L, Allore HG. (2010). Trajectories of disability in the last year of life. *N Engl J Med*;362:1173-80. doi:10.1056/NEJMoa0909087
- 65 Stewart, D., Mair, A., Wilson, M., Kardas, P., Lewek, P., Alonso, A., McIntosh, J., MacLure, K. and SIMPATHY consortium (2016), “Guidance to manage inappropriate polypharmacy in older people: systematic review and future developments”, *Expert Opinion on Drug Safety*, Vol. 16 No. 2, pp. 203–13.

and from an international call for examples through various organizations, including the European Association of Palliative Care and the European Union Geriatric Medicine Society.

The full publication is available [here](#).

European Dementia Palliative Care Project (2014-2016)

This project gathered an interdisciplinary team from Scotland, Czech Republic, Finland, Portugal, Slovenia, Spain and Sweden. It has responded to the challenge to develop a response to improve dementia care and in particular to improve approaches to advanced dementia care through providing educational solutions to a workforce that deliver services, care and support across health and social care. Importantly a distinction was made between the dying phase and dying, and the phase prior to this which is about living with advanced dementia. The objective of the first phase was to develop an inter-professional understanding of best practice for advanced dementia care and family caring, and an understanding of the contribution of different disciplines to the achievement of best practice. The second phase objective was to develop an innovative virtual inter-professional experiential learning and resources to equip the European qualified dementia workforce to transform advanced dementia care and deliver best practice.

PACE Project (EU, FP7 – 2014 to 2019)

This project performed comparative effectiveness research concerning palliative care in long term care facilities in Europe. The aim of the project was to generate evidence on the best ways to deliver effective palliative care that can improve policymaking in this field.

It delivered policy recommendations “[Palliative care for dignity in old age – Addressing the need of older adults in long-term care facilities in Europe](#)”.

The project also developed tools and guidance on how to better manage palliative care in long-term care settings, see [here](#); as well as a MOOC – report available [here](#).

InAdvance Project (EU, H2020 – 2019 to 2022)

The overall aim of the project is to improve the benefits of the palliative care interventions for patients, families and informal caregivers as well as front-line practitioners through the design of effective, replicable and cost-effective early palliative care interventions centred-on and oriented-by the patients. The INADVANCE project has five clinical trials performed in Valencia, Leeds, Inverness, Lisbon and Thessaloniki where early palliative care interventions are being implemented and studied. These interventions will take into consideration palliative care from a holistic approach: understanding the person in need of these services and their physical, psychological, emotional, social and spiritual needs as well as own values and preferences; and inputs from their families and front-line professionals too.



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CHAPTER 4. ENABLING: WHAT ENABLES LONG-TERM CARE

The WHO Europe Country assessment framework for the integrated delivery of long-term care and the implementation framework for integrated care for older adults (ICOPE) considers the system enablers at three levels:

Macro level: development and improvement of long-term care through appropriate legislation and governance, sustainable financing and collaborative leadership for improvement;

Meso level: building capacity in both the paid and unpaid workforce through training, support, working conditions and opportunities for career development;

Micro level: establishing an effective digital infrastructure to enable effective care planning and monitoring, sharing of information between providers and use of assistive technologies.

We address how the system can be best organised across these different elements to enable empowerment, explaining how people who use services and other stakeholders are involved in co-creating/co-designing services. We consider issues related to building capability of the workforce and enabling innovation, including the adoption of technology enabled care solutions. In particular, we address the issue of workforce capacity: the profile and needs of carers, both family and formal (including migrant carers) and voluntary organisations.

DEVELOPMENT AND IMPROVEMENT OF LONG-TERM CARE THROUGH APPROPRIATE LEGISLATION AND GOVERNANCE, SUSTAINABLE FINANCING AND COLLABORATIVE LEADERSHIP FOR IMPROVEMENT

Governance

Healthcare and social care services have traditionally had separate, often complex, governance arrangements distributed between health and social care sectors at national, regional and local government levels. Care and support may be provided by a mix of health and social care professionals from public sector, private for-profit providers, NGOs and independent not for profit providers, as well as informal carers and personal care assistants. The health system is responsible for the care provided by health professionals, while services related to supporting the care user in the activities of daily life are usually organised by the social sector. COVID-19 has raised awareness of the need to break down barriers between services and between formal and informal providers, and to promote collaboration between fragmented services and co-operation rather than competition. There is a growing call for integrated governance arrangements that enable long-term care to be planned, commissioned,



funded and provided as a continuum of health and social care services that include protection, prevention, treatment, care and support, rehabilitation and palliative and end of life care⁶⁶. This requires clarity of roles, effective relationships and both vertical integration between local, regional and national governments and horizontal integration across sectors and with the community and civil society. Governance arrangements should be participatory, creating opportunities for older adults and informal carers to be fully involved in long-term care policy and service development, and inclusive, addressing the inequities frequently experienced by women, migrant carers and underserved communities.

Arrangements to assure the quality of long-term care should be supported by regulatory frameworks and standards, requirements for accreditation, licensing or registration of professionals and providers⁶⁷. Legislation to combat ageism is particularly important in this context, as mounting evidence suggests ageist attitudes and practices are widespread in health and long-term care settings⁶⁸. This includes anti-age discrimination and equality legislation at international and national level, as well as policies at any governance level that promote dignity and equality of status for all individuals, irrespective of their age. The Global Report on Ageism⁶⁹ highlights the importance of promoting policies that aim to change attitudes and perceptions of older adults and strengthening human rights legislation and the enforceability of those rights. In an attempt to quantify national level achievement on policies recognizing and protecting the rights of older people, the Rights of Older people Index (ROPI) proposes a series of structural and process indicators grouped under 10 domains⁷⁰.

66 Lloyd-Sherlock P, Neto J, Comas-Herrera A, Redondo N. Re: Covid-19: why we need a national health and social care service. *BMJ*. 2020;369. doi:10.1136/bmj.m1465.

67 Coste S, Ces S (2019). Mapping long-term care quality assurance practices in the EU Summary Report. Brussels: European Commission - <https://op.europa.eu/en/publication-detail/-/publication/bd0899c2-3293-11ea-ba6e-01aa75ed71a1>

68 WHO 2021, Global report on ageism - <https://www.who.int/teams/social-determinants-of-health/demographic-change-and-healthy-ageing/combating-ageism/global-report-on-ageism>.

69 WHO 2021, Global report on ageism - <https://www.who.int/teams/social-determinants-of-health/demographic-change-and-healthy-ageing/combating-ageism/global-report-on-ageism>

70 Birta, M., Rodrigues, R., Zólyomi, E., Sandu, V. & Schulmann, K. (2019). From disability rights towards a rights-based approach to long-term care in Europe: Building an index of rights-based policies for older people. Vienna: European Centre for Social Welfare Policy and Research - <https://www.euro.centre.org/publications/detail/3514>



THE ROPI DOMAINS

Equal access to & affordability of care & support	Choice, legal capacity & decision-making capacity
Freedom from abuse & mistreatment	Life, liberty, freedom of movement & freedom from restraint
Privacy & family life	Participation & social inclusion
Freedom of expression, thought, conscience, beliefs, culture & religion	Highest standard of health
Adequate standard of living	Remedy & redress

Based on Birtha et al., 2019.

ROPI includes 35 structure and process indicator grouped under these 10 domains.

When applied to data from 12 European countries, the ROPI revealed generally higher levels of achievement on structural indicators than on process indicators, suggesting adopted legislation is not always reflected in the processes and practices that underpin the provision of social support services. Furthermore, the achievement of the same countries on outcome indicators for older adults (as measured by self-reported and statistical indicators) was considerably lower. Such gaps between structural and outcome measures indicate the effectiveness of policies and legislation to promote the rights of older adults crucially hinges on the implementation of strong monitoring and enforcement mechanisms and the dedication of appropriate resources for implementation. In this spirit, mechanisms for monitoring and reporting on quality of long-term care should include assurance of safeguarding and protection against all forms of ageism, elder abuse and neglect in all care settings. How to measure the quality and performance of long-term care are discussed in more detail in Chapter 5.

Sustainable Funding

Financing long-term care systems encompasses a spectrum of activities that include designing policies and eligibility for cash or in-kind benefits and out of pocket contributions, raising and pooling finances, and commissioning and purchasing long-term care services. Funding for long-term care is generally a mix of public, private and citizen funding variably generated at national, regional or municipal levels through general taxation, mandatory social insurance, voluntary private insurance and cost-sharing arrangements⁷¹. Different models of cost-sharing or co-payments, i.e. the contribution by recipients to the costs of the long-term care services they receive, are applied, even in the most developed welfare states. Traditionally

⁷¹ Rodrigues R (2015). Long-term care – the problem of sustainable financing. Luxembourg: European Commission.



most provider contracts have favoured volume and cost-effectiveness over quality of care and quality of life outcomes. More needs to be done to adequately incentivise the market and reward long-term care providers for quality, collaboration, continuity and coordination of care⁷².

European countries differ in the funding of their health care systems and this is reflected in long-term care funding. Some countries are more generous than others, funding a larger part of long-term care costs. The three main sources of funding are taxation, long-term care insurance and out-of-pocket payments or private arrangements⁷³. Examples range from mandatory long-term care insurance in Germany to fully tax funded in Austria, or a mix of both in the case of France and Netherlands.

Leadership for improvement

Integrating care requires collaborative and distributed leadership at all levels – from system and professional leadership models that value older people, carers, providers and the community as equal partners, to distributed leadership that empowers local managers and practitioners as change agents who embrace opportunities from emerging social, technical and workforce innovation. This has implications for how we recruit, train and support the long-term care workforce to continually improve services in collaboration with older people, carers, professional groups, providers and decision makers⁷⁴.

Tubbemoddeln: Innovative participative management model in Swedish nursing homes

Allowing staff and residents to manage the nursing home together and giving older adults the feeling that it is their own home is the basic idea of the Tubbemoddeln, an innovative bottom-up management model originally set up in the nursing homes of the municipality of Tjörn, Sweden. Inspired by the vision of the Danish teacher Tyra Frank and following her motto 'As long as one is alive, one should live', the Swedish model is based on a genuine participative management process which include nursing home residents at all levels in the planning and running of their own living conditions. The Tubberödshus retirement home, for instance, is run and organised by the residents, with the support of the staff, not the other way round. This type of management reflects Sweden's specific contexts and needs. Indeed, the country is faced with a shortage of health professionals

72 King D, Zigante V (2020). Quality assurance practices in long-term care in Europe. Emerging evidence on care market management. Brussels: Publications Office of the European Union - <https://op.europa.eu/en/publication-detail/-/publication/bd0899c2-3293-11ea-ba6e-01aa75ed71a1>

73 OECD (2021), Public and Private Sector Relationships in Long-term Care and Healthcare Insurance, www.oecd.org/finance/insurance/long-term-care-health-care-insurance-in-oecd-and-other-countries.htm

74 The Health Foundation, The Habits of an improver, 2015 - <https://www.health.org.uk/publications/the-habits-of-an-improver>



and nurses in certain regions, such as Tjörn. The aim of Tubbemoddeljen is to ensure a model that fosters maximum residents' involvement to provide quality care with the available staff.

HUMAN ENABLERS

Building capacity in both the paid and unpaid workforce through training, support, working conditions and opportunities for career development

Workforce capacity

Workforce planning is a critical part of the cycle of population needs assessment, strategic commissioning of services and financial planning. To be comprehensive, workforce planning should consider data on capacity and skills from professional bodies and provider organisations alongside information on informal carers, intelligence from national and local labour markets, and insights from the education sector about the future workforce. This is a complex challenge compounded by a dynamic labour market, differing challenges in rural and urban areas, and a need to forecast future supply and demand as well as the emerging need for new skills. Projections should consider the implications of redesigning professional roles, adopting technology enabled care and new ways of providing support at home and closer to home. Robust assessments of the demand for care and the intensity and acuity of needs are required to plan sufficient capacity that guarantees safety and positive outcomes for individuals and their carers.

Informal carers

Most long-term care is provided by informal carers, often spouses and children, who provide care directly and help navigate and coordinate the interaction with formal care services⁷⁵. This care is highly valuable, but largely unrecognised and with limited access to training and support. As most informal care is undertaken by women, long-term care is a gender equality issue associated with lower rates of employment for women resulting in lower income, lack of pension contributions and higher rates of poverty in later life. Many informal carers became more isolated as their usual practical and social support was reduced or suspended during the pandemic⁷⁶. In some countries, new helplines, virtual counselling and carer support groups have been established⁷⁷. However these supports have been accessed more readily by carers who have a higher socio-economic status and are digitally skilled.

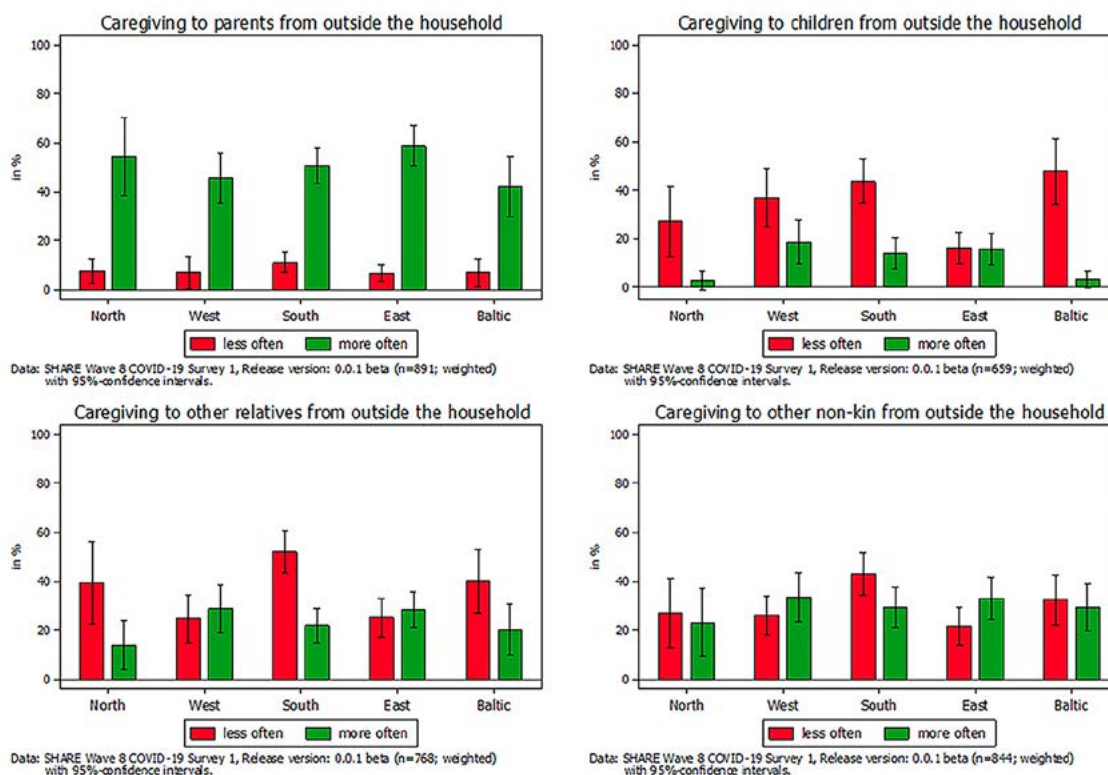
75 Eurocarers' analysis. Informal carers, left aside again? July 2020. <https://eurocarers.org/download/28249/>

76 Carers UK (2020a). Caring behind closed doors: Forgotten families in the coronavirus outbreak, April 2020. London: Carers UK - https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_pages_web_final.pdf, accessed 15 May 2020

77 Lorenz-Dant K. International examples of measures to support unpaid carers during the COVID-19 pandemic. International Long-Term Care Policy Network; 2020 - <https://ltccovid.org/country-reports-on-covid-19-and-long-term-care/>



FIGURE 5 - IMPACT OF COVID-19 EPIDEMIC ON INFORMAL CARE IN EU



Source: <https://www.frontiersin.org/article/10.3389/fpubh.2021.673874>

Domestic workers and personal care assistants

In several countries an increasing number of older adults and family carers are supported at home by domestic workers or personal care assistants. These may be recruited by the older person or family through cash for care schemes as an alternative to in-kind formal care services. Domestic workers or personal care assistants are often migrant workers largely unregulated and rarely supported by training and supervision. They are often employed through irregular contractual arrangements, sometimes on a live-in basis that greatly increases the risk of abuse and exploitation on both sides⁷⁸. The COVID-19 pandemic has worsened their living and working conditions: some have been fired by employers facing

78 Lamura G, Chiatti C, Barbabella F, Di Rosa M (2013). Migrant long-term care work in the European Union: Opportunities, challenges and main policy options. Filling the gap in long-term professional care through systematic migration policies. Berlin: National Institute of Health Science on Ageing, p. 40 - https://www.researchgate.net/profile/Mirko_Di_Rosa/publication/258859028_Migrant_long-term_care_work_in_the_European_Union_Opportunities_challenges_and_main_policy_options/links/00b495294678b43481000000/Migrant-long-term-care-work-in-the-European-Union-Op, accessed 15 May 2020



unexpected financial difficulties or who fear the worker may transmit the virus. Some care assistants have lost both their income and their home, and have been unable to return to their home country due to travel restrictions. There is an urgent need for reform to regulate this sector of the long-term care workforce and to improve their working conditions.

Working conditions

In many OECD countries, recruiting and retaining sufficient long-term care workers is a challenge driven by negative perceptions of the role, poor pay and reward, high workload and often stressful working environments.⁷⁹ The long-term care workforce is predominantly female and it is common for care workers to have zero-hour contracts and to work for multiple care providers⁸⁰. The lack of integration between providers makes it difficult for the workforce to move flexibly across the system as demands change, or to exploit opportunities for professional development and career progression in the sector. This is an issue especially for migrant workers, who often face difficulties in having their previous qualifications recognised.

The long-term care workforce should be managed in a fair, transparent and equitable manner and supported to stay safe and well in their working lives. Ideally, pay and conditions for comparable roles should be standardised across providers, including mandatory access to paid leave in the event of illness and other fair work opportunities available in other sectors. Many workers and informal carers have experienced significant trauma during the COVID-19 pandemic, with a negative impact on their mental health and wellbeing. The Quadruple Aim⁸¹ highlights the critical importance of workforce well-being for high quality care. There is a need to invest in adequate health protection and psychological support for wellbeing in long-term care services, alongside effective procurement policies and delivery chains for testing, hygiene and personal protective equipment for staff and family carers. Supply of health protection and infection prevention equipment should be supported by guidance and training for both care workers and family carers. The need for physical distancing and, if necessary, safe isolation may require adapting the physical environment of some long-term care facilities. As home care workers visit multiple homes, they also need, like those they care for, access to health protection support, equipment and training.

79 OECD (2020), *Who Cares? Attracting and Retaining Care Workers for the Elderly*, OECD Health Policy Studies, OECD Publishing, Paris - <https://doi.org/10.1787/92c0ef68-en>.

80 Women are well-represented in health and long-term care professions, but often in jobs with poor working conditions. In: *Gender equality*. Paris: Organisation for Economic Co-operation and Development; 2019 - <https://www.oecd.org/gender/data/womenare-well-represented-in-health-and-long-term-care-professions-but-often-in-jobs-with-poor-workingconditions.ht>, accessed 21 June 2020

81 Bodenheimer, T and Sinsky, C. From Triple to Quadruple Aim: Care of the Patient Requires Care of the Provider. *Annals of Family Medicine*, 2014; 12(6): 537–76. DOI: <https://doi.org/10.1370/afm.1713>



Training

Training is required to support the current and future long-term care workforce to have the knowledge, skills and confidence to deliver holistic assessments and care planning and to provide safe, effective and person-centred care and support that enhance the dignity and functional ability of older adults at home and in care homes. There are programmes for initial training and upskilling. The ratio of professionally qualified staff in the long-term care sector is usually lower than in healthcare services, yet the required skill set is increasingly diverse: from care-related competencies, communication and interpersonal skills to technical competencies in using equipment and embracing new health and information technologies⁸². While some long-term care facilities employ nurses, many lack support from suitably skilled health professionals to meet the changing acute, rehabilitative and palliative care needs of residents who have an increasingly complex mix of multiple physical, cognitive and sensory problems.

Most formal carers are not required to have qualifications before they enter employment. However they are required to complete vocational training within a defined period following registration. High quality learning and clearly defined qualification, accreditation and career development pathways have the potential to raise the status and attractiveness of long-term care work. Training, supervision, feedback and support to improve performance in their role should be available for all paid staff and for unpaid carers. Interdisciplinary training should include topics such as dementia, palliative care, nutrition, safeguarding, communication and emotional and psychological support. Training can draw on relevant competency frameworks such as WHO's core competencies for integrated care⁸³ and the European interprofessional capability framework for frailty⁸⁴. Delivery of training should be sensitive to levels of health literacy and digital inclusion of the workforce⁸⁵.

Education programmes to combat ageism and ableism in training for health and social care professionals

The Learning by Living Immersion Program at the University of New England College of Osteopathic Medicine in Maine, USA teaches medical students about life as a care home resident through firsthand experience. Students are given a faux health

- 82 EU Skills Panorama (2014) Skills for social care Analytical Highlight, prepared by ICF GHK and CEDEFOP for the European Commission
- 83 Langins M, Borgermans L. Competent health workforce for the provision of coordinated/ integrated health services. Working Document. Copenhagen: WHO Regional Office for Europe; 2015 - https://www.euro.who.int/__data/assets/pdf_file/0010/288253/HWF-Competencies-Paper-160915-final.pdf
- 84 Roller-Wirnsberger et al. European Collaborative and Interprofessional Capability Framework for Prevention and Management of Frailty—a consensus process supported by the Joint Action for Frailty Prevention (ADVANTAGE) and the European Geriatric Medicine Society (EuGMS) Aging Clinical and Experimental Research - <https://doi.org/10.1007/s40520-019-01455-5>
- 85 Moreira, L. (2018), "Health literacy for people-centred care: where do OECD countries stand? OECD Health Working Papers, No. 107, OECD Publishing, Paris - <https://dx.doi.org/10.1787/d8494d3a-en>

status, diagnosis, and treatment plan, and are cared for in a care home for 10 days as if they are an actual resident. The program fosters understanding and empathy and informs students of the real life implications of care treatment plans.

Improving attractiveness of the the social care sector

The FORESEE Project focuses on the impact of COVID-19 on the social services sector and aims to increase the attractiveness of the social care sector by tackling issues faced by the care workforce through social dialogue. The project, set to run from February 2021 to February 2023, involves 13 partners from 9 EU countries and is co-funded by the European Commission. The project includes a training program on social dialogue piloted in Greece, Romania, Poland, and Portugal, and three national events to discuss strategies and recommendations for more attractive social services.

Mitigating care brain drain in Europe

Caritas Switzerland has program called Caritas Care, where caregivers from Eastern European countries can participate in a work exchange for 6 weeks at a time in Switzerland. Caregivers are given language and cultural training in their origin countries at Caritas, and then can participate in this circular model of care where they work for 6 weeks in Switzerland, return to their home country for 3 months (and continue working for Caritas in their home country) and then can return to Switzerland again for 6 weeks. Caregivers can participate in this program long term. The aim is to mitigate the “care drain” of workers to Western European countries by providing a means for them to work in a western European country periodically and legally for higher pay.

ESTABLISHING AN EFFECTIVE DIGITAL INFRASTRUCTURE

Digital communication and information systems

Continuity and coordination of care and monitoring of quality are enabled by interoperable ICT systems and processes to store, exchange and communicate information between different health and social care providers. Health and social care data are usually collected under separate systems, leading to difficulties linking data for the same individual. Few countries have information and monitoring systems that include individual-level data about the characteristics, needs and outcomes of people who use formal long-term care services, and about the type and quality of care that they are receiving. Where individual-level data are available, they generally cover only those who use publicly funded services. They may include information on chronic disease prevalence and medications, but less often include granular information on functional ability and levels of care dependence and carer support, which are required for effective population health planning and targeting of resources. The ICT infrastructure should enable long-term care to be integrated with strong,



community-oriented primary care⁸⁶ and with risk prediction tools to target health promotion, self-management and proactive preventative interventions that aim to improve population health and health equity⁸⁷.

Online tool to better understand older people's preferences in relation to long-term care

"What Matters to Me" is an online tool used for eliciting preferences from older adults about their long-term care and promoting conversation between the older user, physicians, and family carers. Researchers at the Maastricht University Medical Center (The Netherlands) developed this tool with a user-centered design in which the older adult end user influences the design process. To facilitate elicitation of preferences, questions are organized into 5 categories: health; family and friends; living conditions; daily life; and finances. A pilot study with 71 users of the "What Matters to Me" tool was conducted and results showed satisfaction, user-friendliness, and promising application for health professionals, family carers, and older adults needing care.

Application to tackle inappropriate prescribing

The iSIMPATY project tackles the issue of inappropriate prescribing by training pharmacists to conduct medicine reviews and take a shared approach with managing multiple medications. The project is run by partners in Northern Ireland, Scotland, and the Republic of Ireland, and is funded by the European Commission until March 2023. The project has created an "Managing Multiple Medicines" app for providers and patients currently in use in Scotland.

An international interdisciplinary Special Interest Group on Appropriate Polypharmacy and Adherence is facilitated by the International Foundation for Integrated Care.

Assistive technologies

COVID-19 has accelerated the adoption, uptake and normalisation of digital solutions to support health protection messaging, contact tracing, self-care, remote and mobile monitoring of symptoms and chronic disease, video enabled triage and consultations, remote working and enhanced information sharing. These developments build on the established telecare and assistive living technologies addressed in Chapter 3. Adoption of these technologies may pose specific challenges for many formal and informal carers who

86 Declaration of Astana - Global Declaration on Primary Health Care, 2018 - www.who.int/docs/default-source/primary-health/declaration/gcphc-declaration.pdf

87 Michael Marmot, Jessica Allen, Tammy Boyce, Peter Goldblatt, Joana Morrison (2020) Health equity in England: The Marmot Review 10 years on. London: Institute of Health Equity



are digitally excluded or need to be upskilled before they can fully exploit the potential of these new technologies for the benefit of the people they support⁸⁸.

The **UN Independent Expert on the enjoyment of all human rights by older persons** published a report in July 2017 examining the **impact of assistive and robotics technology, artificial intelligence and automation on the human rights of older persons**. The report provides an overview of the existing international and regional human rights standards and analyses the potential and challenges of the use of such technology for the enjoyment by older persons of their human rights. This analysis is followed by the Independent Expert's conclusions and recommendations aimed at assisting States in designing and implementing appropriate and effective frameworks to ensure the promotion and protection of the rights of older persons.

Key elements of this report are:

- Need for assistive technologies to foster autonomy and independence but without increasing social exclusion.
- Give older persons the choice to accept or refuse the technological support proposed to them.
- Older persons shall keep control over information that will be collected through technologies, and these technologies should be flexible enough ('self-learning') to adapt to older persons' preferences and lifestyles.
- The use of these technologies should not replace human care and do not substitute States' obligation to support older people by creating the necessary structures, services and allocating budget for long-term care.
- Equal access to assistive technologies should be ensured to all older adults regardless of their level of income, ethnic or cultural origin, religion, physical or mental ability, gender, or place of residence.
- Assistive technologies and robotics should support older persons' participation in social and public life.
- Further exploring appropriate mechanisms to monitor these technologies - in particular robots.
- Need to explore further the substantive elements of a right to assisted living in old age, focusing on the intersection of ageing and disability and/or on how the right to care and support can be protected on the basis of a life-cycle approach.

The full report is available [here](#).

88 OECD (2016), "Skills for a Digital World, Policy brief on the future of work Ministerial Meeting on the Digital Economy Background Report", OECD Digital Economy Papers, Vol. 250,- <https://doi.org/10.1787/5jlwz83z3wnw-en?>

Kispeter, E. (2018), *What digital skills do adults need to succeed in the workplace now*, Warwick, Institute for Employment Research.



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CHAPTER 5. LONG-TERM CARE SYSTEM PERFORMANCE: HOW TO ACHIEVE HIGH QUALITY, AFFORDABLE CARE

Through the adoption of the European Pillar of Social Rights in 2017⁸⁹, all EU Member States have recognized “Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services (Principle 18. Long-term care)”. Fulfilment of this right now crucially hinges on the resolve of each European country to adopt and implement effectively policies that support the development of equitable and high performing long-term care systems. The challenge ahead to ensure the empowerment of older adults is (1) sufficient care capacity to cover population needs, while (2) ensuring care is equitably distributed according to users’ care needs and (3) maintaining high quality of care provision, that reflects the preferences of users.

LONG-TERM CARE COVERAGE: CAPACITY AND AVAILABILITY

Deinstitutionalisation (i.e. the shift of care service provision from residential care institutions towards community-based settings) has been the hallmark of long-term care system development across Europe over recent decades. Underpinned by a shared understanding that home- and community- based care provision reflects user preferences, is aligned with a rights-based approach to care and is economically more sustainable, European countries have pursued policies to reduce reliance on residential care provision⁹⁰. Progress however has been very uneven, with southern and eastern European countries lagging far behind those in the north and west⁹¹. The share of older adults (65+) who use long-term care services in their own homes varies between 13% in the Netherlands (32% of 80+ population), 12% in Sweden (30% for 80+ population), 3.5% in Estonia (6% of 80+ and 0.7% in Portugal (1.4% of 80+) ⁹².

Insufficient development of formal care services generates significant pressure on communities and families to compensate for capacity gaps through informal care provision.

89 European Pillar of Social Rights, 2021, https://ec.europa.eu/info/strategy/priorities-2019-2024/economy-works-people/jobs-growth-and-investment/european-pillar-social-rights_en

90 S. Ilinca, R. Rodrigues, K. Leichsenring, “From care in homes to care at home: European experiences with (de)institutionalisation in long-term care”, European Centre for Social Welfare and Dec. 2015

91 Spasova, S., Baeten, R., Coster, S., Ghailani, D., Peña-Casas, R. and Vanhercke, B. (2018). Challenges in long-term care in Europe. A study of national policies, European Social Policy Network (ESPN), Brussels: European Commission - <https://op.europa.eu/en/publication-detail/-/publication/c12c65f9-c6b6-11e8-9424-01aa75ed71a1/language-en>

92 OECD Health data, 2014 - <https://www.oecd.org/els/health-systems/oecd-health-statistics-2014-frequently-requested-data.htm>



Informal care remains the main source of support for older adults across Europe. Estimates place the contribution of families, friends and communities at 80% of all long-term care provided⁹³, with an expected monetary value that far exceeds public expenditure on long-term care services and cash benefits combined⁹⁴.

Informal care provision rates vary significantly across countries. According to recent data from the European Quality of Life Survey (2016), approximately 10% of the total population is providing informal care in Romania, Austria, Ireland and Sweden, while the share reaches over 25% in Malta, Belgium or Greece. A disaggregation by gender and age reveals a well-established, common European pattern: women are significantly more likely to provide informal care and particularly among them middle-aged and older women.⁹⁵ Recent and projected changes in population structure, workforce mobility and migration patterns, labor market attachment of women, further increases of retirement age, as well as changes in cultural norms are all conspiring to create what is described as a crisis of familial care availability in the future⁹⁶.

EQUITABLE DISTRIBUTION OF CARE

Gaps in care provision lead to unmet or under-met care needs for those older adults who cannot access resources, leading to a consequent increase in the risk of negative psychosocial and health outcomes. As evidence for unmet care needs among older adults in Europe has been mounting in recent years⁹⁷, it is becoming increasingly apparent that the patterns

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- 93 Hoffmann, F., & Rodrigues, R. (2010). *Informal Carers: Who Takes Care of Them?* Policy Brief 4/2010, Vienna: European Centre - [https://www.scirp.org/\(S\(351jmbntv-nsjt1aadkposzje\)\)/reference/referencespapers.aspx?referenceid=2910964](https://www.scirp.org/(S(351jmbntv-nsjt1aadkposzje))/reference/referencespapers.aspx?referenceid=2910964)
- 94 Chari et al., 2015; Paraponaris et al., 2012; Rothgang et al., 2006
- 95 Zigante, V. (2018). *Informal care in Europe: Exploring Formalisation, Availability and Quality*, Brussels, European Commission: Directorate-General for Employment, Social Affairs and Inclusion - <https://op.europa.eu/en/publication-detail/-/publication/96d27995-6dee-11e8-9483-01aa75ed71a1>
- 96 Spasova, S., Baeten, R., Coster, S., Ghailani, D., Peña-Casas, R. and Vanhercke, B. (2018). *Challenges in long-term care in Europe. A study of national policies*, European Social Policy Network (ESPN), Brussels: European Commission - <https://op.europa.eu/en/publication-detail/-/publication/c12c65f9-c6b6-11e8-9424-01aa75ed71a1/language-en>
- Pickard, L. (2015). A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032. *Ageing and Society*, 35: 96-123
- 97 Bien B, McKee KJ, Döhner H, Triantafyllou J, Lamura G, Doroszkiewicz H, Krevers B, Kofahl C. Disabled older people's use of health and social care services and their unmet care needs in six European countries. *Eur J Public Health*. 2013 Dec;23(6):1032-8. doi: 10.1093/eurpub/cks190. Epub 2013 Jan 18. PMID: 23334818.
- Herr M, Arvieu JJ, Aegerter P, Robine JM, Ankri J. Unmet health care needs of older people: prevalence and predictors in a French cross-sectional survey. *Eur J Public Health*. 2014 Oct;24(5):808-13. doi: 10.1093/eurpub/ckt179. Epub 2013 Nov 27. PMID: 24287029; PMCID: PMC4168041.
- Abdi S, Spann A, Borilovic J, de Witte L, Hawley M. Understanding the care and support needs of older people: a scoping review and categorisation using the WHO international classification of functioning, disability and health framework (ICF). *BMC Geriatr*. 2019 Jul 22;19(1):195. doi: 10.1186/s12877-019-1189-9. Erratum in: *BMC Geriatr*. 2020 Jan 22;20(1):23. PMID: 31331279; PMCID: PMC6647108.



of unmet care closely follow those of well-established social stratification measures. Women are more likely to provide informal care, often to a spouse, but also more likely to rely on formal care provision themselves. Women also account for the vast majority of residential care users, a gender gap that cannot be fully explained by differential survival rates but that is closely tied with gender differences in widowhood, health status and social position⁹⁸. Socio-economic status, whether measured by income or educational achievement also plays an important role. Analyses of comparative survey data across Europe reveal poorer people are more reliant on informal care provision, a result that is indicative of remaining barriers in access to formal care services⁹⁹. Even after differences in care needs between socio-economic groups are accounted for, use of informal is strongly skewed towards lower income groups in the majority of European countries.

Affordability of long-term care: a challenge in many countries

The challenge of ensuring equitable access to long-term care in Europe is closely linked to the affordability of care services – that is, the ability of older adults with care needs to finance the costs associated with often intensive and long-lasting care. Unlike health care systems, where the principles of universal insurance and access at the point of use are ensuring high levels of financial protection, long-term care use is often capped (i.e., entitlement to a limited quantity of publicly financed services) and subject to considerable out-of-pocket co-payments¹⁰⁰. Consequently, the level of financial risk that people face if they develop long-term care needs is very high and households are forced to rely on accumulated wealth, if such is available, in order to finance needed care.

In a recent study, the OECD estimates the cost of home-based care for older adults with severe care needs is 2.5 times higher than medium income, and more than 3.5 times higher than the average income in the lowest income groups¹⁰¹. If the costs of needed care

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- 98 Einiö, E. K., Guilbault, C., Martikainen, P., & Poulain, M. (2012). Gender Differences in Care Home Use among Older Finns and Belgians. *Population-E*, 67(1), 71-96.
Huber, M./Rodrigues, R./Hoffmann, F./Gasior, K. and B. Marin (2009) Facts and Figures on Long-term Care – Europe and North America. Vienna: European Centre for Social Welfare Policy and Research.
- 99 S. Ilinca, R. Rodrigues, A.E. Schmidt (2017), « Fairness and Eligibility to Long-Term Care: An Analysis of the Factors Driving Inequality and Inequity in the Use of Home Care for Older Europeans”, *International Journal of Environmental Research and Public Health* 14(10):1224, DOI:10.3390/ijerph14101224
R. Rogrigues, S. Ilinca, A.E. Schmidt, “Income-rich and wealth-poor? The impact of measures of socio-economic status in the analysis of the distribution of long-term care use among older people, October 2017, *Health Economics* 27(10), DOI:10.1002/hec.3607
- 100 OECD, 2020 - <https://www.oecd.org/health/health-systems/social-protection-for-older-people-with-ltc-needs.htm>; Spasova, S., Baeten, R., Coster, S., Ghailani, D., Peña-Casas, R. and Vanhercke, B. (2018). Challenges in long-term care in Europe. A study of national policies, European Social Policy Network (ESPN), Brussels: European Commission - <https://op.europa.eu/en/publication-detail/-/publication/c12c65f9-c6b6-11e8-9424-01aa75ed71a1/language-en>
- 101 OECD, 2020 – Spending on long-term care - <https://www.oecd.org/health/health-systems/Spending-on-long-term-care-Brief-November-2020.pdf>



far surpass an individual's ability to pay from their regular income, they have the option of either using household wealth to cover the expenditure or going without needed care. As a consequence, older adults living in households with little or no accumulated wealth are placed at a disadvantage. Even those older adults who can rely on medium incomes and an average level of wealth accumulation may have to face the possibility of impoverishment due to the onset of severe care needs. The costs associated with care for severe needs are so high that it is estimated that only the richest 10% of the population could expect to cover them from income, in the absence of publicly funded benefits¹⁰².

It is important to also note that out-of-pocket payments and financial protection vary across types of long-term care services and types of provider (i.e. public, for-profit, non-profit). Public financing for care in residential settings is considerably higher than that for community and home-based care¹⁰³. In fact, in most European countries, publicly funded residential care acts as the final safety net for older individuals with care needs¹⁰⁴. Considering that co-payments for home-based care can easily surpass the ability to pay of low income older adults even at a moderate level of care needs, it becomes apparent that the opportunity to age in place and with dignity is not afforded to all individuals equally. Similarly, as the role of market-based care provision increases, richer individuals are increasingly more able to access needed care in a timely manner and at higher quality standards, an opportunity that is not afforded to lower socio-economic status groups.

Regional inequalities in care and decentralization

Population ageing over the last decades has disproportionately affected the rural areas of Europe. The share of older adults living in rural and remote localities is larger than national averages (see chapter 2 for further details), placing local communities under increased pressure to provide necessary support. However, the demographic imbalance between predominantly urban and rural areas is not reflected in the territorial distribution of long-term care services. On the contrary, long-term care providers are overwhelmingly concentrated in or around densely populated areas, indicative of a long-standing focus on efficiency of supply processes rather than of an orientation towards prioritizing demand-side characteristics in the development of long-term care.

The unbalanced distribution of formal care providers is closely linked to the decentralized governance structures that are common in long-term care. In most European countries long-

102 OECD, 2020 – Spending on long-term care - <https://www.oecd.org/health/health-systems/Spending-on-long-term-care-Brief-November-2020.pdf>

103 OECD, 2020 – Spending on long-term care - <https://www.oecd.org/health/health-systems/Spending-on-long-term-care-Brief-November-2020.pdf>

104 Muir, T. (2017), "Measuring social protection for long-term care", OECD Health Working Papers, No. 93, OECD Publishing, Paris, <https://doi.org/10.1787/a411500a-en>.

term care systems are decentralized, meaning that responsibilities for financing, organizing and providing care are held at the regional or local level. Less national control over long-term care system functions allows local authorities to design and implement locally appropriate solutions to locally defined problems. However, local variability also has considerable drawbacks, in that it creates conditions that can reinforce and exacerbate regional inequalities.

When availability of services is conditioned by the size of local budgets, smaller and less industrialized localities are placed at a considerable disadvantage. Similarly, local control over the definition of eligibility criteria for publicly funded long-term care undermines the principle of horizontal equity – i.e. the equal treatment of equals; people with the same levels of care needs receive the same amount of care. Financial transfers between governance levels or nationally set eligibility and entitlement rules, which are common in social insurance based European long-term care systems, can alleviate regional inequalities. However, they do little to correct the effect of the same adverse incentives on the development of private for-profit care provision. Sustained efforts to increase provider competition and create long-term care markets that might operate more efficiently than publicly run systems (also described as the privatization and marketization of care) are encouraging private providers to seek more affluent care markets, where stable demand and higher willingness to pay for care services can be expected. As a result, the significant rise in private care provision has alleviated care coverage gaps primarily in urban regions, while rural communities remain severely under-served.

RuralCare is a European innovation project in social services consisting of the design, testing and evaluation of an innovative systemic approach, for the provision of integrated long-term care, adapted to people living in rural areas depending on their values, desires and individual preferences.

The project tests a multilevel partnership for the provision of care, including public and private actors and coordination of social and health services at local, regional and national levels, with the participation of the users, with the aim to address the challenges of accessibility, affordability, quality and sustainability in unpopulated rural areas and thus make it easier for people to stay at home, with a support plan appropriate to their life project. Based in Spain, Castilla y Leon with the partnership of ESN (European Social Network).

MEASURING THE QUALITY OF CARE

Care provision also needs to ensure the services provided are responsive to the individual's needs, delivered at the right time and provided by staff with relevant professional and interpersonal skills – or in other words that the quality of the care is appropriate.



Measuring and improving the quality of long-term care is a key objective for policy makers and is an issue of international concern¹⁰⁵. With an ageing population, limited financial resources, a diminishing workforce and a general focus on servicing the individual care-consumers and their carers, long-term care provision should accommodate many demands and requirements.

However, due to its multidimensional and elusive nature, quality of care is a notoriously difficult concept to define¹⁰⁶. According to Malley & Fernandez (2010), the complexity of capturing quality of long-term care is due to three main factors:

- Performance of social care services are individually experienced and thus difficult to entangle, measure, count or verify;
- social care services are labour intensive and typically vary significantly from service provider to service provider, between different people who receive services and even from day to day, with changing needs;
- consumption and provision of services are simultaneous and inseparable, for which reason both the person receiving care and the care provider influence the quality of the service provided.

One could expect the quality of long-term care to reflect clinical and professional standards in the sector, with staff holding the competences necessary to maintain or improve outcomes for people who receive long-term care, e.g. reducing the incidence of undesired outcomes such as pressures ulcers¹⁰⁷. However, relational aspects, such as the relationship to and social contacts with staff, are also of the utmost importance in long-term care¹⁰⁸.

Appropriate staff-user ratios and continuity of staff at point of care matter greatly. Other more procedural quality aspects are also important, such as individualised assessments, care and support planning and personalised care. This is beneficial in the prevention of falls

105 Murakami, Y. and F. Colombo (2013). "Regulation to improve quality in long-term care." OECD/European Commission, *A Good Life in Old Age*: 143-176.

106 Sheryl Zimmerman, PhD, Ann L. Gruber-Baldini, PhD, Philip D. Sloane, MD, MPH, J. Kevin Eckert, PhD, J. Richard Hebel, PhD, Leslie A. Morgan, PhD, Sally C. Stearns, PhD, Judith Wildfire, MPH, Jay Magaziner, PhD, MS Hyg, Cory Chen, Thomas R. Konrad, PhD, *Assisted Living and Nursing Homes: Apples and Oranges?*, *The Gerontologist*, Volume 43, Issue suppl_2, April 2003, Pages 107–117, https://doi.org/10.1093/geront/43.suppl_2.107

107 Malley, J., & Fernández, J.-L. (2010). *Measuring Quality in Social Care Services: Theory and Practice*. *Annals of Public and Cooperative Economics*, 81, 559-582. <https://doi.org/10.1111/j.1467-8292.2010.00422.x>

108 Rosalie A. Kane, DSW, *Long-Term Care and a Good Quality of Life: Bringing Them Closer Together*, *The Gerontologist*, Volume 41, Issue 3, 1 June 2001, Pages 293–304, <https://doi.org/10.1093/geront/41.3.293>
Murakami, Y. and F. Colombo (2013). "Regulation to improve quality in long-term care." OECD/European Commission, *A Good Life in Old Age*: 143-176



and reduction of side effects of chronic conditions, as well as in the improvement of older people's functional ability and wellbeing¹⁰⁹.

A useful and often-used approach to operationalise and measure quality of care is Donabedian's division of quality into structures, processes and outcomes (See Box below¹¹⁰).

Structural quality refers to the organisational characteristics, material resources and human resources in the system that are required to attain the required standards. Indicators can encompass items such as availability of basic equipment, staff (e.g., user-staff ratios, professional mix, education and training); characteristics of the facility (e.g., size and accreditation) and the composition of the cohort who are receiving care (age, gender, caseload and payer mix).

Process quality refers to the actions required to attain the standards, such as planning, needs assessment, execution, integration of services, monitoring and sanctioning of overuse/underuse of care and poor technical performance.

Outcome indicators of quality are often of a clinical nature and include objective outcomes, such as mortality rate, number of accidents or adverse events, changes in cognitive or physical functioning, changes in health status and conditions as well as subjective measures on QoL or ratings of the quality of the services.

Quality indicators in community care, based on Donabedian

Structure measures: Input measures reflecting attributes of the service/provider and concern the organizational characteristics, material resources or human resources.

Process measures reflect the way the systems and processes work to deliver the desired outcome

Outcome measures reflect the impact on the user and demonstrate the end result of care and whether it has ultimately achieved the aim(s) set.

109 Suhonen, Riitta & Välimäki, Maritta & Leino-Kilpi, Helena. (2008). A review of outcomes of individualised nursing interventions on adult patients. *Journal of clinical nursing*. 17. 843-60. 10.1111/j.1365-2702.2007.01979.x.

110 Donabedian, A. (1980). "The Definition of Quality and Approaches to Its Assessment" Ann Arbor: Health Administration Press: 8-11



User satisfaction and outcomes

There has been a tendency to shift the measurement of care performance from process to (user-reported) outcome measures¹¹¹. However, there is no set universal standard for indicators measuring users' outcomes. The values relating to the quality of life of vulnerable people have often been absent from regional or national quality systems. This is partially due to the difficulty in measurement. However, one way to measure quality is to apply user satisfaction measures. For instance, the European Quality of Life Survey (2016) reports how users of long-term care services across a number of European countries rate various aspects of service provision. Users include direct and indirect users, where the latter also include family members and other persons close. Generally, users of long-term care services are more critical of the quality of the services than are users of all other public services, such as childcare, public transport, and the education system¹¹². For instance, across all countries users of long-term care services give an average score of 5.7 to long-term care but 6.9 for the health care services. Country differences are substantial. For instance, users of long-term care give the lowest ratings in Bulgaria and Greece (4.4) and highest in Malta and Luxembourg (7.7). While there is generally a social gradient in the use of both informal and formal care, this is less so in regards to user ratings of long-term care services, at least when compared to other social and health care services where there are larger differences between user ratings. Also, the user ratings seem particularly affected by differences in availability and access to services, rather than for instance differences in health and frailty of the older population¹¹³.

Other ways of reporting how users perceive the services is to apply standardized ways of measuring quality of life. These include measurement such as WHO-Five Well-being Index (WHO-5) or EuroQoL-5D which is more health related¹¹⁴. A more appropriate outcome measure focusing on care related quality of life, is The Adult Social Care Outcomes Toolkit (ASCOT) measure. This is the only measure focusing specifically on the areas of quality of life that can reasonably be attributed to social care services. The measure encompasses 8 distinct domains of social care related quality of life (see Figure 6). These domains cover the basic (personal cleanliness and comfort, accommodation cleanliness and comfort, food and drink, and feeling safe) and higher order (social participation, occupation, and control over

111 Joling, Karlijn & Van Eenoo, Liza & Vetrano, Davide & Smaardijk, Veerle & Declercq, Anja & Onder, Graziano & Hout, Hein & van der Roest, Henriëtte. (2018). Appendix 2 List of Quality Indicators.

112 Eurofound, European Quality of Life Survey, 2016 - <https://www.eurofound.europa.eu/surveys/european-quality-of-life-surveys/european-quality-of-life-survey-2016>

113 Eurofound, European Quality of Life Survey, 2016 - <https://www.eurofound.europa.eu/surveys/european-quality-of-life-surveys/european-quality-of-life-survey-2016>

114 Kate Goodrich, Edward Garcia, Patrick H. Conway, A History of and a Vision for CMS Quality Measurement Programs, The Joint Commission Journal on Quality and Patient Safety, Volume 38, Issue 10, 2012, Pages 465-AP1, ISSN 1553-7250, [https://doi.org/10.1016/S1553-7250\(12\)38062-8](https://doi.org/10.1016/S1553-7250(12)38062-8)



daily life) aspects of social care related quality of life (SCRQoL). The final domain, dignity, differs from the other domains, reflecting the impact of the care process on how people feel about themselves. As a recent development ASCOT can now also be used to measure SCRQoL for the informal carer¹¹⁵.

FIGURE 6 – ASCOT DOMAINS

DOMAIN TITLE	DOMAIN DESCRIPTION
Control over daily life	The service user can choose what to do and when to do it, having control over his/her daily life and activities
Personal cleanliness and comfort	The service user feels he/she is personally clean and comfortable and looks presentable or, at best, is dressed and groomed in a way that reflects his/her personal preferences
Food and drink	The service user feels he/she has a nutritious, varied and culturally appropriate diet with enough food and drink he/she enjoys at regular and timely intervals
Personal safety	The service user feels safe and secure. This means being free from fear of abuse, falling or other physical harm and fear of being attacked or robbed
Social participation and involvement	The service user is content with their social situation, where social situation is taken to mean the sustenance of meaningful relationships with friends and family, and feeling involved or part of a community, should this be important to the service user
Occupation	The service user is sufficiently occupied in a range of meaningful activities whether it be formal employment, unpaid work, caring for others or leisure activities
Accommodation cleanliness and comfort	The service user feels their home environment, including all the rooms, is clean and comfortable
Dignity	The negative and positive psychological impact of support and care on the service user's personal sense of significance

In the evaluation of outcomes of community care, a number of goal-based measures are also often applied. One such example is the individualised Canadian Occupational Performance Measure (COPM)¹¹⁶. It is a client-centered instrument designed to identify the occupational performance problems experienced by the user. It allows the user to establish

115 Batchelder, Laurie & Malley, Juliette & Burge, Peter & Lu, Hui & Saloniki, Eirini-Christina & Linnosmaa, Ismo & Trukeschitz, Birgit & Forder, Julien. (2019). Carer Social Care-Related Quality of Life Outcomes: Estimating English Preference Weights for the Adult Social Care Outcomes Toolkit for Carers. *Value in Health*. 22. 10.1016/j.jval.2019.07.014.
Full toolkit and associated guidance: www.pssru.ac.uk/ascot

116 <http://www.thecopm.ca/learn/>



goals for the service intervention and to return to these and evaluate whether they have been achieved. Areas of everyday living explored during the interview include self-care, productivity or leisure. The COPM is for instance often used in reablement in home care services, an enabling approach that aims to support older adults to maximise their competencies to manage their everyday life as independently as possible¹¹⁷, where one of the components is to develop a goal-oriented treatment plan¹¹⁸.

Quality monitoring and assurance

A particular focus should be given to systems which can help monitoring and evaluating the quality of the services delivered. While the United States has been in the forefront of the development of systems for quality measurement and assurance of long-term care, European countries have been lagging behind developing such systems or processes¹¹⁹. In Europe, interest in developing quality assurance is more recent, but a set of prerequisites for ensuring quality may include shared vision of stakeholders, aims of quality management, clear responsibility, aspects of service delivery to be addressed, costs and cost-effectiveness and involvement of staff and users¹²⁰.

With regards to service quality, many countries are looking into general quality assurance systems. This would often involve the registration of service providers, regular reports by providers against nationally agreed standards and the inspection of service facilities and deliveries.

A number of quality assurance systems have been developed at the European level including EQUASS (European Quality in Social Services)¹²¹, E-Qalin¹²², ISO and the recent Voluntary European Quality Framework for Social Services, developed by the Social Protection Committee (SPC). Service providers are advised to have their own quality management system installed in-house. The reporting of such quality assurance systems can be used to inform providers about the level of performance and where improvements are needed. Poor

117 Aspinal, F, Glasby, J, Rostgaard, T, Tuntland, H and Westendorp, RG (2016) New horizons: reablement – supporting older people towards independence. *Age & Ageing* 45, 574–578.

118 Metzeltin, S. F., Rostgaard, T., Parsons, M., & Burton, E. (2022). Development of an internationally accepted definition of reablement: a Delphi study. *Ageing & Society*, 42(3), 703-718. [PII S0144686X20000999]. <https://doi.org/10.1017/S0144686X20000999>

119 Nies, H., K. Leichsenring, R. Veen, R. Rodrigues, P. Gobet, L. Holdsworth, S. Mak, E. Hirsch, D. M. Repetti and M. Naiditch (2010). "Quality Management and Quality Assurance in LongTerm Care European Overview Paper."

120 Nies, H., K. Leichsenring, R. Veen, R. Rodrigues, P. Gobet, L. Holdsworth, S. Mak, E. Hirsch, D. M. Repetti and M. Naiditch (2010). "Quality Management and Quality Assurance in LongTerm Care European Overview Paper."

121 For more information: <https://equass.be/>

122 For more information : <https://www.ean.care/en/education/quality-management-system-e%E2%80%91qalin>

performance should not necessarily mean end of funding though. For instance, Surrey County Council (UK) provides grants to providers who have performed poorly in national inspections, in order to help them to improve their services¹²³.

On the basis of the SPC Framework, a European coalition led by AGE Platform Europe delivered, in 2012, a European Quality Framework for Long-term care services. This framework identified 11 quality principles:

- Respectful of human rights and dignity
- Person-centred
- Preventative and rehabilitative
- Available
- Accessible
- Affordable
- Comprehensive
- Continuous
- Outcome-oriented and evidence-based
- Transparent
- Gender and culture-sensitive

European Quality Framework for Social Services, developed by the WeDO EU-funded project, source AGE Platform Europe, 2012

123 ESN, Developing Community Care, 2011 - https://www.esn-eu.org/sites/default/files/publications/2011_Developing_Community_Care_Report_EN.pdf

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CHAPTER 6. RETHINKING: LONG-TERM CARE POST-PANDEMIC

As we earlier discussed, the question of appropriate long-term care for Europe's ageing population has become more pressing in the light of the devastating mortality rates in 2020 caused by the SARS-CoV-2 virus, which led to the coronavirus disease pandemic – COVID-19.

The pandemic and subsequent containment measures implemented in all European countries highlighted the vulnerabilities within our long-term care systems. The high mortality rates, especially in long term care settings, and the high death rates among care workers, have brought many concerns to the fore. In particular that long-term care homes were both underprepared and underequipped to protect their residents.

Over reliance on residential care services, under-development, under-recognition and under-valuing of community-based care alternatives, lack of informal carer support programs, dominant focus on physical health, and the difficulties of ensuring safe working conditions for a strained long-term care workforce were clear issues. The pandemic also highlighted the deepening of both gender and socio-economic inequalities¹²⁴. Women, low-income individuals and marginalised groups were identified as being more exposed to the risk of contracting the virus and more vulnerable to the negative economic and mental health consequences of the subsequent containment measures.

The current landscape of long-term care services is complex and difficult for older persons, families and professionals to navigate¹²⁵. Fragmented services delivered by different providers may result in a negative care experience, and even harm, through failures of communication, inadequate sharing of information, poor medicines reconciliation, duplication of investigations, and avoidable hospital admissions or readmissions. People who have multiple chronic conditions and complex or frequently changing needs benefit greatly from continuity and coordination of care¹²⁶.

124 WHO 2021, Drawing light from the pandemic: A new strategy for health and sustainable development A review of the evidence, Edited by Professor Martin McKee - <https://apps.who.int/iris/handle/10665/345027>

Preventing and managing COVID-19 across long-term care services : policy brief. Geneva: World Health Organization; 2020 - https://apps.who.int/iris/bitstream/handle/10665/333074/WHO-2019-nCoV-Policy_Brief-Long-term_Care-2020.1-eng.pdf?sequence=1&isAllowed=y

125 Spasova, S., Baeten, R., Coster, S., Ghailani, D., Peña-Casas, R. and Vanhercke, B. (2018). Challenges in long-term care in Europe. A study of national policies, European Social Policy Network (ESPN), Brussels: European Commission - <https://op.europa.eu/en/publication-detail/-/publication/c12c65f9-c6b6-11e8-9424-01aa75ed71a1/language-en>.

126 Continuity and coordination of care - A practice brief to support implementation of the WHO Framework on integrated people-centred health services. WHO (2018). Geneva <https://apps.who.int/iris/bitstream/handle/10665/274628/9789241514033-eng.pdf?sequence=1&isAllowed=y>



Services for older adults are best delivered as integrated care, encompassing healthcare, social care, housing, community and voluntary services operating seamlessly together and working alongside older adults and family carers¹²⁷.

As European countries work to reform and reshape their long-term care systems after the impacts of Covid-19 pandemic, it is essential to refocus these efforts around the values and goals of dignity, respect, solidarity and empowerment. Thinking about and portraying older adults as frail, disempowered and dependent reinforces deeply embedded ageist attitudes and stereotypes. It is the shared responsibility of European governments, policy makers, care providers and communities to combat ageism in all its forms and to recognize older people, with or without care needs as equally valuable members of their communities. The UN Decade for Healthy Ageing 2021-2030 sets as its first area for action to “change how we think, feel and act towards age and ageing”¹²⁸. In the same spirit, ***it is high time we change the way we think, feel and act towards care and caring.***

Changing the narrative on ageing and care

The #AgeingEqual Campaign is a European-wide campaign from AGE Platform Europe which aims to raise awareness on ageism, establish a long-lasting community of self-advocates, and design a platform to amplify the voices of older adults. Every year the campaign ramps up around the time of the International Day of Older adults (October 1).

The World Health Organization Global Campaign to Combat Ageism aims to ultimately create a world for all ages (#AWorld4AllAges) by building a coalition, raising awareness, and conducting research. The campaign started in the Fall of 2021 with a series of events centered on ageism and ageing.

Policy Brief Euroageism Project on *“Ageism in the media - Policy Measures to Reduce Stereotypical Representations of Older adults in LongTerm Care”*. This brief calls for more authentic, balanced, diverse and thoughtful portrayals of older adults in the media, as well as seeking accountability of content producers as a critical way of reducing the portrayals of older adults that may lead to ageism. Policy measures are suggested for mitigating ageism in the process of generating media content (digital and print) about older adults and later life relating to long-term care.

Local campaigns

Manchester – “Valuable not vulnerable” highlights positive stories and realistic depictions of older adults responding to the challenges of coronavirus. And

127 Araujo de Carvalho I, Epping-Jordan J, Pot AM, Kelley E, Toro N, Thiyagarajan JA, et al. Organizing integrated health-care services to meet older people’s needs. *Bull World Health Organ.* 2017;95(11):756–63

128 WHO 2021, Action plan for a Decade of Healthy Ageing 2020–2030. Available at: https://cdn.who.int/media/docs/default-source/decade-of-healthy-ageing/final-decade-proposal/decade-proposal-final-apr2020-en.pdf?sfvrsn=b4b75ebc_25&download=true



in doing so, counters the many negative depictions and stereotypes of older adults during the pandemic, including the labelling of entire age groups as vulnerable or frail. <https://ageing-better.org.uk/blogs/valuable-not-vulnerable-how-greater-manchester-changing-narrative-ageing>

Biscay Government observatory on media: its objective is to identify the stereotyped contents about older adults that are disseminated in the Basque media, and to develop a critical view of them. <https://ageing-equal.org/the-older-persons-council-of-biscay-spain-launches-a-new-observatory-to-monitor-ageism-in-the-media/>

What does the British public think when they hear the words “social care”? A source with inspiring posts on framing: <https://socialcarefuture.blog/2018/06/22/what-does-the-british-public-think-when-they-hear-the-words-social-care/> It stresses the idea of avoiding the negative connotations of social care and embracing a new narrative that fits well with a human rights-based approach.

There is a need to develop a vision of care focused on realising individual and societal goals of dignity and wellbeing, rather than on solving care needs and meeting growing deficits.

There is a need to raise awareness of and promote the immeasurable value of care work and of family care for social cohesion as well as for the economic sustainability across Europe. There is a need to place equity at the very core of care systems and prioritize fairness and user-empowerment in all systemic reform efforts.

Furthermore, we should recognise families and social networks have always been and remain the backbone of care provision throughout Europe. The sustainability of long-term care systems is therefore first and foremost a question of supporting families and communities to continue to provide the care that is needed. Long-term care services should thus include a systematic approach to identify and value informal carers as equal partners, and support them to access the right information, advice, cash benefits and services. Informal carers should be offered emotional support, advocacy, respite opportunities and, when needed, financial support to enable them to stay well and continue their caring responsibilities.

The following key challenges can be identified:

- Elder abuse
- Gaps in provision and unmet care needs
- Affordability
- Underdevelopment of home- and community-based services and availability of informal care
- Role of for-profit providers
- Continuity of staff
- Legislative gaps on older peoples’ autonomy and decision-making capacity
- Lack of processes to ensure older adults are empowered to shape the development of care systems



ELDER ABUSE

Elder abuse is defined as a “single or repeated act or a lack of appropriate action occurring within any relationship in which there is an expectation of trust, that causes harm or distress to an older person”¹²⁹. This can include physical, sexual, psychological, and emotional abuse as well as financial abuse, abandonment, and neglect. As elder abuse is associated with loss of dignity and respect for those who suffer such violence, it constitutes a violation of their human rights¹³⁰.

While evaluating the scale and impact of elder abuse across Europe and globally is rendered difficult by a chronic lack of data and systematic monitoring, recent estimates place prevalence in community-based settings at 1 in 6 individuals¹³¹. Most commonly, older adults are exposed to psychological abuse (more than 1 in 9) and financial abuse (approximately 1 in 15), whereas physical and sexual abuse affect less than 3%, and respectively 1% of the older population¹³². Functional dependence, poor physical and mental health, low socio-economic status and female gender act as individual level risk factors which combine with perpetrator, victim–perpetrator relationship and community characteristics to place some groups of older individuals at increased risk of experiencing abuse¹³³. The situation is even more dire in residential care settings, where one in three residents report psychological abuse, while one in seven have experienced physical or financial abuse¹³⁴. Studies find the vast majority of staff in residential care settings report having observed and perpetrated themselves acts

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- 129 WHO 2021, Action plan for a Decade of Healthy Ageing 2020–2030. Available at: https://cdn.who.int/media/docs/default-source/decade-of-healthy-ageing/final-decade-proposal/decade-proposal-final-apr2020-en.pdf?sfvrsn=b4b75ebc_25&download=true
- 130 World Health Organization. Elder Abuse Fact Sheet. Geneva: World Health Organization, 2018 - Available at: https://www.euro.who.int/__data/assets/pdf_file/0008/373904/fs-elder-abuse-eng.pdf
- 131 Yon Y, Mikton CR, Gassoumis ZD, Wilber KH. Elder abuse prevalence in community settings: a systematic review and meta-analysis. *Lancet Glob Heal* 2017;1:365–56.
- 132 Yon Y, Mikton CR, Gassoumis ZD, Wilber KH. Elder abuse prevalence in community settings: a systematic review and meta-analysis. *Lancet Glob Heal* 2017;1:365–56.
- 133 Pillemer, K., Burnes, D., Riffin, C., & Lachs, M. S. (2016). Elder abuse: global situation, risk factors, and prevention strategies. *The Gerontologist*, 56(Suppl_2), S194-S205
Yon, Y., Mikton, C., Gassoumis, Z. D., & Wilber, K. H. (2019). The prevalence of self-reported elder abuse among older women in community settings: a systematic review and meta-analysis. *Trauma, Violence, & Abuse*, 20(2), 245-259.
Storey, J. E. (2020). Risk factors for elder abuse and neglect: A review of the literature. *Aggression and violent behavior*, 50, 101339.
Donder, L. D., Lang, G., Ferreira-Alves, J., Penhale, B., Tamutiene, I., & Luoma, M. L. (2016). Risk factors of severity of abuse against older women in the home setting: A multinational European study. *Journal of women & aging*, 28(6), 540-554.
- 134 Yon, Y., Ramiro-Gonzalez, M., Mikton, C. R., Huber, M., & Sethi, D. (2019). The prevalence of elder abuse in institutional settings: a systematic review and meta-analysis. *European journal of public health*, 29(1), 58-67.



of abuse¹³⁵, although variability in measurement and study design limits opportunities for pooling or comparing results¹³⁶.

The estimated rates of elder abuse in European communities and residential care facilities are alarming and should be addressed with urgency. Worrying reports of increases in the rates of abuse against older adults in recent years, and especially in the aftermath of the COVID pandemic¹³⁷, call for immediate and sustained interventions at European and national level. It is well established that social isolation and the lack of social support for older adults and their informal caregivers can act as a significant risk factor for elder abuse in the community. As pandemic control measures have increased isolation for carers and older adults throughout Europe, it is important to consider the effects on the safety of vulnerable older adults and step up interventions to prevent and detect elder abuse in both community and residential care settings.

FIGURE 7 – INFOGRAPHIC - ABUSE OF OLDER PEOPLE: A HIDDEN PROBLEM



Source: UN Decade of Healthy Ageing, 15 June 2022

- 135 Yon, Y., Mikton, C., Gassoumis, Z. D., & Wilber, K. H. (2019). The prevalence of self-reported elder abuse among older women in community settings: a systematic review and meta-analysis. *Trauma, Violence, & Abuse*, 20(2), 245-259
- Botngård, A., Eide, A. H., Mosqueda, L., Blekken, L., & Malmedal, W. (2021). Factors associated with staff-to-resident abuse in Norwegian nursing homes: a cross-sectional exploratory study. *BMC health services research*, 21(1), 1-20.
- 136 Malmedal, W., Kilvik, A., Steinsheim, G., & Botngård, A. (2020). A literature review of survey instruments used to measure staff-to-resident elder abuse in residential care settings. *Nursing Open*, 7(6), 1650-1660.
- De Donder, L., Luoma, M.-L., Penhale, B., Lang, G., Santos, A. J., Tamutiene, I., ... Verté, D. (2011). European map of prevalence rates of elder abuse and its impact for future research. *European Journal of Ageing*, 8(2), 129. <https://doi.org/10.1007/s10433-011-0187-3>
- 137 Makaroun, L. K., Bachrach, R. L., & Rosland, A. M. (2020). Elder abuse in the time of COVID-19—Increased risks for older adults and their caregivers. *The American Journal of Geriatric Psychiatry*, 28(8), 876.
- Drommi, M., Ponte, A., Ventura, F., & Molinelli, A. (2021). Elder abuse in Europe's "most elderly" city: an update of the phenomenon based on the cases reported to the Penal Court of Genoa from 2015 to 2019 and literature review. *Aging clinical and experimental research*, 1-7.
- Press release: Hourglass UK <https://wearehourglass.org/safer-ageing-week-2020-and-how-hourglass-pivoted>



GAPS IN CARE PROVISION AND UNMET CARE NEEDS

Inequalities in unmet care needs and access to long-term care services remain ubiquitous throughout Europe. Large gender and socio-economic status differences remain in the use of formal and informal care. Over-reliance on informal care and disproportionately low use of care services among poorer groups are particularly pronounced in countries that emphasize familialism over formal care development, and cash benefits over in kind service provision (e.g. Spain, Italy). This mix of long-term care system features has consistently been linked with higher inequalities in access to care¹³⁸. In order to ensure equitable access to care services for all those who need it, European countries should develop policy framework and eligibility criteria that decouple the access and cost of care from the specific socio-economic or familial circumstances of older individuals and their households.

AFFORDABILITY

The evidence we reviewed points to a considerable financial risk faced by households whose members develop long-term care needs. This risk, however, is often under-rated by private individuals as well as by policy-makers and social protection systems. This is due to the combined effects of a tendency to underestimate the total costs associated with care that can span many years and with the inclination to assume severe care needs and therefore very high costs for high intensity care services are a rare occurrence. In fact, available data shows a third of people age 65 and above in Europe report severe activity limitations. It should then not be surprising that available estimates suggest up to 16% of individuals aged 65 and above can expect large long-term care expenses over their remaining lifetime and approximately 5% will face very high costs, surpassing \$250.000¹³⁹. Despite these considerable risks, even in the most generous European long-term care systems, affordability of formal care services remains low for those older adults who develop severe care needs, particularly if they opt for receiving care in the home rather than in an institutional care setting. While in some European countries, social protection systems cover a large part of the cost for home care, therefore reducing the size of the population at risk of poverty (Belgium, Netherlands, Finland, Germany), in others, millions of older adults remain exposed to the risk of poverty due to costs associated with home care for severe needs.

138 S. Ilinca, R. Rodrigues, A.E. Schmidt (2017), « Fairness and Eligibility to Long-Term Care: An Analysis of the Factors Driving Inequality and Inequity in the Use of Home Care for Older Europeans », *International Journal of Environmental Research and Public Health* 14(10):1224, DOI:10.3390/ijerph14101224

Albertini M, Pavolini E. Unequal Inequalities: The Stratification of the Use of Formal Care Among Older Europeans. *J Gerontol B Psychol Sci Soc Sci*. 2017 May 1;72(3):510-521. doi: 10.1093/geronb/gbv038. PMID: 26224754; PMCID: PMC5927152.

Bakx, P., de Meijer, C., Schut, F. and van Doorslaer, E. (2015), 'Going formal or informal, who cares? The influence of public long-term care insurance', *Health Economics*, vol. 24, pp. 631–43.

139 Kemper P, Komisar HL, & Alecxih L (2005/2006). Long-term care over an uncertain future: What can current retirees expect? *Inquiry*, 42: 335-350



Limited social protection and large barriers in access to long-term care services in Europe can act to exacerbate existing socio-economic inequalities both within and across generations. Poorer older adults are more likely to develop care needs but are also the group less able to afford the out-of-pocket costs. This results in increased pressure on family members to either spend down household wealth or provide intensive informal care that can compensate for unmet formal care needs, ultimately exposing these carers to higher health risks and worse socio-economic outcomes. To break this cycle of intra- and inter-generational inequalities perpetuated through the transmission of dis-advantage in health and access to care within families, European long-term care systems should improve financial protection and prioritize equity in care use in all long-term care settings.

UNDERDEVELOPMENT OF HOME- AND COMMUNITY-BASED SERVICES AND AVAILABILITY OF INFORMAL CARE

The European Pillar of Social Rights supports the principle of deinstitutionalisation and prioritises home care (provided at the home of a person in need of care) and non-institutional community-based long-term care services. This should be supported by good quality residential care where home care is not viable due to lack of an informal support network, or the complexity or intensity of long-term care needs. Formal long-term care services are provided by an array of health and social care professionals from public sector, private for-profit providers and independent not for profit providers. Services can be grouped into six categories: home care; day centre services; housing with care; residential and nursing care homes; telecare and assistive technology services; and support services for informal carers. It is important to provide the right balance of long-term care services and to make access simple and flexible but the landscape is difficult for older persons, families and professionals to navigate. Fragmentation often results in delays, waste, harm and a poor care experience through failures of communication, inadequate sharing of information, poor medicines reconciliation, duplication of investigations, and avoidable hospital admissions or readmissions.

Successful deinstitutionalisation hinges on developing a well-balanced mix of formal care services in the community and targeted support measures for informal caregivers. Despite efforts to strengthen home-based care, capacity growth has not kept up with growing needs for support in the population, leading many countries to tighten eligibility criteria, therefore limiting access for those with low or moderate care needs¹⁴⁰. At the intersection

140 Spasova, S., Baeten, R., Coster, S., Ghailani, D., Peña-Casas, R. and Vanhercke, B. (2018). Challenges in long-term care in Europe. A study of national policies, European Social Policy Network (ESPN), Brussels: European Commission - <https://op.europa.eu/en/publication-detail/-/publication/c12c65f9-c6b6-11e8-9424-01aa75ed71a1/language-en>

G. Meagher, M. Szebehely, "The politics of profit in Swedish welfare services: Four decades of Social Democratic ambivalence", Sept. 2018, *Critical Social Policy* 39(52):026101831880172, DOI:10.1177/0261018318801721

Rostgaard, T., & Matthiessen, M. U. (2019). Hjælp til svage ældre. VIVE - Det Nationale Forsknings- og Analysecenter for Velfærd



of limited residential capacity growth and insufficient development of community-based solutions, large formal care capacity gaps are being created.

Yet deinstitutionalisation - the move to home based care - has been the hallmark of long-term care system development across Europe over recent decades¹⁴¹. Underpinned by a shared understanding that home- and community- based care provision reflects user preferences, this is aligned with a rights-based approach to care and is economically more sustainable. Progress however has been very uneven, with southern and eastern European countries lagging far behind those in the north and west¹⁴². The share of older adults(65+) who use long-term care services in their own homes varies between 13% in the Netherlands (32% of 80+ population), 12% in Sweden (30% for 80+ population), 3.5% in Estonia (6% of 80+ and 0.7% in Portugal (1.4% of 80+)¹⁴³.

While considerably more acute in eastern European countries, the challenge of ensuring availability of formal care services is faced by all long-term care systems in Europe, generating significant pressure on communities and families to compensate for capacity gaps through informal care provision.

The demand for informal care will continue to increase as the European population continues to age, although patterns of caregiving within families might change. Increased availability of formal care in the community allows informal caregivers to reduce their involvement with intensive caregiving tasks, allowing them to better reconcile caregiving with other work and family responsibilities and therefore facilitating higher numbers of family and community members to participate in care and support activities¹⁴⁴. To ensure sustainability and avoid the creation of large care gaps that will inevitably lead to care needs being unmet, it is essential for long-term care systems to strike a balance between policies focused on development of formal care services and those focused on supporting families and communities to provide needed care – and in a way so that it is acceptable and in accordance with prevailing norms about the mix of formal and informal care in the given society.

141 S. Ilinca, R. Rodrigues, K. Leichsenring, "From care in homes to care at home: European experiences with (de)institutionalisation in long-term care", European Centre for Social Welfare and Dec. 2015

142 Spasova, S., Baeten, R., Coster, S., Ghailani, D., Peña-Casas, R. and Vanhercke, B. (2018). Challenges in long-term care in Europe. A study of national policies, European Social Policy Network (ESPN), Brussels: European Commission - <https://op.europa.eu/en/publication-detail/-/publication/c12c65f9-c6b6-11e8-9424-01aa75ed71a1/language-en>

143 OECD Health data,2014 - <https://www.oecd.org/els/health-systems/oecd-health-statistics-2014-frequently-requested-data.htm>

144 Verbakel E. How to understand informal caregiving patterns in Europe? The role of formal long-term care provisions and family care norms. *Scandinavian Journal of Public Health*. 2018;46(4):436-447. doi:10.1177/1403494817726197



ROLE OF FOR-PROFIT NURSING HOMES

In general, the literature rather unequivocally indicates a tendency towards better quality of care by non-for-profit providers, especially for nursing homes¹⁴⁵. There are indications that non-for profit nursing home providers in particular perform well on structural factors such as staffing levels and qualifications, while scoring less well on procedural factors including participation in formulation of care plans, time lapse between evening meal and breakfast, and food alternatives¹⁴⁶.

CONTINUITY OF STAFF

One of the important structural factors which is also high-lighted in recent responses to prevent COVID-19 spreading is to ensure continuity of staff¹⁴⁷. This can be done for instance by providing full-time employment contracts so that staff are in more secure positions and do not need to take up employment in various facilities.

Key challenges exist, however. Poor working conditions and very low remuneration; large skills gaps and low professionalization; uncoordinated and distortionary policies to ensure capacity gaps are filled.

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- 145 Ulf Hjelmar, Yosef Bhatti, Ole Helby Petersen, Tine Rostgaard, Karsten Vrangbæk, Public/private ownership and quality of care: Evidence from Danish nursing homes, *Social Science & Medicine*, Volume 216, 2018, Pages 41-49, ISSN 0277-9536, <https://doi.org/10.1016/j.socscimed.2018.09.029>
Ragnar Stolt, Paula Blomqvist, Ulrika Winblad, Privatization of social services: Quality differences in Swedish elderly care, *Social Science & Medicine*, Volume 72, Issue 4, 2011, Pages 560-567, ISSN 0277-9536, <https://doi.org/10.1016/j.socscimed.2010.11.012>
Winblad U, Blomqvist P, Karlsson A. Do public nursing home care providers deliver higher quality than private providers? Evidence from Sweden. *BMC Health Serv Res*. 2017 Jul 14;17(1):487. doi: 10.1186/s12913-017-2403-0. PMID: 28709461; PMCID: PMC5512814.
V.R. Comondore et al, Quality of care in for-profit and not-for-profit nursing homes: systematic review and meta-analysis, *BMJ* (2009)
- 146 Ulf Hjelmar, Yosef Bhatti, Ole Helby Petersen, Tine Rostgaard, Karsten Vrangbæk, Public/private ownership and quality of care: Evidence from Danish nursing homes, *Social Science & Medicine*, Volume 216, 2018, Pages 41-49, ISSN 0277-9536, <https://doi.org/10.1016/j.socscimed.2018.09.029>
Ragnar Stolt, Paula Blomqvist, Ulrika Winblad, Privatization of social services: Quality differences in Swedish elderly care, *Social Science & Medicine*, Volume 72, Issue 4, 2011, Pages 560-567, ISSN 0277-9536, <https://doi.org/10.1016/j.socscimed.2010.11.012>
Winblad U, Blomqvist P, Karlsson A. Do public nursing home care providers deliver higher quality than private providers? Evidence from Sweden. *BMC Health Serv Res*. 2017 Jul 14;17(1):487. doi: 10.1186/s12913-017-2403-0. PMID: 28709461; PMCID: PMC5512814.
V.R. Comondore et al, Quality of care in for-profit and not-for-profit nursing homes: systematic review and meta-analysis, *BMJ* (2009)
- 147 WHO 2020, Preventing and managing COVID-19 across long-term care services: Policy brief, 24 July 2020 - https://www.who.int/publications/i/item/WHO-2019-nCoV-Policy_Brief-Long-term_Care-2020.1



LEGISLATIVE GAPS ON OLDER PEOPLES' AUTONOMY AND DECISION-MAKING CAPACITY

Challenges include the lack of consistent understanding and standards around older people's autonomy and independence in the European region. The understanding of autonomy and independence in old age is often limited to situations of ill-health and impairment. Several texts foresee restrictions to autonomy and provide for measures to allow older adults to live independently in the community only "for as long as possible". These limitations entail a narrower definition of the rights to autonomy and independence in the context of old age than in disability¹⁴⁸.

A right to autonomy, independence, choice, control and legal capacity should aim to ensure the full, effective and meaningful participation of older adults in social, cultural, economic, public and political life and educational and training activities.

Autonomy is the ability to live according to one's wills and preferences on an equal basis with others. It includes the ability to make one's own choices and decisions in all aspects of life and to have them respected. It also includes the ability to maintain their legal capacity to exercise those choices and decisions (See Annual Report of the Independent *Expert* on the enjoyment of all human rights by older persons, August 2015).

Independence is the ability to keep the control over one's life, and to exercise one's own choices and decisions in all spheres of life. Independence means that the older person is not deprived of the opportunity of choice and control regarding personal lifestyle and daily activities, nor from the ability to remain fully integrated in society and in community life (See definition of independent living in the General Comment No. 5 (2017) on living independently and being included in the community of the Committee of the Rights of Persons with Disabilities).

Despite the commitment of the European Union to promote older people's independence (article 25 of the EU Charter of Fundamental Rights), to date, it has not adopted any specific policy action targeting older adults rights. The Council of Europe CM(2014)2 recommendation recognises explicitly to older adults the right to legal capacity on an equal basis with others, but this is a non-binding instrument whose implementation is insufficient. National constitutions lack specific references to older people's autonomy and independence, but older adults are indirectly covered by general provisions (where those exist). In the few

148 On the intersection between age and disability, and on the specific challenges facing older persons with disabilities, see the report of the Expert Group Meeting on Supporting Autonomy and Independency of Older Persons with Disabilities, 2017: https://www.ohchr.org/Documents/Issues/Disability/SupportingTheAutonomy/SummaryNote_EGM_OPWD.docx



cases where secondary national law refers to autonomy and independence in old age, these are primarily related to health and care law or mental capacity acts.

Report of the UN Independent Expert on the enjoyment of all human rights by older persons: the right to autonomy and care (August 2015)

Among the recommendations addressed to States, we can read:

“States should design and implement effectively **national policies and action plans on ageing that include specific provisions on autonomy and care**, in a comprehensive and intersectoral manner.

“States should establish **national councils on ageing, with older persons** among its members, to design and develop policies, including care, that correspond to their needs and respect their autonomy. Such councils should guarantee pluralism, represent the diversity of older persons and receive sufficient funding so that they can function properly and effectively.”

Source: A/HCR/30/43 – 13 August 2015

There are mechanisms for the participation of older adults in consultations, which are sometimes compulsory; however, such participation is unequal in terms of meaningfulness and real impact. Moreover, given the little action undertaken around the autonomy and independence of older persons, opportunities for participation are scarce.

Ad-Hoc Ethical Laboratory during the COVID-19 Pandemic in Biscay

This committee has been set up to take shared decisions to protect the rights of persons experiencing dependency and recommendations for home care and residential care settings.

Methodology:

- Creation of a Consultative committee coordinated by the Minister for Social Action and with the participation of 10 representatives from: Council for the Elderly; Round Table for Civil Dialogue (families/people with disabilities); Biscay Social Intervention Ethics Committee; Zahartzaroa - Basque Association of Geriatrics and Gerontology; Professional Associations for Social Work, Psychology, Nursing and Medicine of Biscay; other expert from Academia
- Continuous deliberation meetings every 3 weeks on possible resolutions to be adopted in situations that arise, involving the rights of older adults and



people with disabilities, and consequences of the decisions that are being adopted at broader level

- Preparation of reflection documents in working groups
- Establishment of telematic forums for training and regular dialogue open to professionals, entities, and citizens.

LACK OF PROCESSES TO ENSURE OLDER ADULTS ARE EMPOWERED TO SHAPE THE DEVELOPMENT OF CARE SYSTEMS

Based on its survey, the InCARE project insists on the need to “intensify public engagement efforts and ensure the voices of care users, their informal carers, families and communities are heard and acted upon, in order to rebuild trust in the long-term care systems”¹⁴⁹. Still we lack processes for participatory approaches through regular engagement and representation in decision-making processes and bodies, especially those promoting a shift towards empowerment.

The question of co-production, engagement and empowerment is not new and has been quite a lot researched in different sectors¹⁵⁰, it is still a challenge when it comes to long-term care. This challenge echoes very much the legislative gaps explored above, as well as the need for a change of narrative on ageing and care: as the UN Independent Expert on the Enjoyment of All Human Rights by Older Persons states: “**Ensuring that older persons are in position to lead autonomous lives** to the greatest extent possible - irrespective of their physical, mental and other conditions – **requires a radical change in the way society perceives ageing.**” And she adds “**Ageist attitudes** still persist throughout the world, leading to discriminatory practices towards older persons, including in care settings. Age-based discrimination **generates a lack of self-esteem and disempowerment**, and undermines an older person’s perception of autonomy. This is particularly true when they are in need of care to maintain or regain autonomy”¹⁵¹.

149 InCARE, Submission to the EU call for evidence on the European Care Strategy, March 2022 - https://incare.euro.centre.org/wp-content/uploads/2022/03/InCARE-project_-Input-to-call-for-evidence-on-accessible-and-affordable-long-term-care.pdf

150 A. Realpe and Prof. L.M Wallace, “What is co-production?”, the Health Foundation Inspiring Improvement, 2010 - <https://qi.elft.nhs.uk/resource/what-is-co-production/>

151 Report of the UN Independent Expert on the enjoyment of all human rights by older persons: the right to autonomy and care, A/HCR/30/43 – 13 August 2015 - <https://www.ohchr.org/en/special-procedures/ie-older-persons/annual-reports>



Definitions

The terms “empowerment”, “engagement” and “co-production” are often used interchangeably to describe policies or interventions that seek to achieve such goals, but in reality they represent distinct if overlapping strategies.

- **Empowerment is about supporting people and communities to take control of their own health needs** resulting, for example, in the uptake of healthier behaviours, the ability of people to self-manage their own illnesses and changes in people’s living environments.
- **Engagement is about people and communities being involved in the design, planning and delivery of health services**, enabling them to make choices about care and treatment options or to participate in strategic decision-making on how, where and on what health resources should be spent. Engagement is also related to the community’s capacity to self-organize and generate changes in their living environments.
- **Co-production is about care that is delivered in an equal and reciprocal relationship between clinical and non-clinical professionals** and the individuals using care services, their families, carers and communities. Co-production therefore goes beyond models of engagement, since it implies a long-term relationship between people, providers and health systems where information, decision-making and delivery are shared.

Source: World Health Organization (2015), WHO global strategy on people-centred and integrated health services: interim report - <https://apps.who.int/iris/handle/10665/155002>

Although very much focused on healthcare the above definition promoted by the WHO offers an interesting frame and highlight how much the relationships among the different stakeholders needs to be reviewed to attain a more equal partnerships between people who use services, carers and professionals¹⁵².

152 Social Care Institute for Excellence, Co-production in social care: what it is and how to do it – At a glance, SCIE At a glance 64, Published: October 2015 - <https://www.scie.org.uk/publications/guides/guide51/at-a-glance/>



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NOS 4 CD

1= 15€

2= 25€

3= 37€



CHAPTER 7. A NEW MODEL OF LONG-TERM CARE EMPOWERMENT

RECOMMENDATIONS

Our report aligns itself with and argues for strengthening the commitment to a rights-based approach to care in Europe, calling for a **Long-Term Care Empowerment Model, which brings long-term care for older adults in line with the recognised health care empowerment approach.** We believe that a human rights-based approach and respect for diversity of needs should be central to the design of any model of long-term care.

The goals of 21st Century long-term care

- To support older adults to lead meaningful lives, to promote quality of life; and to empower older adults, even at the end of their lives;
- To ensure dignity, autonomy and self-determination, as well as equality and non-discrimination for all older adults ;
- To promote healthy ageing, defined as the process of developing and maintaining the functional ability that enables wellbeing in older age;
- To enable the inclusion and social participation of older adults , allowing them to remain active and engaged members of their communities should they so desire.

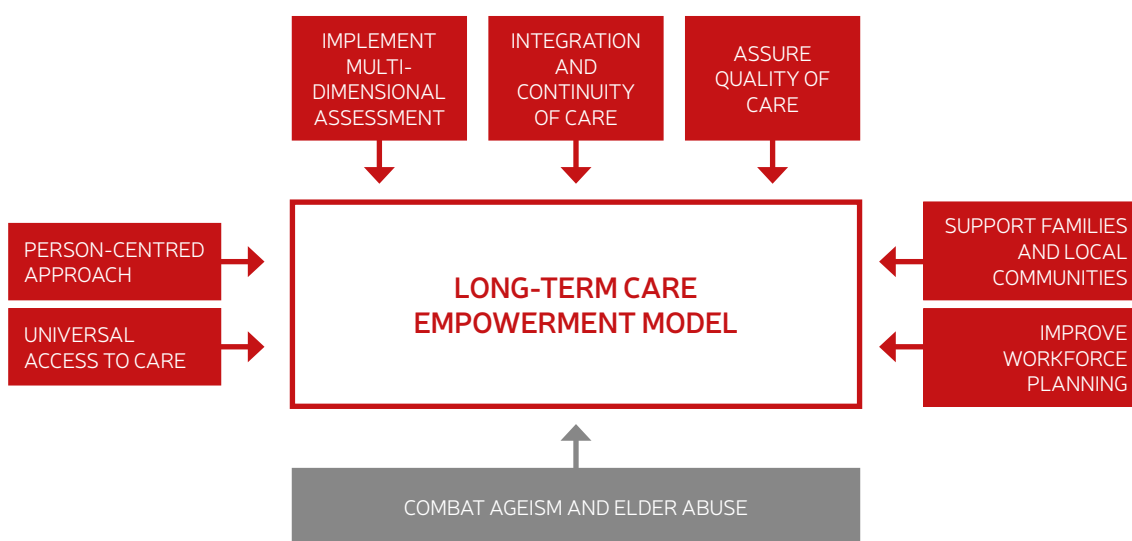
In a Long-term care Empowerment Model it is important to take into account the variety of contextual factors which this Report has highlighted:

- Social and environmental – socio-economic and educational status, income, housing may be either constraining or empowering;
- Cultural background, gender norms, and generational factors. In particular, due to generational effects, attitudes and expectations, older adults are sometimes fearful of challenging care provider's plans and should be reassured and empowered to do so;
- Institutionalised ageism interferes with an individual's level of empowerment in his or her long-term care and should be addressed;
- Individual characteristics should be acknowledged and addressed - personality, negative life experiences, such as trauma and psychosomatic disease, anxiety and depression inhibit empowerment.



What do we need to make this happen?

FIGURE 8 – THE ACCELERATORS



Combat ageism and elder abuse and mistreatment:

Legislation to combat ageism is particularly important in this context, as mounting evidence suggests ageist attitudes and practices are widespread in health and long-term care settings. This includes anti-age discrimination and equality legislation at international and national level, as well as policies at any governance level that promote dignity and equality of status for all individuals, irrespective of their age. The Global Report on Ageism highlights the importance of promoting policies that aim to change attitudes and perceptions of older adults and strengthening human rights legislation and the enforceability of those rights.

This should include

- Strengthening policies and legislation that address age discrimination and human rights laws
- Introducing educational interventions in both formal and non-formal educational contexts
- Promoting intergenerational contact through interventions that foster interaction and cooperation between people of different ages
- Raising awareness about the scale and impact of elder abuse and mistreatment and recognize it as a public health problem

Person-centred approach:

Governance arrangements should be participatory, creating opportunities for older adults and informal carers to be fully involved in long-term care policy and service development, and inclusive, addressing the inequities frequently experienced by women, migrant carers and underserved communities.

This should include

- Establishing care systems which empower older adults through placing them, their families and communities, at the centre of system design and organization, rather than a focus on diseases and disabilities;
- Enabling those receiving care and support to express their own needs and decide on their own priorities through a process of information-sharing, shared decision-making and action planning;
- Placing the development of collaborative relationships between older adults and care professionals at the heart of service delivery;
- Supporting people with long-term conditions to have the knowledge, skills and confidence to manage their condition effectively in the context of their everyday life.

Ensure universal access to care:

Governments should both address the insufficient development of formal care services which generates significant pressure on communities and families to compensate for capacity gaps through informal care provision, and provide financial and practical support for these families, households and communities.

This should include:

- Revising and reviewing eligibility assessments to consider only care needs; decoupling entitlements to care and support from the socio-economic characteristic of users and their families;
- Ensuring individuals can access care without undue financial burden to themselves and their families;
- Ensuring care is available where and when it is needed and improving coverage in small, rural and remote communities.



Ensure integration and continuity of care.

There is a growing call for integrated governance arrangements that enable long-term care to be planned, commissioned, funded and provided as a continuum of health and social care services that include protection, prevention, treatment, care and support, rehabilitation, reablement, and palliative and end of life care.

This should include:

- Developing care pathways that ensure long-term care services are well integrated with primary and specialist care provision;
- Improving intermediate care arrangements that allow individuals to seamlessly transition between care levels and care settings as their needs change
- Supporting the coordination of formal and informal support and create the conditions in which informal carers can collaborate as equal partners with formal care teams

Implement a multi-**dimensional assessment**. This should combine elements from comprehensive assessments around the needs of individuals needs, informal caregivers and family members, and communities.

Support families and local communities to provide care.

Informal care remains the main source of support for older adults across Europe. Estimates place the contribution of families, friends and communities at 80% of all long-term care provided, with an expected monetary value that far exceeds public expenditure on long-term care services and cash benefits combined. The use of informal care is particularly skewed towards lower income groups in the majority of European countries. Recent and projected changes in population structure, workforce mobility and migration patterns, female employment rates, increases of retirement age, are threatening the availability of familial care.

This should include:

- Ensuring well-developed and readily available support for informal caregivers which addresses their health and well-being;
- Combatin gendered care stereotypes and thereby encouraging equitable distribution of care tasks within families, and between formal and informal caregivers;
- Ensuring that older adults, their families and communities are meaningfully engaged in the design of care services and empowered to shape them;
- Supporting grassroots, socially innovative initiatives to develop care models and solutions that build on local community strengths.

Assure the quality of care.

Arrangements to assure the quality of long-term care should be supported by regulatory frameworks and standards, requirements for accreditation, licensing or registration of professionals and providers.

These should include

- Developing quality criteria, in collaboration with older adults themselves and their informal carers;
- Registrating and monitoring the activities of service providers;
- Reporting by providers against nationally / regionally agreed standards;
- Strengthening surveillance capacity and infection prevention in long-term care settings.

Improve workforce planning.

Workforce planning should consider data from professional bodies and provider organisations on capacity and skills alongside information on informal carers, intelligence from national and local labour markets, and insights from the education sector about the future workforce.

Projections should consider the implications of redesigning professional roles, adopting technology enabled care, and exploring new ways of providing support and care at home.

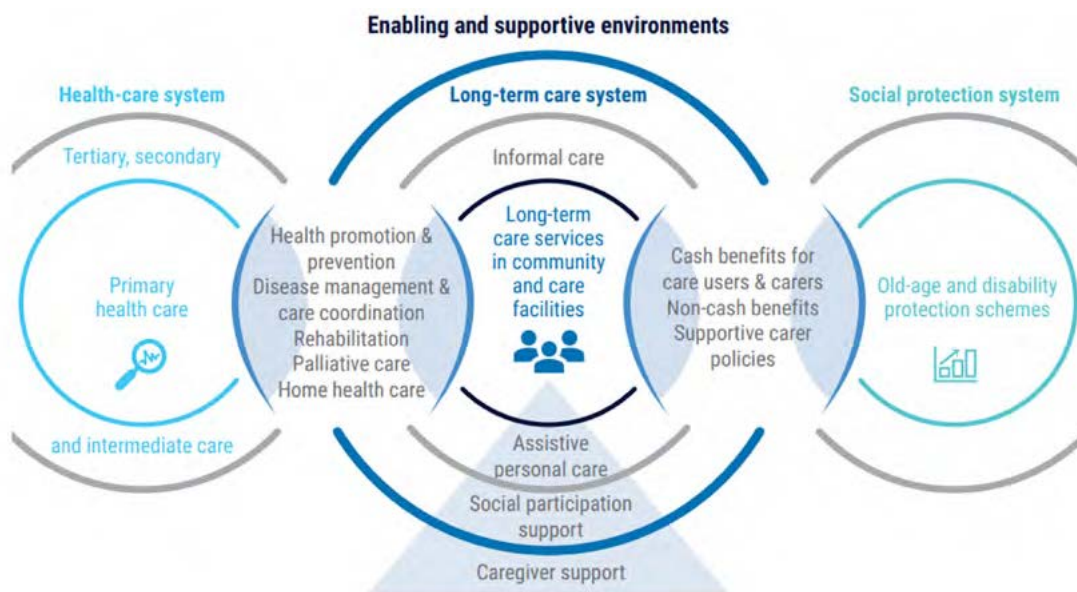
These should include

- Reforming the regulation of the long-term care workforce sector so as to improve working conditions, including improvement of financial remuneration and status
- Developing access to training to enable both the current and future long-term care workforce to have the knowledge, skills and confidence to deliver holistic assessments and care planning, to provide safe, effective and person-centred care and thereby enhancing the dignity and functional ability of older adults, both at home and in care homes;
- Promoting sustainable and fair management of cross-border mobility of the care workforce, thereby enabling opportunities for professional development and career progression for migrant workers in the sector.



The long-term care workforce should be managed in a fair, transparent and equitable manner and supported to stay safe and well in their working lives.

FIGURE 9 A MAPPING OF LONG-TERM CARE SYSTEMS



Source: WHO Regional Office for Europe, 2022

Transition Plan for Long-Term Care in Biscay (presented in September 2021)

The vision of this plan is to transform long-term care towards a culture of care in which people are accompanied to develop their life project. It is a very first attempt to implement the Long-Term Care Empowerment Model as described in this report.

Purpose:

- Promote a culture of care
- Care should be adapted to ageing and its changing old age stages with different expectations and needs... because caring is, above all, a relationship
- Care should provide a life worth living, despite the difficulties.



- New view of family caregiving with the harmonisation of professional and caregiving life, with social recognition.
- Eliminating the gender gap: caregiving should be a task of shared responsibility, individual and collective, personal and institutional.

Key factors:

- Improve home care thanks to new technologies
- Advance the personalisation of care
- Improve the link between residential care settings and hospitals thanks to specialised team
- Develop trainings for formal and informal carers
- Ensure coordination between social and health care with the support of new technologies
- Promote research, innovation and entrepreneurship^

Four strategic projects:

- Etxetic day care centre (care support at home)
- Personalised care in nursing home
- Regional reference centres
- Training

For more information, visit the website of the Government of Biscay - https://web.bizkaia.eus/eu/web/comunicacion/berriak/-/news/detailView/22055?_News_redirect=%2Fes%2Fweb%2Farea-de-prensa



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ACRONYMS

COPM: Canadian Occupational Performance Measure

ECDC: European Centre for Disease Prevention and Control

EEA: European Economic Area

EQLS: European Quality of Life Survey

EU: European Union

EU-27: 27 members states

EU28: 27 members states + UK

ICOPE: Integrated Care for Older People (WHO framework)

ICT: Information and Communication Technologies

OECD: Organisation for Economic Co-operation and Development

NGO: Non Governmental Organisation

ROPI: Rights of Older People Index

SCRoL: Social Care Related Quality of Life

SPC: Social Protection Committee

UNECE: United Nations Economic Commission for Europe

WHO: World Health Organisation



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TERMINOLOGY

Availability of care refers to ensuring the existing supply of care is sufficiently developed to respond to the care needs of the population.

Accessibility of care refers to ensuring care services can be reached and used with reasonable ease by those who need them at the time they are needed.

Affordability of care (also described as economic accessibility of care) refers to the users' ability to cover the costs of needed care without being exposed to financial hardship or impoverishment.

Acceptability or adequacy of care refers to providing care that is consistent with the preferences, ethical principles and expectations of care users and their families.

Appropriateness denotes the fit between the services provided and the user's need, its timeliness, and whether the correct approach of care is given, including the professional and interpersonal skill of the staff.

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

Community care The range of non-residential care services.

Deinstitutionalisation is the shift of care service provision from residential care institutions towards community-based professional settings.

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



Elder abuse is a single or repeated act or a lack of appropriate action occurring within any relationship in which there is an expectation of trust, that causes harm or distress to an older person.

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

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

Home care is care provided at the home of a person in need of care.

Inequalities in access to care refer to systematic, avoidable and unfair differences in ability to access and use needed care, as well as in the quality and experience of care, across groups of people defined by a given social location (e.g. gender, age, income, geography).

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

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

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

Long-term care refers to a broad range of personal, social and medical services and support that ensure people, with or at risk of a significant loss of intrinsic capacity (due to mental or physical illness and disability), can maintain a level of functional ability consistent with their basic rights and human dignity (WHO Europe, 2022)

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

Residential care is care provided in a residential setting for older adults living in accommodation with permanent caring staff.

