



CALL TO GOVERNMENTS
**AGEING AND
LONG-TERM CARE**



The Global Ageing Network

is an international network of leaders in ageing services, housing, research, technology, and design.

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PREFACE

This paper is a call to governments to learn about the unique challenges—and opportunities—that the growing number of older adults poses to governments worldwide. In the coming pages, we will share with you

- The current state of long-term care for older adults,
- How we can shift away from the current reliance on informal caregivers that affects economies in countries around the world, and
- New paradigms and funding models for a sustainable long-term care system that offers high quality of life for older adults and those who care for them.

Why Consider Long-Term Care?

One of the biggest successes of the last decades is more and more accessible health care and preventative care, including vaccination, better nutrition, healthier lifestyles, new medicines and methods, advanced technologies, and even more public spending for health care. These efforts resulted in a great success worldwide, though in differing levels in different countries. We all live longer.

Along with that progress, healthy life expectancy has been increasing much more slowly than the life expectancy rate. This situation has one simple outcome. We are living longer, but at the end of our lives we will likely need care, support, and assistance with our activities of daily living (ADL) and instrumental activities of daily living (IADL).

We will need this help to live our lives with dignity, to be respected as human beings. We

each want to be not a care recipient, but a client determining the structure and content of our care. Being treated and looked after with dignity is one of the fundamental human rights. However, the long-term care system does not achieve that level of respect in all countries.

A New Vision

To live longer but high-quality lives, with dignity, respect, self-determination, and independence—and to enable this life for all older adults—we must change our long-term care systems. We are at a crossroads. As the ageing population grows, there are too many challenges to keep doing things the way we have been doing them in the past decades.

Why Change?

As a world, we are ageing. And our long-term care systems are facing many challenges—a rapidly ageing population, rising dementia rates, workforce shortages, insufficient attention of public authorities, and more.

We cannot leave this challenge only to families. Already, informal caregivers are struggling with exhaustion, deteriorating quality of life, and loss of income that feed into negative macroeconomic impacts. Now it is time for our governments to address this multi-layered issue that affects both the quality of life of the most vulnerable citizens and economic factors that affect everyone.

A Call to Governments

This paper is a **call to the governments all over the world** and a **call to long-term care**

experts and providers to consider all of these deep challenges, potential changes, and action items—and then to move toward the future vision.

Every year that we avoid or postpone the decision to make, reshape, or reform long-term care systems and settings means substantially more costs and/or crucial impacts in the future.

The starting point is different for each country of our world. Some developed countries have good, quality long-term care systems yet challenges that prevent them from offering affordable and sustainable care. In other countries, the long-term care sector is either neglected or not prioritized. Many developing countries do not have long-term care settings or sufficient social protection tools to assist their older adults and family members who are seeking help. All countries will need to take actions and make changes to meet this important vision.

How this Report Can Help

This report is meant to stand with all countries, to help them understand the need for long-term care and create the critical support structures that will help their citizens thrive. Please note that the report presents long-term care challenges from a trusted firsthand perspective.

All of the authors are internationally recognized leaders in long-term care who are also frontline experts—all have the experience of providing long-term care. They represent the

grassroots experience, having personally seen the needs, expectations, and struggles of older adults and family caregivers.

Achieving this Future Vision

In addition to providing important background, the report offers a path forward. It suggests we shift our focus from residential care concepts to community-based concepts to find a balance of all the long-term care services and support models.

It recommends we consider innovations such as digitalization and new care concepts. It also emphasizes that we must change our mindset—that we must see older adults as part of society, not the responsibility of their families alone, and that we look at ageing care as a way to positively support living.

What Does It Take to Change?

It takes a lot to change. We have to be strong, courageous, and firm. We need a vision, belief, and conviction. Sometimes, changing requires the bravery to admit that we may have been wrong or may have overlooked a critical social need.

Most importantly, we have to know that these changes will move us forward, not backward. We encourage you to join us in committing to this necessary bravery!

Together, we can and must do better. Please join us.

Dr. Jiri Horecky, MSc., MBA

Global Ageing Network chairman 2022/2023

"Call to the government" WG chairman

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AUTHORS



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Jiri Horecky has been involved in the social services sector since 1999 and has managed organizations providing social services. He lectures on management of social services at the universities and is the finalist for Manager of the Year 2021 in the Czech Republic.

Since 2007, Horecky has been the president of the Association of Social Services in the Czech Republic. Later, he became the president of the Union of Employers' Associations in the Czech Republic. Since 2016, he served as president of European Ageing Network. In 2017, he was elected as the vice-president of the Federation of Social Employers Europe. He is also a board member of Social Services Europe, and since 2022 he has chaired the board of the Global Ageing Network. Horecky is also in academia and has published more than 120 articles and biographies about social services, long-term care, and employment.



Stuart C. Kaplan, MBA

Stuart Kaplan is a forward-thinking executive with extensive experience in strategic, fiscal, and operational stewardship for non-profit health care, human services, and affordable housing. As CEO of Selfhelp Community Services in New York, he oversees independent living programs for 25,000 older adults, including survivors of the Holocaust. He is currently working on ideas to reframe policy and views on aging.

Kaplan's commitment to the wider community is evidenced by his voluntary role on boards and executive committees, including as immediate past treasurer for the Global Ageing Network, LeadingAge New York, UJA Federation of New York, LiveOn NY, and Center for Aging Services Technology in Washington, D.C. Kaplan is an ardent advocate for the development of housing with services models for older adults. Previously, Kaplan was executive vice president at St. Mary's Healthcare System for Children, providing long-term care and rehabilitation for children with special health needs and terminal illnesses. He has written and presented on the subject of non-profit ethics, Holocaust survivors, housing with services, gerontechnology, subacute care, and palliative care for adults and children.



Dan Levitt, MSc., CHE

Dan Levitt is an international TEDx speaker, elder care leader, writer, and gerontologist, specializing in helping others to create better lives for seniors. Levitt's purpose is to teach people how to transform the lives of older adults across the globe. As a popular professional speaker, he has delivered inspiring keynote speeches impacting thousands of people on five continents. As CEO of KinVillage, Leavitt shepherds the enhancement of social, spiritual, and care needs for more than 300 older persons, inspiring a team of over 400 employees and volunteers with a commitment to continuously improving the quality of life. Leavitt is an adjunct professor in gerontology at Simon Fraser University; an adjunct professor, School of Nursing, University of British Columbia; and a sessional instructor, British Columbia Institute of Technology. He is also a surveyor with Accreditation Canada, as well as a board member of Common Age and the International Federation of Ageing and a past board member of the Global Ageing Network.



Katie Smith Sloan, MA

Katie Smith Sloan has devoted her career to advocating for the rights of older adults. As executive director of the Global Ageing Network, a dynamic group of providers and other stakeholders around the world, Sloan manages a platform for the exchange, learning, and innovation in services and supports to older adults. She also serves as president and CEO of LeadingAge, a U.S.-based association of over 5,000 mission-driven providers across the continuum of housing, supports, and long-term care. In her dual roles, Sloan is focused on making the world a better place to grow old. Her commitment to service extends to other organizations, as evidenced by her board service with the Centre for Aging and Brain Health Innovation (CHABI), HelpAge USA, Dementia Friendly America, the Alliance for Home Care Quality and Innovation, and the Long Term Quality Alliance. She is a frequent speaker on issues critical to the sector.



Megan Davies MSc

Megan Davies is in the final stages of Ph.D. at the University of Basel and Maastricht University under the TRANS-SENIOR network and training program. Her research focuses on optimizing transitions into long-term residential care for older adults, with a focus on person-centered care using ethnographic methods to improve quality of life for residents following a move into care. Her Ph.D. project, titled Tri-national Ethnographic Multi-case Study of Quality of Life in Long-term Residential Care (TRIANGLE), has included ethnographic studies in Switzerland, the UK, and the Netherlands and has included periods of data collection in long-term residential care during the COVID-19 pandemic. Megan has a background in sports science, where her focus was the impact of physical activity on neuropsychological dementia symptoms. She has also worked to explore experiences of and factors influencing physical activity in people living with HIV.



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Freek Lapré works as a certified management consultant (CMC) mainly in long-term care, home health care, hospitals, health insurance companies, pension funds, investment banks, and housing corporations for Dutch and international clients, including in Europe, the U.S., China, and Australia. Along with his work as a consultant, he is an executive professor at the TIAS Business School of the Tilburg University in the Netherlands and is involved in the Master Health Administration (MHA) and other Master programs, including the Master Business Administration (MSc-BA). He holds a certificate in Higher Education Teaching from the Harvard Derek Bok Center for Teaching and Learning and is involved in executive training programs for management in elderly care and services in Europe and China.

**Donald Macaskill, Ph.D.**

Dr. Donald Macaskill has worked for many years in the health and social care sectors across the United Kingdom. A particular professional focus has been issues related to bereavement, palliative care, and individual human rights. For 13 years, he ran his own equality and human rights consultancy focusing on adult protection, risk, and personalization. He is the CEO of Scottish Care, the representative body for care providers in the independent sector in Scotland. He sits on a number of governmental committees and working groups and is a trustee of a number of charities.

On a panel at the 2021 Global Ageing Network virtual summit, Dr. Macaskill named what he considers the most challenging key issue facing our sector globally. He wisely advised that we must challenge the presumption that we know best. “Only then can we transform our field and what it means to grow old,” he said. That transformation starts with “older adults taking responsibility and ownership of their power.”

“Only then can we transform our field and what it means to grow old.”

AGEING POPULATION

An introduction to the challenges and opportunities.

Population ageing is a global phenomenon. The world is growing older due to several significant factors. People are living longer. Birth rates are falling dramatically. And many countries experienced a significant growth in population after World War II—the baby boom. The growth in the number and the proportion of older adults is impacting almost every country in the world.

Global Growth in the Number of People over Age 65

Age 65 is most often the age at which we begin to identify an individual as an older adult, and age 65 is the benchmark used for population ageing. In 2019, there were 703 million people aged 65 and over in the world. Projections are that number will double to 1.5 billion in 2050, with one in six people in the world age 65 or older.ⁱ

In 2000, the percentage of the population aged 65 and older exceeded 15% in 19 countries; now that number is 104 countriesⁱⁱ. The fastest growth in population ageing has been in Eastern and Southeastern Asia, Latin America, and the Caribbean. In Southeastern and Eastern Asia, the population aged 65 and over almost doubled between 1990 and 2019, from 6% to 11%. Looking ahead, the percentage of people aged 65 and older is projected to at least double by 2050 in these regions as well as in Northern Africa and in Western, Central,

and Southern Asia. Overall, three of four older adults will not be living in high-income countries in 2050.ⁱⁱⁱ

Increased Longevity

The significance of this increase is not just in the sheer magnitude of the growth. People are also living longer. In the period between 2015–2020, a person aged 65 could expect to live, on average, an additional 17 years. Due to health care improvements, environmental issues, and better nutrition, by 2050 that number will have increased to 19 years. While there is some variation by country, overall, we can expect life expectancy at age 65 to increase significantly. In addition, the gender gap between men's and women's life expectancy is expected to shrink over the next few decades and be more aligned.^{iv}

It is significant to note that in the last two years, in spite of gains in the recent decades, the increase in life expectancy at birth in the United States has declined by 1.5 years from 2019 to 2020. It has reached the lowest level since 2003, according to new provisional data from the U.S. Centers for Disease Control and Prevention.^v The drop in life expectancy in 2020 was the largest one-year decline since World War II, when life expectancy declined 2.9 years between 1942 and 1943. Time will tell whether the U.S. experience is an anomaly or a trend.

The growth in the number and the proportion
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More People Living Healthier Lives

People are not only living longer but also living more years in good health, according to the World Health Organization (WHO).^{vi} WHO monitors the Healthy Life Expectancy (HALE) index. Their data shows that both life expectancy and healthy life expectancy rise with national income levels. However, the fastest improvements were reported in low-income countries, gaining over 11 years in life expectancy and nearly 10 years in HALE in 2000–2019. This is largely due to progress in reduced mortality among children under five years of age. Years living with a disability are also decreasing. Thus, we are seeing not just an extension of life but an extension of a healthy life, although both are not happening at the same pace.

At least half of the growing population of older adults will need some long-term care services.

At least half of the growing population of older adults will need some long-term care services. Healthy longevity is the state in which years in good health approach the biological life span, with good physical, cognitive, and social functioning, and it enables well-being across populations. Major disrupters to healthy longevity include ageism, disease, poverty, pollution, and inequity. As Victor J. Dzau, president of the U.S. National Academy of Medicine, writes, “Humanity needs to fundamentally shift how we are preparing for population aging to maximize the number of years lived in good health—not simply extend the number of years lived.”^{vii}

Coming Challenges to Long-Term Care

The increase in longevity has significant implications for our systems and our infrastructure for long-term care. At least half of the growing population of older adults will need some long-term care services for a period of time in their lives. The ability to meet that need will be challenged by a number of factors, including the increasing imbalance between young and old. The gap between number of people aged 65 and older relative to the number aged 20–64 and typically in the labor force will widen, creating a caregiving and financial challenge.

The share of the “dependent” population is calculated as total older adult and youth population expressed as a ratio of the total population. The older adult dependency ratio is defined as the ratio between the older adult population and the working-age population, which is typically 15–64 years old.^{viii} The charts below show the growing gap.^{ix}

Caregiving Challenge

Birth rates are falling dramatically.^x As of 2015, birth rates in nearly every region except Africa have dropped below the “replacement rate”—the rate of births required to keep a population stable. In India, for example, in 2022 there were 17.1 births per 1,000 people, a drop of 1.23% from 2021. In Israel, with a birth rate of 19.2 births per 1,000 people, the drop is even more pronounced at 1.49% from 2021–2022.ⁱ

Low birth rates contribute to a more than doubling of the “old age dependency ratio,” which poses a particular challenge to the ability to support people as they age.

Demographic dependency ratios, 2016–2070 (%)

	Old-age dependency ratio (65+/15–64)			p.p. change	Very old-age dependency ratio (80+/15–64)			p.p. change	Total dependency ratio (0–14 and 65+)/(15–64)			p.p. change
	2016	2060	2070		2016	2060	2070		2016	2060	2070	
BE	28.4	43.5	45.2	16.7	8.5	16.9	18.4	9.8	54.7	71.0	72.5	17.8
BG	31.5	63.0	56.2	24.7	7.2	24.6	26.8	19.6	52.9	89.3	81.6	28.7
CZ	28.1	55.7	49.7	21.6	6.1	22.9	23.3	17.2	51.6	83.6	75.6	23.9
DK	29.5	45.0	50.2	20.8	6.7	17.1	18.9	12.1	55.5	71.2	77.7	22.2
DE	32.2	55.1	55.9	23.7	8.9	21.4	24.1	15.1	52.3	79.9	81.0	28.7
EE	29.7	55.7	52.7	23.0	8.1	20.9	24.9	16.9	54.6	83.2	79.0	24.4
IE	20.9	44.2	41.2	20.4	4.9	18.7	19.0	14.1	55.4	75.4	70.2	14.9
EL	33.4	67.2	63.1	29.7	10.3	32.7	31.0	20.7	55.8	89.6	86.0	30.2
ES	28.6	53.2	46.6	18.0	9.2	26.9	22.4	13.1	51.5	81.8	75.3	23.8
FR	30.4	43.3	44.8	14.4	9.4	19.0	18.9	9.5	59.8	73.0	74.6	14.8
HR	29.3	53.7	56.2	26.9	7.5	20.3	23.3	15.9	51.5	77.0	80.0	28.5
IT	34.5	61.0	60.3	25.8	10.5	28.4	26.8	16.3	55.6	83.3	83.5	27.8
CV	22.2	55.7	61.0	38.7	4.9	18.2	25.4	20.5	45.6	75.9	81.7	36.1
LV	30.5	65.2	53.8	23.3	7.9	25.0	27.3	19.5	54.2	97.1	81.8	27.7
LT	29.0	63.9	53.1	24.1	8.1	25.7	24.9	16.8	51.2	94.4	79.3	28.1
LU	20.6	44.6	48.9	28.2	5.8	16.2	19.5	13.7	44.3	69.9	74.9	30.6
HU	27.5	53.2	52.0	24.5	6.4	21.6	22.0	15.5	49.1	79.8	78.6	29.5
MT	29.1	53.9	55.8	26.6	6.4	20.1	24.3	17.9	50.6	80.5	82.3	31.7
NL	28.1	44.3	48.4	20.3	6.8	17.5	18.7	11.8	53.2	70.7	76.1	22.9
AT	27.6	51.3	54.4	26.9	7.4	19.3	22.3	14.9	48.8	75.6	79.2	30.4
PL	23.7	64.9	62.2	38.5	6.1	24.4	30.3	24.2	45.6	90.3	86.7	41.1
PT	32.1	64.9	67.2	35.1	9.3	30.2	29.8	20.5	53.6	85.8	89.7	36.2
RO	26.3	56.7	52.8	26.6	6.4	23.3	24.4	18.0	49.1	84.7	80.8	31.7
SI	28.1	55.0	50.2	22.1	7.6	23.4	23.8	16.3	50.5	82.0	76.5	26.0
SK	21.0	59.4	56.8	35.8	4.5	22.3	26.2	21.7	42.9	85.6	82.7	39.7
FI	32.8	49.7	52.0	19.1	8.3	18.8	21.7	13.5	58.7	75.9	78.3	19.5
SE	31.6	42.7	43.2	11.6	8.1	15.7	17.5	9.4	59.5	73.0	73.0	13.5
UK	27.9	43.5	46.0	18.0	7.5	16.5	18.5	11.0	55.4	71.2	73.7	18.3
NO	25.2	44.1	47.2	22.1	6.4	16.5	18.7	12.3	52.3	71.1	74.6	22.3
EA	30.9	52.3	51.8	20.9	9.1	22.7	22.6	13.6	54.3	78.5	78.4	24.1
EU*	29.6	51.6	51.2	21.6	8.3	21.6	22.3	14.0	53.5	78.2	78.0	24.6
EU27	29.9	53.1	52.2	22.4	8.4	22.5	23.0	14.6	53.2	79.5	78.9	25.7

Source: Commission services, Eurostat 2015–based population projections.

With lower birth rates, fewer individuals will be available to provide professional hands-on care for older adults.

Fewer working-age people will be contributing to the economy, which means fewer public funds to support social programs, including long-term care. Fewer individuals will be available to provide the professional hands-on care that so many older adults will need in later life. And fewer children will be available to support their older family members. A more complete picture of informal care is described later.

Diversity Among Older Adults

While it is common to define people on the basis of age, it is important to note that older adults are not homogenous. Varied physical, cultural, and social environments, personal characteristics, and many other factors create great diversity among older adults. Our systems of long-term care must recognize and support this diversity.

Financial Challenges of Long-Term Care

Long-term care services and supports are expensive. Older adults and services for older adults are largely financed through public transfers or personal finances, when available, and wages.^{xii} Particularly in Europe and Latin America, older adults depend heavily on public transfers, which support almost two-thirds of their spending.

In these countries, population ageing will put increased financial pressure on these older adult support systems, unless patterns of taxation and benefits change. In other countries where public transfers are relatively low, such as many Southern and Southeastern Asian countries, the financial burden will fall on individuals and families.

The risk in these countries is that, without adequate social protection programs, inequities in access to services and supports will grow dramatically. In other countries such as the U.S., Canada, the Netherlands, and the U.K., although they use differing long-term care models, population growth will challenge financial allocations and the sustainability of long-term care.

Opportunities with Population Ageing

Demographics alone do not paint a complete picture. The “longevity economy” is taking hold. “As the demographics of global ageing are transforming and accelerating, it is now critical to build a new understanding of the shifting physiological, cognitive, social, family and psychological realities of the longevity economy.”^{xiii}

Increased attention from businesses and the social sector show that we are starting to em-

In some countries, population ageing will put increased financial pressure on older adult support systems, unless patterns of taxation and benefits change.

brace the opportunities that come with more older adults. Discoveries in science, medicine, and lifestyles enable people to maintain good health longer. Examples include innovation in service delivery and technology, among other things. While this progress may delay the onset of the need for services and supports for some, the need for long-term care will remain with us.

Importance of Government Investment in Older Adults

As the numbers of older adults grow, governments will have no choice but to invest in the supports older adults need, to give them agency and to protect their rights, including the right to long-term care.

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WHAT IS LONG-TERM CARE FOR OLDER ADULTS

Learn long-term care's definition, structure, and characteristics.

Daily health care requirements for the older population have increased in a steadily increasing aging population due to worsening chronic illness, multi-morbidities, acute illness, or deterioration of mental health.^{xiv} This situation has increased the need for long-term care in later life. Long-term care is an overarching term for health, social, and residential care provided to people with chronic illness over an extended period of time.^{xv}

Definition

Long-term care for older adults can vary depending on needs and includes assistance with activities of daily living (ADLs) such as washing, dressing, and mobilizing or assistance with instrumental activities of daily living (IADLs) such as managing medication and finances and needing assistance with food preparation and house maintenance. Care can also include types of medical care. Long-term care can take place at home, or alternatively it can be provided in residential homes for older adults.

According to WHO, long-term care services for older adults include the following: "Traditional health service such as management of chronic conditions, rehabilitation, palliation, promotion and preventative services. However, long-term care services should also include

assistive care services such as caregiving and social support for older people. All these services must be integrated and provided in a continuum with the underlying core principles of person-centred care."^{xvi}

There is pressure globally to ensure both accessible and affordable long-term care.

Global Need for Accessible and Affordable Long-Term Care

There is pressure globally to ensure both accessible and affordable long-term care. Formal provision of care varies country to country, depending on demographics, public policy, and economic status. Although the majority of Organisation for Economic Co-operation and Development (OECD) countries have government schemes, which contribute to provision of care for all types of long-term care, this structure again varies by country.^{xvii}

Considering the demographic effects in the coming years, health expenditures for the older population likely will grow significantly in OECD countries and more so in non-OECD countries.^{xviii}

Home Care and Informal Caregivers

Home care generally remains the preferred type of long-term care for older adults, as it continues social contact and daily routines. In addition, there can be a perceived cost benefit to remaining at home as long as possible, although in reality, costs of daily care support and needed home alterations mean that home care costs can surpass residential care (See Figure 1).

Informal care is still more common than formal care, and older adults prefer it.

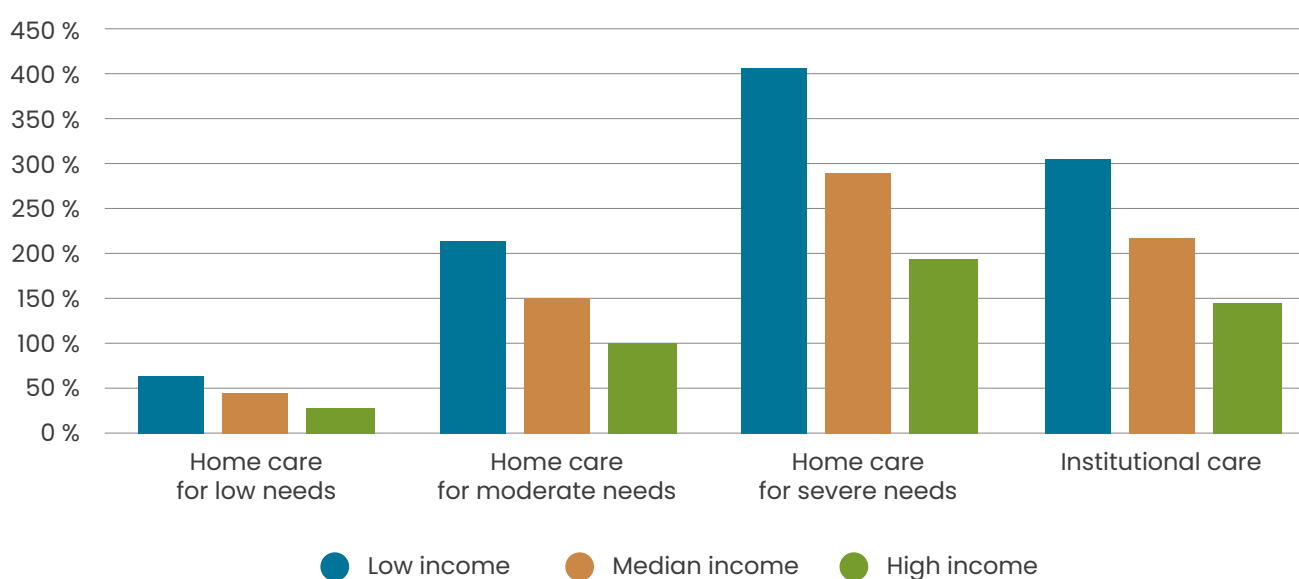
Long-term care at home is necessary for older adults who require further support due to functional or cognitive decline. This support can include personal and instrumental activities of daily living.^{xix} Long-term care at home can be provided by informal caregivers, which are

defined as relatives, spouses, or friends providing support due to a person's age, physical or mental illness, or a physical or learning disability.^{xx} Formal paid services can also provide this support.

Despite demographic and social changes resulting from smaller family sizes and altered working patterns, informal care is still more common than formal care, and older adults prefer it.^{xxi} Informal care is most commonly provided by a spouse, who may also be living with age-related comorbidities, or an adult child, who may also be caring for their own family and/or working at the same time.

As a result, informal caregivers are at increased risk of mental and physical stress, which can lead to caregiver burden and ultimately the risk of an earlier care home placement for the person being cared for.^{xxii}

The total costs of long-term care for moderate and severe needs are not affordable across different settings without social protection



Note: Bars show unweighted averages for jurisdictions in 19 Member States. The costs of residential care include the provision of food and accommodation, so are over-estimated relative to homecare.

Source: OECD analyses based on the long-term care social protection questionnaire and the OECD income distribution database.

Community-Based Services Support In-Home Care

Services within the community complement the home care services designed to support older adults with activities of daily living. These services act as a further resource of support to both the person needing assistance and their family members. Services can include general household assistance (cleaning, financial, etc.), day centers for people living with dementia, counseling services for caregivers, transportation services, respite care, and more.

Access to community services aims to keep older adults in their own homes for longer.

Providing access to community services aims to keep older adults in their own homes for longer, which can meet their individual preferences and fit with financial needs.^{xxiii}

Increased Need for Long-term Residential Care

Long-term residential care is an umbrella term for residential environments providing care to older adults who live there on a permanent 24/7 basis. Nursing homes and care homes are examples.^{xxiv} Long-term residential care facilities provide both medical services and a home environment for older adults.^{xxv}

In 2013, the number of people in OECD countries living in long-term residential care was 2.3% of the total population, which was up from 1.9% in 2003. Of those living in long-term residential care in Europe, up to 80% of residents are made up of people experiencing cognitive decline or living with a dementia.^{xxvi} Levels of daily health care requirements for





older adults due to worsening chronic illness, multi-morbidities, acute illness, or deterioration of mental health have increased in an aging population.^{xxvii}

This situation, combined with changes in social trends such as reduced informal support from families as more women work outside the home, has increased the necessity of long-term residential care in later life.^{xxviii}

The setup of long-term residential care homes for older adults differs in each country. Care home regulations are decided by country, and the provisions for care can be decided by a federal government or by individual states, regions, counties, or cantons. Having either state-run or privately operated long-term residential care homes is common, and these homes vary in the levels of care provided.

Conclusion

Both home care and long-term residential care are designed to support older adults at a time when a decline in physical or mental capabilities cause an increased need for assistance. The choice between remaining at home with care or moving into long-term residential care depends on individual circumstances, including finances, support networks, and preferences of older adults and their family members.

Ultimately, either version of care should aim to maintain the level of quality of life for the older adult receiving care. It should also reduce any potential burden on the caregiver, so that they can enjoy time with their loved one.

Care should aim to maintain the older adult's quality of life
and reduce caregiver burden.

LONG-TERM CARE TODAY

Understand why long-term care is vitally important.

The demographic realities of the older adult population are discussed elsewhere in this paper. The numbers are staggering, especially in relation to younger-age cohorts who comprise part of the caregiver workforce for long-term care (LTC). While advances in medicine have helped increase life expectancy, estimations are that 50% of people over 65 will need long-term care services in the course of their lives. LTC includes a variety of services designed to meet a person's health or personal care needs on a continuing basis.

The Long-Term Care System in Perspective

Long-term care is commonly thought of as a physical place where nursing and paraprofessional services are rendered over a long period of time, several months or longer. In more recent times, LTC has also expanded to the home setting, where a variety of services and supports can be provided and designed to meet a person's health or personal care needs at home.

The LTC system is a continuum of programs, typically spanning independent living with services to skilled nursing and end-of-life

care. Interim components include retirement communities, adult day care, home health care and assisted living. Each program incrementally provides additional structure and services to meet increasing levels of support.

Many factors drive long-term care decisions: the need for certain health services and supports, the ability of informal caregivers, the accessibility of one's living environment, geography, economics, and an individual's personal wishes. Above all, personal choice and maximizing one's dignity and independence are critical. Each type of service is designed to meet a specific need; therefore, a robust long-term care system will have the full continuum available and accessible to older adults.

The choice of a long-term care program is often influenced by individual financial status and ability to pay. Where governments provide payment for long-term care, older adults have more individual choice. However, some governments only pay for LTC when higher levels of services are needed, such as care in a facility.

Importance to Individual and Family

Perhaps the most important reason for a robust long-term care system is to help people perform everyday living activities that enable them to stay connected to their community and maintain their dignity. Identity and connection are essential to mental and physical health, especially as one ages. Family and friends are significant contributors to com-

The programs provide an orderly approach for addressing health and personal care support, in a facility or at home.

batting social isolation, and those closest to an older adult may be the first to see a decline in abilities.

While planning ahead for long-term care needs is preferable to making decisions at a time of crisis, it is rare. Planning ahead allows older adults and their family or informal caregivers to become familiar with terminology and resources that will be beneficial over time.

Overreliance on family caregivers could lead to negative macroeconomic results.

Challenges of Family Caregivers

The LTC system must be responsive to the target population—older adults and family members. It is well documented that when and if an individual should need assistance with daily living activities, their overwhelming preference is to receive that support at home. Many countries have met that preference with a robust set of services that can be offered in the home—from paraprofessional services to nursing and therapies.

When care is provided in the home, family caregiving becomes an important part of the LTC system. The individual attention, personal preferences, and loving care of a family member are irreplaceable. But the 24/7 responsibility can be taxing over a prolonged period of time. As a result, a combination of family and salaried home care workers is optimal, often supplemented by technologies that can monitor health.

Overreliance on family caregivers can lead to negative results. Employed family members





Each component of the system uses professional staff to develop an individualized care plan for an older adult.

often have difficulty reentering the labor market after caregiving. They may strain their physical and mental health while providing care, leading to higher health care costs. In the aggregate, the result may have a negative impact on labor markets and countries' economies.

Continuum Design and Efficiency

Nursing homes or care facilities are essential in the continuum because they offer a continuous health-oriented, safe environment. When an older adult is living with dementia, has mobility limitation or serious illness, the LTC system's care facility resource may be the most appropriate resource to meet the individual's challenging needs. While end-of-life care can ideally be provided at home, a care facility can provide families with the needed respite while a loved one receives careful medical and supportive attention at this later stage of life.

Each program in the system uses professional staff to develop an individualized care plan for the older adults. This plan addresses specific health and daily living priorities. Integrated goals and time frames motivate all to work in unison in the best interests of the care recipient. Absent an organized approach, the recipient may languish amidst multiple well-intentioned but disconnected programs and resources.

Long-Term Care as a Safety Net

The importance of the LTC system is to serve as an effective safety net to meet older adults at their level of need for support with activities of daily living, health care, choice, and access. The system also provides support to family members who may be unfamiliar with available resources and may be too close to assess the balanced decision-making necessary as caregiving needs and choices evolve. Options are important, and government should give considerable attention to designing a system that is affordable and accessible and fosters independence to the greatest extent possible.

The importance of the long-term care system is to serve as an effective safety net for older adults.

KEY CHALLENGES

INFORMAL CAREGIVERS

Learn why family caregivers are the backbone of long-term care and what challenges they face.

Informal and Family Caregivers

An informal caregiver is an individual who provides regular care (personal care and/or help with household activities, including childcare) over an extended period on a non-market basis to a care recipient in the informal caregiver's close social environment. Often, family members serve as informal caregivers.

Family caregivers act as informal carers and provide care on a regular basis. Providing informal care can hinder their formal labor market participation, resulting in loss of income and lower accumulation of pension rights. Risks of poverty, increased mental and physical health challenges, and social exclusion are associated with intensive informal caregiving. There is some evidence that more generous formal care provisions lead to less prevalence of intensive informal care.

Risks of poverty, increased mental and physical health challenges, and social exclusion are associated with intensive informal caregiving.

Women and Informal Caregiving

Women are more likely to provide informal care and provide care for more hours over a long duration, often years rather than months.

The overrepresentation of women in informal care may impact gender equality, as caregiving may affect women's ability to work outside the home. In many developing countries, the ability to provide family care is under pressure as women have entered the workforce.

Informal caring is possibly the most important part of how long-term care is organized.

The COVID-19 pandemic brought additional challenges for informal caregivers, in addition to general concerns about how to avoid infecting family and friends. Reportedly, support for caregivers that was already insufficient decreased after the outbreak, and some informal caregivers were not able to balance paid work and caring responsibilities. Undoubtedly, measures such as paid medical leave can be taken to better prepare caregivers and care recipients for a similar situation in the future.

Informal caring is an important, if not the most important, part of the long-term care system. It is distinct from paid caregiving—whether full time, live-in, from an agency or formal service, or through a direct relationship between the care recipient and the caregiver.





Informal Long-Term Caregivers Are Fundamental to Caregiving

Because of the variability and informality of informal caregiving, no reliable official statistics exist on the number of informal caregivers providing long-term care. Though estimates will depend on the survey and methodology used, the statistics below suggest that informal caregivers are fundamental to caregiving in the European Union (EU).^{xxix}

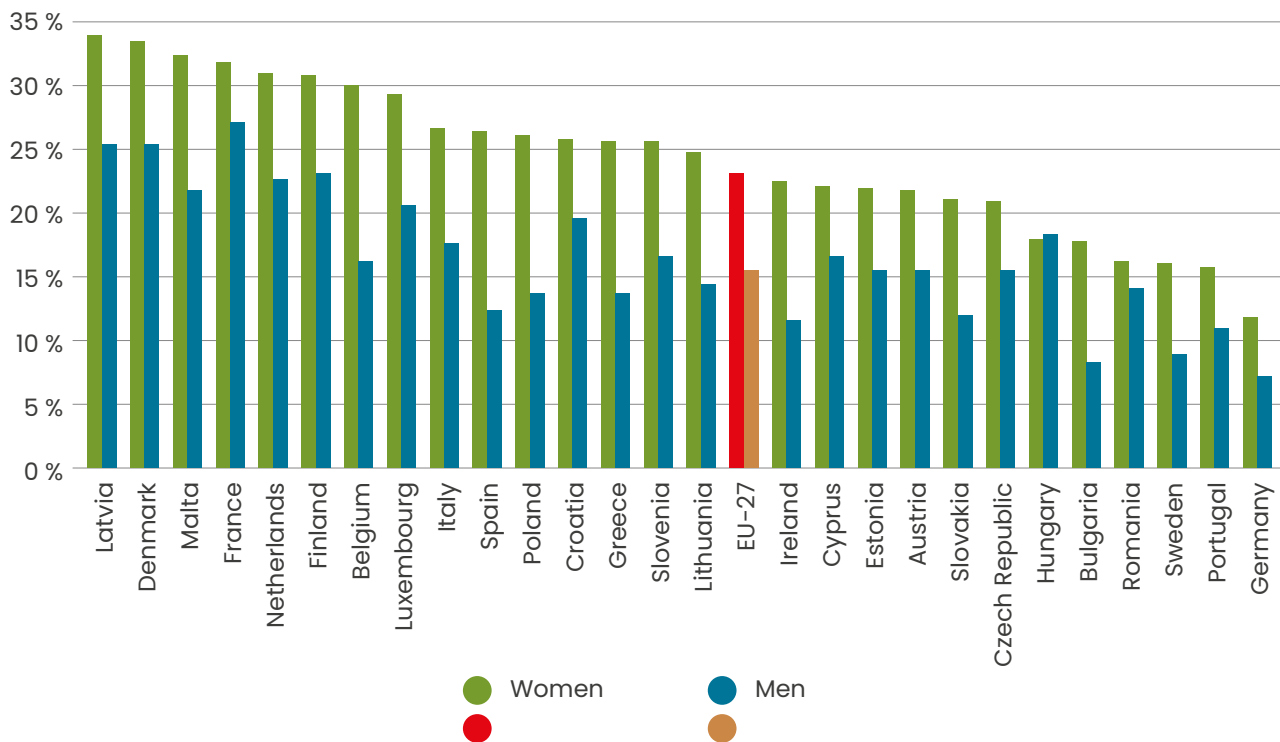
- Eurofound estimates, based on the European Quality of Life survey, that around 44 million people above the age of 18 years in the EU provide informal care more than twice a week.^{xxx}
- In line with this figure, EC & SPC (2021a) report from a recent study^{xxxi} that between 12–18% of the EU population aged 18 years and above provide LTC at least once per week, corresponding to more than 50 million people.
- Eurocarers, a European organization raising issues of concern to informal caregivers, estimates that 80% of all caring in the EU is performed by informal caregivers.
- Of people aged 65+, more than 7 million people (8%) receive informal care in the EU27. For the subgroup of people aged 75 and above, the number relying on informal care amounts to 11%.^{xxxii}

Employment rate decreases
with the intensity of care
provided.

Reduced Employment Rate of Informal Caregivers

The majority of working-age informal caregivers combine caring with paid work, but the employment rate decreases with the intensity of care provided, according to the Informal

The share of women aged 45–64 providing informal care is higher, in almost all Member States, than the share of men in the same age group



care in Europe report, EC 2018. Statistics support this finding:

- At the EU level, two thirds (64%) of informal caregivers of working age (18–64) are employed.^{xxxiii} This is slightly less than the 67% employment rate in the total working-age population.
- The employment rate of low-intensity caregivers (less than 10 hours of informal care per week) of working age (71% at the EU level) is higher than for the total working-age population in all EU Member States (67%). However, the employment rate decreases with the intensity of informal care, ranging from 71% (less than 10 hours per week) to 63% (10–19 hours), 57% (20–39 hours), and 35% (40 or more hours) at EU level.

Complementary research finds a link with the provision of formal care.

- In EU Member States where formal long-term care is least available, the employment rate among frequent caregivers is 10 percentage points below that of other people.
- In EU Member States where formal long-term care is most commonly used, this employment gap is just 3 percentage points.^{xxxiv}

Informal caregiving also affects the ability to find and keep jobs.

- Among people aged 18–64 providing informal care to household members, 21% of those who searched for work were employed one year later, compared with 24% for inactive people in general aged 18–64 searching for work (excluding people with a disability).^{xxxv}

Economic Pressure and Government's Role

Much informal caregiving is provided by family members out of duty and love as well as financial considerations. Financial factors may affect the decision to continue informal caregiving, to hire external help, or to consider placement in a long-term care home.

There is a gap in regulations for home care and support, especially for informal care.

While formal long-term care is heavily regulated, there are few, if any, regulations for informal home care and support. Regulating quality of care and quality of life is difficult, given the informality of these arrangements. In contrast, formal long-term care is regulated around quality indicators that are sometimes tied to funding, inspection, and accreditation. Ideally, we would be able to protect informal caregivers from potentially unsafe working conditions, but this is complicated when caring for family members.

Support Needed for Informal Caregivers

Governments should consider ways to provide pension rights and other benefits to informal caregivers.

Costs of Leaving Formal Work

Intensive informal care can hinder full-time or part-time participation in formal work, with a detrimental longer-term impact on career progression and earnings. Informal caregivers who stop working while providing informal care experience a significant direct annual net wage loss. Depending on the indirect effect on later career progression and wages, the total

cost of caring could rise as length of informal caregiving relationships continue.

The risk of poverty, risks to mental and physical health, and social exclusion are associated with intensive informal caregiving. Though some countries provide pension credits for a period of long-term caring, if those are not available, longer periods of informal care can affect pension rights' accumulation. Caregivers may also suffer from lack of access to social security benefits, such as health care or unemployment benefits.

Need for Training Informal Caregivers

The quality of care that informal caregivers are able to provide is a concern, because usually they are not professionally trained in personal care tasks. Informal caregivers need access to training to gain that knowledge. They also need access to respite care and time off from caring. Governments can support training and respite programs for informal caregivers.

Informal caregivers usually are not professionally trained in personal care tasks.

Ensuring Safety and Quality of Care

Even with support measures available, quality of care is difficult to monitor, and the care recipient may not have access to complaint mechanisms if problems arise. In the worst cases, this scenario can lead to fundamental rights' abuses.

Countries around the globe face several challenges in attracting formal long-term caregivers.

Ageing Demographics

The need for long-term care can occur at all ages, but the share of people in need of LTC rises steeply with age, in particular after the age of 75. Demographic ageing will mean an increase in the number of people in need of LTC in the coming decade and beyond, requiring more caregivers, especially informal caregivers.

Countries around the globe face several challenges in attracting formal long-term caregivers who can provide respite and support for informal caregivers. Expanding the LTC workforce will be a prerequisite for fulfilling a human right principle that everyone has the right to affordable long-term care services of good quality, in particular home care and community-based services.

Policy reforms are required to deliver on this goal. A framework can guide the development of sustainable long-term care to ensure that older adults can find the best care and the best life balance for them. Against this background, the ageing economy is ground zero for formal and informal long-term caregivers and their working conditions, and associated policy changes are needed to address these challenges.

The Way Forward: Supports for Informal Caregivers

Governments are encouraged to implement additional measures to ensure that informal caregivers do not suffer financial setbacks and do have supports for the physical and emotional impacts of providing care. Policymakers should consider providing the following supports for informal caregivers:

- Strengthening job-leave provisions,
- Creating tax incentives and supplementing pension plan contributions,

- Bolstering respite support, and
- Offering care management to coordinate the care recipient's supports and procure access to additional programs such as home delivered meals and adult day programs, plus information to support the caregiver.

Designing policies to help older adults age at home and to build up long-term care infrastructure is needed.

New investments are needed to improve the quality and safety of the full continuum of long-term care:

- Significantly more investment in long-term care,
- Better access to formal home care, and
- Strong support for informal care.

Over the next decades, it is important to find a balance between formal and informal care, ensuring both the individual and system levels have enough capacity. An integrated system of informal and formal care depends on care coordinators to support informal caregivers while connecting older adults with needed programs and services. A robust care navigation function can guide older adults through programs and services within the continuum of care.

Policies Can Address Long-Term Care Gaps

As attention has shifted to life beyond the pandemic, a window of opportunity to reform long-term care has opened. Policymakers should move quickly to address the gaps in long-term care that place an unreasonable burden on informal caregivers. New and thoughtful policies can help older adults receive the long-term care services that will improve their quality of life—at home, in long-term care facilities, and in their communities.

KEY CHALLENGES

DEMENTIA ONSET

Understand the costs and challenges of caring for someone with dementia.

The word “dementia” describes a group of symptoms that includes problems with memory, thinking, or language, and changes in mood, emotions, perception, and behavior. Dementia is not a natural part of ageing. It is caused when the brain is damaged by disease. The most common types of dementia are Alzheimer’s disease and vascular dementia.^{xxxvi}

Older people living with dementia represent a huge care strain for formal and informal caregivers. In the professional care sector, in some countries, the majority of new residential settings being built are special nursing homes for people mainly with dementia

Challenges of Caring for Someone with Dementia

Informal caregivers sometimes have great difficulty caring for family members until the end of their lives, especially without professional support, help, and relief. These caregivers often need adjustments to their living environment. They often do not know how to communicate with and understand people with dementia or how to provide care and support for them. In addition, caregivers face the extreme mental demands of watching their loved one’s personality break down due to dementia.

Caregivers face extreme mental demands of watching their loved one’s personality break down due to dementia.

Older people with dementia represent a big care responsibility for society at large, health and social systems, families, and caregivers. It has a significant impact on what long-term capacities are needed now and in the future and how the social protection and social services systems should be organized and focused.

Economic Impact of Dementia

Dementia has a substantial and growing economic impact worldwide. Every three seconds, someone in the world is diagnosed with dementia. The most up-to-date global estimate, published in the 2021 World Alzheimer Report, indicates that the global cost of dementia exceeded US \$1.3 trillion, an annual cost today in excess of US \$2.8 trillion. Forecasts expect this number to double by 2030 and continue to rise.



Every 3 seconds someone in the world develops dementia.



The total estimated annual world-wide cost of dementia is over US\$ 1.3 trillion. This figure is forecast to rise to US\$ 2.8 trillion by 2030*.

* WHO Global status report 2021



Estimated growth in number of people with dementia 2019–2050*.

* WHO Global status report 2021

The costs of caring for people with dementia are higher in higher-income countries. The costs are disproportionate relative to disease prevalence. Much of the responsibility of caring for people with dementia falls on families rather than on health care systems. The costs fall into three broad categories: direct health costs, social care costs, and informal family care costs. Direct health costs account for a modest one-fifth of global dementia costs. In high-income countries, informal care and formal social care each account for roughly 40% of costs. As country income level declines, the contribution of informal care increases.

In low-income and lower-middle-income countries, the dominant cost relates to unpaid care provided by the family, with approximately 94% of people with dementia living at home.

Rising Numbers of Dementia

Globally, Alzheimer's Disease International (ADI) estimates 75% of people with dementia are not diagnosed, equating to 41 million people who are likely living with dementia but do not have a formal diagnosis.



Globally, ADI estimates 75% of people with dementia are not diagnosed. That equates to 41 million people undiagnosed.

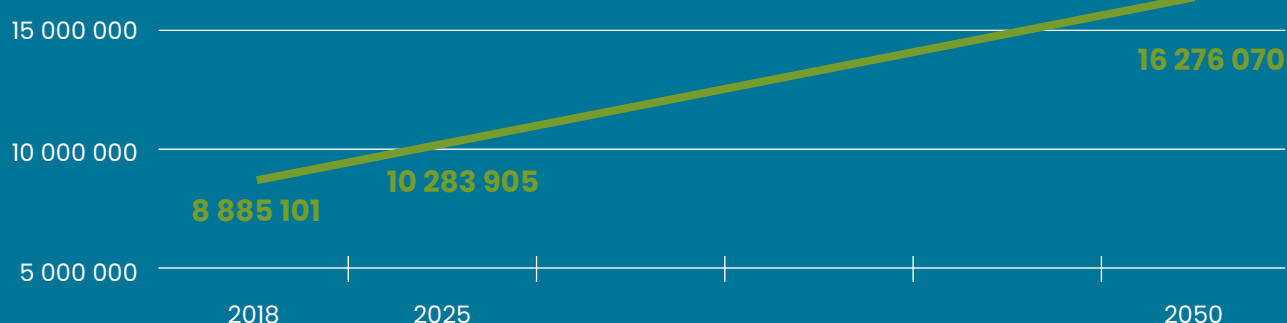


Rates of underdiagnosis are inversely related to the income of countries, from around 60% in HIC to above 90% in LMIC.

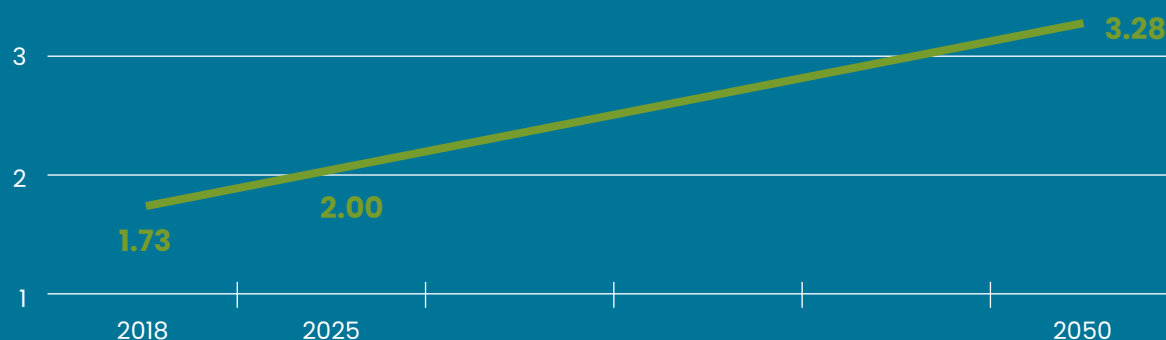


68% of people said they were given inadequate information at diagnosis. Conversely, 98% of Alzheimer and dementia associations stated that they provide updated diagnosis information on their websites.

The number of people with dementia in Europe EU 28 from 2018 to 2050



The number of people with dementia in Europe EU 28 as % of the total population from 2018 to 2050



The number of people living with dementia doubles every 25-30 years. In fact, in some European countries, the increase is 5% every year.

The graph below indicates that by the year 2050 in Europe, over 16 million people will be living with dementia, a rise from approximately 9 million people today.

While governments are proposing long-term care systems reforms or modifications, they must take into account this significant group of people living with dementia that is projected to grow in large numbers.

3 Major Impacts

The rising numbers of people with dementia will bring major impacts in three areas:

1. On public budgets (costs for social services, health care services, social protection, etc.).
2. On informal caregivers, mostly family members facing reduced quality of life, increased costs, impacts on their physical and mental health, withdrawal from the labor market, etc.
3. On human resources, as the rising number of people with dementia will require more and more caregivers, nurses, social workers, and other related professionals.

KEY CHALLENGES LONG-TERM CARE AND LIMITED RESOURCES

Explore the reasons that limited resources – underfunding and unsustainable funding models, staff shortages, isolation of older adults and caregivers, and more – challenge the sector.

The elder care sector faces limited resources, especially financial, staff, and society resources.

Governments

Governments are struggling with the increasing need for support and care for the ageing population.^{xxvii} They are, in many cases, rethinking their responsibility for financing professional long-term care. Some countries have universal coverage for their citizens' need for long-term care, based on taxation and co-payments.^{xxviii} However, the ageing population is putting pressure on this sub-system of solidarity, because the tax base is shrinking as populations age and tax rates are not keeping pace with the increasing financial costs of long-term care for older adults.

Cutting costs by shrinking coverage leads to more pressure on families and a lower quality of care and support for older adults. Raising the bar to limit access to residential care leads to higher rates of loneliness, social isolation, and increasing pressure on informal caregivers, like adult children. Reliance on in-

formal caregivers leads to more absenteeism in work and therefore to higher costs for employers and lower economic activity.

The challenge of governments is to create a sustainable long-term care funding system that is financially and socially acceptable to citizens.

The challenge of governments is to create a sustainable funding system for the long-term care sector for older adults, while making the increased expectation on their citizens both financially and socially acceptable. Society as a whole needs to be supportive of finding a solution to increase support and care for older people in an ageing society, not solely the social and health care sector. While there is a lot of rhetoric about the need for comprehensive policies on healthy ageing and prevention, they are far from a reality and are not keeping pace with the increasing numbers of older adults.

Unsustainable Funding

Many governments are freezing or cutting budgets for the long-term care sector, (although some increased funding during the height of the COVID-19 pandemic). These cuts put the providers under high pressure to deliver a higher volume of care at the same level of quality with the same or fewer funds. As stated before, in general, this funding system is not sustainable and must be thoroughly reformed.^{xxxix} It is recognized that this is one critical need among many including the Ukraine war and the energy crisis, which are putting demands on public budgets.

Staff Shortages

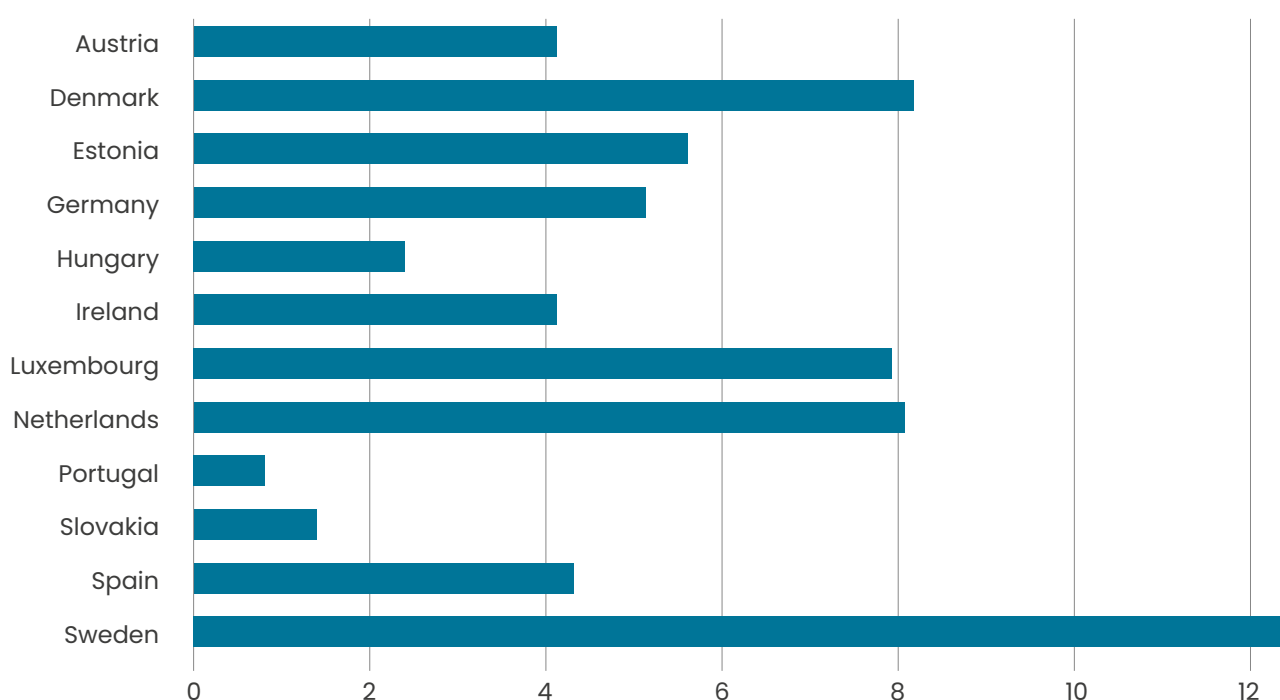
Social services employers, including long-term care providers, are Europe's biggest job creators with over 10 million employees, most of whom are women. Two million new jobs have been created since 2008, and many more are needed in response to the increase

in demands of an ageing society. This demand is continuously growing throughout the EU. However, staff turnover is high in the long-term care sector,^{xi} while the influx of new staff in the sector is lower than needed.

A complicating factor is the relatively high age of the current staff, who will retire in the coming decade. The median age across countries is 45 years, which is a year and one-half older than the general workforce.^{xli} The following figure shows the share of long-term care workers who are 65 years and over.^{xlii}

These combined factors lead to an unprecedented understaffing of the long-term care sector. In some countries, another factor is exacerbating the problem even more: the need to achieve qualifications for many positions, which requires lengthy education programs. Therefore, there is a lag between interest and availability.

Long-term care workers as a percentage of the population aged 65 years old and over, selected countries, 2015 (headcount)



Source: OECD Stat – https://stats.oecd.org/Index.aspx?DataSetCode=HEALTH_REAC

Costs of Focusing on Medicalization and Residential Care

Old age is a stage in life and not a disease. However, in some parts of the world, the support and care of older people currently is in the form of medical and nursing care. This perspective leads to a high degree of medicalization with multiple protocols and care and support based on the precautionary imperative. Every uncertainty in the life of the older person is seen as a risk and needs to be prevented by a zero-tolerance policy, sometimes by the government or the sector itself. A lot of checklists and procedures lead to bureaucracy.

The current focus on residential care makes caring for older adults costly.

Quality-of-life issues, like feeling lonely or depressed, are often solved by medication. While old age often comes with a feeling of declining condition and with multiple co-morbidities, it does not always require a 24/7 medical environment.^{xliii}

A medical strategy makes caring for older adults costly, as it is mainly focused on residential care. Ageing in place—in one's home or flat, is often seen by governments as a cheaper substitute for residential care. As long as the social context stays the same, where professional caregivers are providing the care, the costs are not likely to be less.

An Unfairly Distrusted Sector

The long-term care sector is underappreciated and lacks the trust of the public and policy makers. Policymakers and the media often provide a negative image, focusing on low-quality care and high costs.^{xliv} This unfair





depiction makes the sector an unattractive place to work and impacts the family members and the older adults themselves. Occasionally, there are lapses in quality that get outsized attention. When positive things happen, they are not news. This negative publicity increases staff shortages. A culture of naming and shaming and an avoidance of liability in care practices can be the result.

Society

Isolation of Older Adults and Caregivers

Society segregates many older people who are in need of care and support for conditions such as dementia. That means that solutions for the care of older people are sought solely in the long-term care sector instead of being seen as a societal challenge. We are all ageing and, therefore, there is a responsibility for all generations to seek solutions.^{xlv} Age-friendly neighborhoods that co-create with professionals offer a possible direction to realize society's responsibility.

Need for Advance Housing Planning

People live most of their lives in an environment that supports their needs. Many do not plan for their housing and care at later stages of life. In practice, it is best for people to plan ahead, particularly since the chronic shortage of affordable and accessible housing complicates the ability to make decisions in a time of need.

Conclusion

The long-term care sector for older adults is already struggling with limited resources:

- Budgets that are not growing to keep pace with the ageing of societies, resulting in insufficient availability of services of all kinds,
- Staff shortages are acute, and
- Negative perceptions of the sector exacerbate the challenges described above.

Governments must prioritize the needed transformation of long-term care for older adults in a suitable environment. The lack of affordable housing frustrates this transformation. Addressing these issues should be a top priority for governments.

There is a responsibility for all generations to seek solutions for the care of older people.

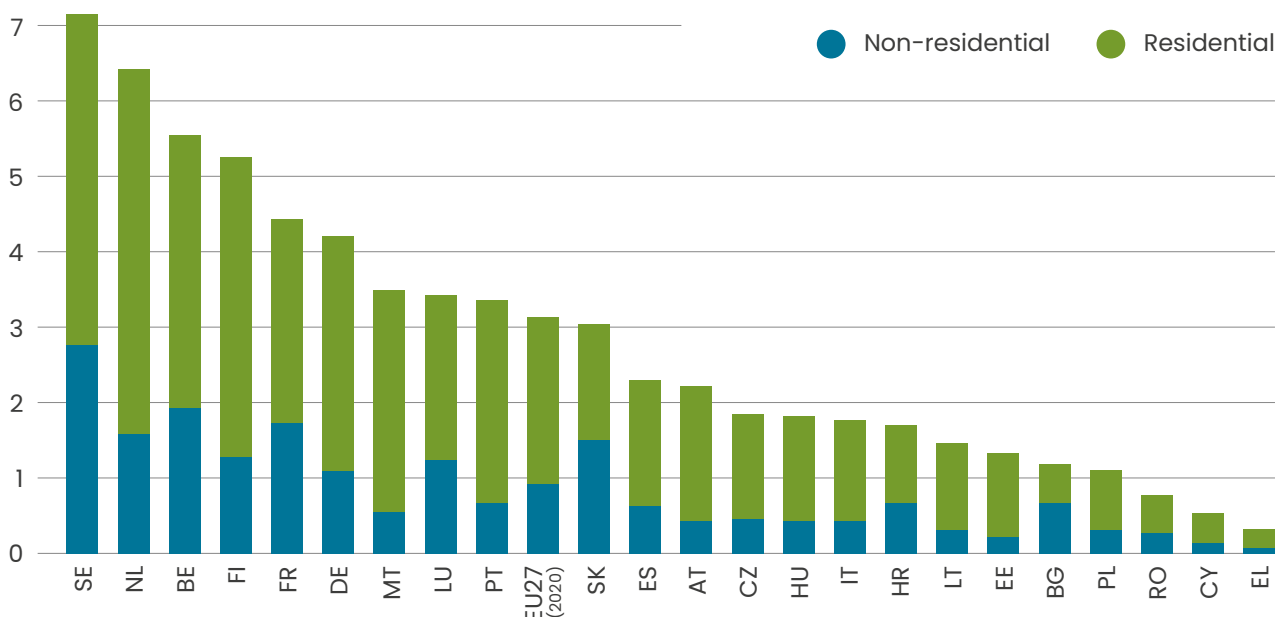
KEY CHALLENGES HAVING AN ADEQUATE SKILLED & QUALITY WORKFORCE & CAREGIVERS

Learn why changes to recruitment, pay, and appreciation for caregiving roles are essential.

Having a sufficient, quality workforce is the lifeblood of any care organization. Yet recruiting and retaining that workforce can pose major challenges, and those challenges underpin much of the response required from local and national governments.

In many countries, long-term care employs a significant percentage of the entire workforce, but this growth has stagnated in recent years in most OECD countries. (See *Table One* and *Table Two*.)

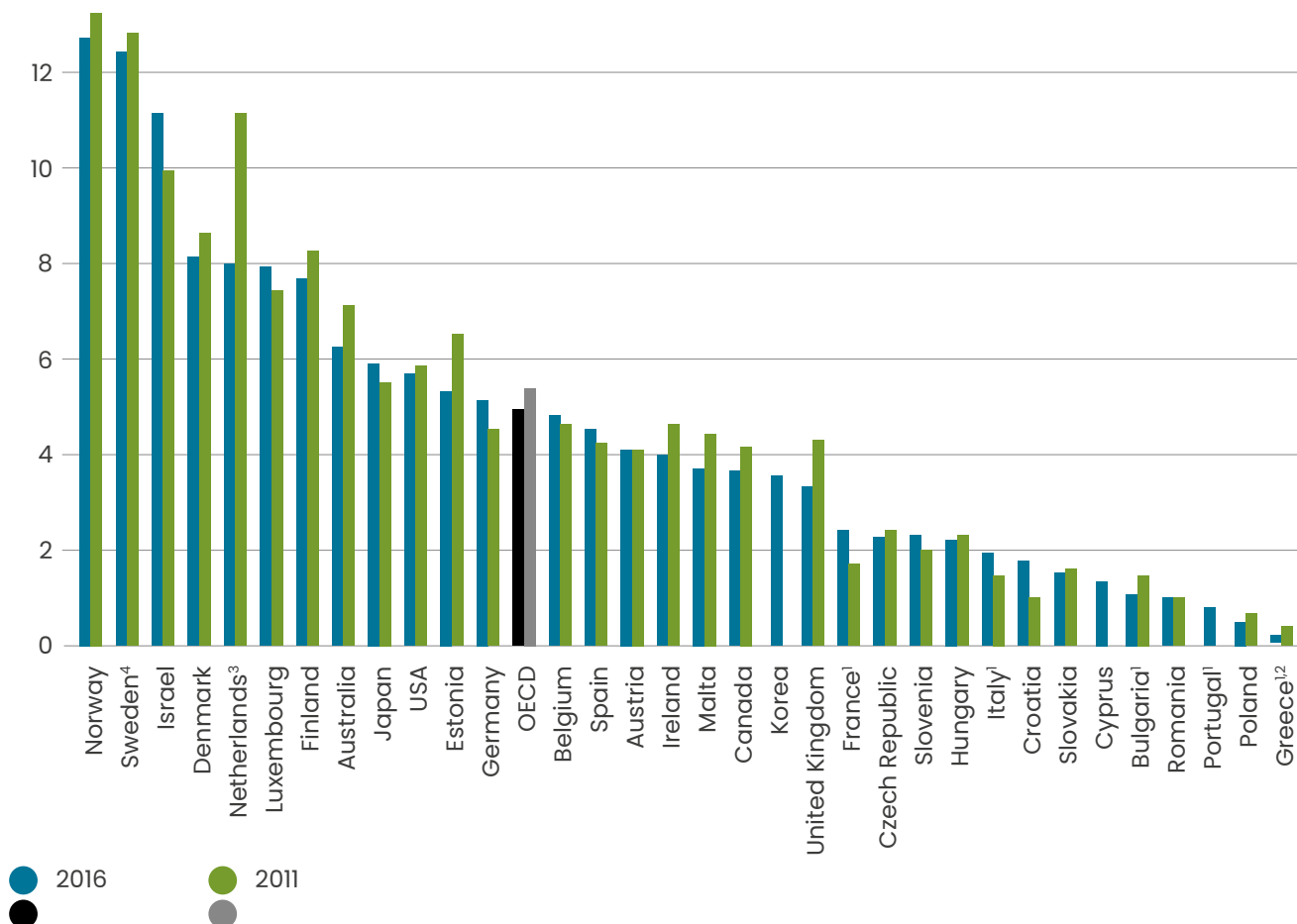
Table one: Long-term care workers as a share of the total workforce, by Member State, 2019 (%)



Notes: Annual overages of quarterly data. For some countries observations are missing and thus not all of the LTC workforce may be captured for certain age groups (Cyprus) or for the category NACE 88.1 (Denmark, Ireland, Latvia, Slovenia). The last four countries have been excluded.

Table two: In over three-quarters of OECD countries, growth in LTC workers per 100 elderly people has stagnated or decreased

Number of LTC workers per 100 individuals aged 65 and over, in 2011 and 2016 (or nearest year)



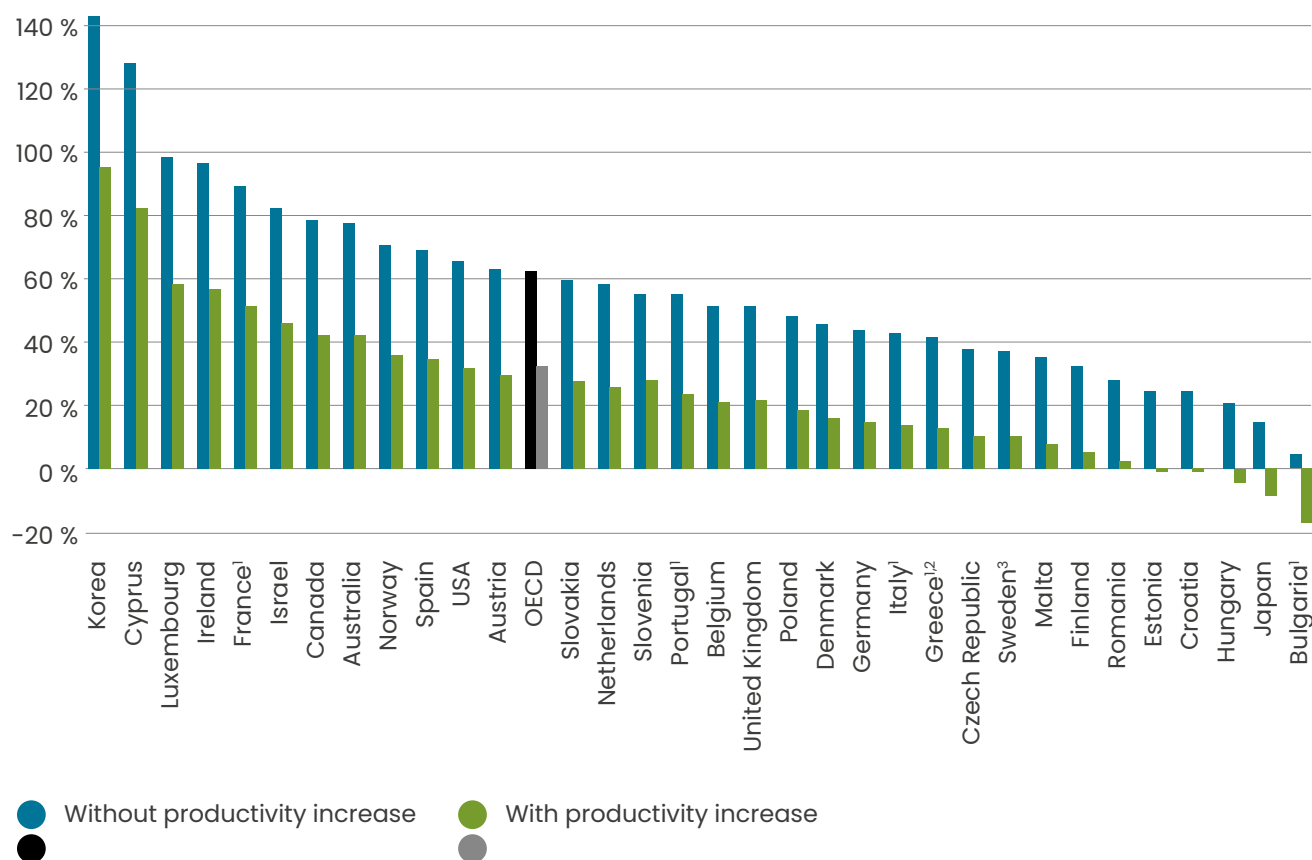
Note: The OECD data point is the unweighted average of the 28 OECD countries shown in the chart. EU-Labour Force Survey data are based on specific 4-digit codes of the international standard classification of occupations (ISCO) and the 2-digit codes of the classification of economic activities (NACE). 1. Data are based on ISCO 3-digit and NACE 2-digit codes. 2. Data must be interpreted with caution, as sample sizes are small. 3. The decrease in the Netherlands is partly due to a methodological break in 2012 as well as reforms. 4. Data refer only to the public sector in Sweden. Source: EU-Labour Force Survey and OECD Health Statistics 2018, with the exception of the Quarterly Labour Force Survey for the United Kingdom and ASEC-CPS for the United States; Eurostat Database for population demographics (data refer to 2011 and 2016 or nearest year).

Virtually every country, regardless of its demographic, is facing a social care workforce crisis, as studies from the European Ageing Network and the OECD make evident. Numerous challenges exist, including a struggle to recruit staff into the sector, problems of image and understanding of the value of the

care role, and difficulties in retaining existing staff against competition from other sectors. Of urgent significance is the reality of an ageing workforce. Study after study highlights the need to recruit additional staff. (See Table Three for statistics.)

Table three: An additional 60% LTC workers are needed by 2040

Number of additional LTC workers needed by 2040 to keep the ratio constant
as a share of the total number of workers in 2016



Note: OECD is The unweighted average of the 28 OECD countries shown in the chart. 1. Data are based on ISCO 3-digit and NACE 2-digit codes. 2. Data must be interpreted with caution, as sample sizes are small. 3. Data refer only to the public sector.

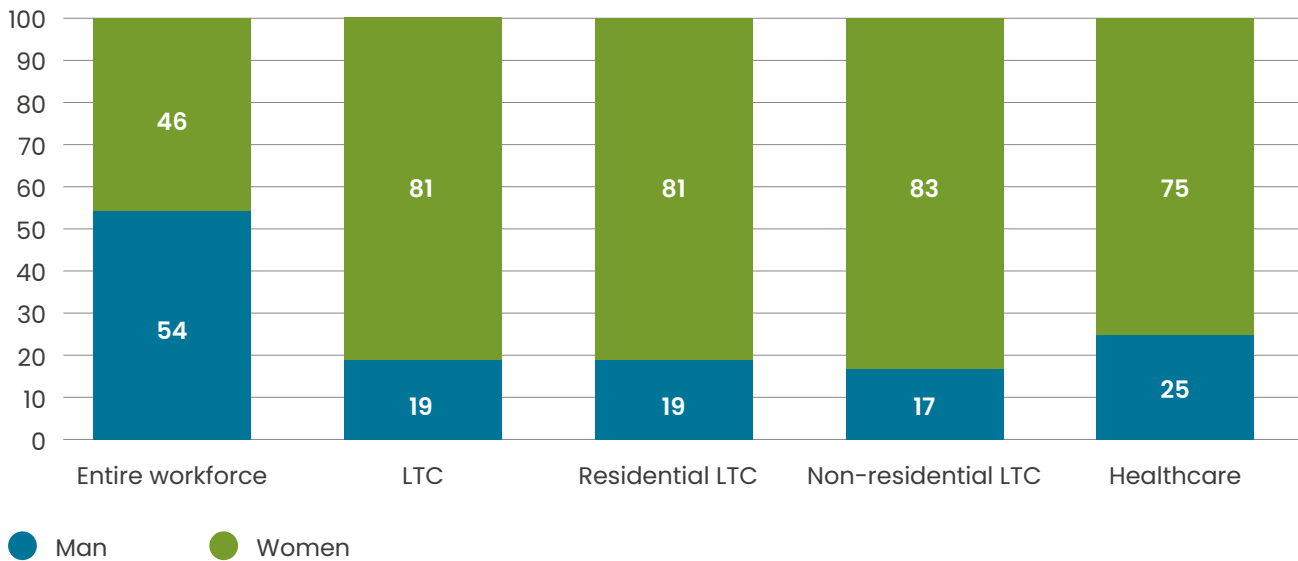
Source: EU-Labour Force Survey and OECD Health Statistics 2018, with the exception of the Quarterly Labour Force Survey for the United Kingdom and ASEC-CPS for the United States; Eurostat Database for population demographics (data refer to 2016 or nearest year).

As noted above, one of the major issues facing the long-term care sector is that the median age of the workforce across countries is 45 years, which is one and one-half years older than the general workforce.^{xlvi} There are several ways for national and local governments to address these issues in partnership and collaboration with those who employ, manage, and support the workforce.

Attractiveness of Role: Appreciation and Value of Care Gender Discrimination

Within the care workforce is a very real issue of gender segregation. Most of those employed are women, and the task and role of care support is often perceived and dismissed as “women’s work.” Negating the value of the role has led to many harmful outcomes, including diminishing social care as being of limited so-

Table four: Long-term care workforce by gender, compared with healthcare and the entire workforce, EU27 and the UK, 2019 (%)



*Note: Annual averages of quarterly data.
Source: Eurofound analysis of LFS extraction provided by Eurostat*

cietal worth and value. (See Table Four). The socio-economic contribution of social care to the economic well-being of a society is rarely noted or acknowledged.

We are calling on both national and local governments to invest in raising awareness of the value of social care, to address issues of gender discrimination from early years of education onward, and to undertake appropriate media profiling of the role in order to increase awareness and knowledge of the value of long-term care for older adults.

Diversity and Complexity of Caregiving Roles

Along with the lack of perceived value comes a lack of real and robust understanding of the nature of the care role itself. The general population, regardless of society and nation, fails to understand care for older adults as being much more than simple and valuable tasks of helping and caring to enable a person's independence and health.

The complexity of tasks involved – from basic personal care and health care and low-level clinical tasks to technical skills such as moving and handling, hoisting, offering pharmaceutical intervention, handling care management and administration, etc. – are rarely appreciated or acknowledged as core to the role of long-term care.

We are calling on both national and local governments to invest in raising awareness of the diversity of roles in long-term care to achieve the following:

- Increase awareness and help address the sector's recruitment and retention challenges, which block efforts to provide care to older adults;
- Work with secondary schools, colleges, and universities to create positive career pathways that highlight the sector's complexity and dynamic across all settings.

The complexity of the tasks involved are rarely appreciated or acknowledged as core to the role of long-term care.

Reward and Remuneration

The most frequently quoted reason for staff leaving long-term care and for recruiting shortfalls are the relatively low rates of reward and remuneration for frontline care staff. Various national and local administrations have sought to address these issues in their own way, recognizing the reality of the challenge as a sector that has faced systemic issues of low pay and poor terms and conditions.

We are calling for a global and united effort to exchange learning and support practices across the nations so that we can learn from successful models and approaches and address this major issue, which fundamentally will require substantial global financial investment. We believe that the issue of workforce terms and conditions merits a deliberate focus from the International Monetary Fund.

Recommendations for Recruitment and Retention

Many diverse strategies exist to attract people to work in long-term care, and these need to be built on with concerted and shared effort. Support must be given to share what works well and to cascade these approaches and models to other communities and nations.

We call upon national and local governments to allocate distinct, ongoing resources to support the care workforce's well-being.

We recognize that the pandemic has affected caregivers' mental health, and we call upon both national and local governments to allocate distinct resources on an ongoing basis to support the care workforce's well-being.

In particular, emerging evidence shows that a disproportionate number of long-term-care workers have developed symptoms of long COVID, and we call upon national and local governments to again prioritize this critical workforce in any interventions and support.

We also need to examine what we consider to be core attributes, skills, and tasks for frontline care and nursing staff to undertake. Frontline workers spend a disproportionate amount of time handling paper-based recording, reporting, and activity monitoring that other agencies and regulators require.

Learning and Development

Part of what keeps someone in a role and enhances their self-worth and growth is the extent to which they can continuously learn, develop, and progress along a career pathway within an organization or a sector. Models of learning and development within long-term care are now mature and tested, but they are often inadequately resourced. When funding is limited, this area tends to be the first to suffer restrictions.

We are calling on commissioners and contractors of long-term care services to ensure that appropriate priority and weight is given to organizations that seek to foster reflective practice and career development and to innovate around learning, leadership, and development.

Developing a Career for the Future with Technology

The long-term care sector embraces the future by pursuing emerging insights in relation to life-long conditions such as dementia and delirium. Globally, the sector is at the cutting edge of new technologies and approaches utilizing digital, robotics, and technological advances.

We call on local and national governments to develop a strategy for technology in the care workplace.

To maximize the benefits of new technology, the existing and emerging workforce needs to be properly skilled and equipped in the use of technology and respectful of the rights and autonomy of individuals being supported and cared for, regardless of environment. This approach requires a steep change in the way we train and nurture our workforce. In many senses, the fourth industrial revolution requires a global effort to share learning, innovate in an

inclusive manner, and maximize available resources.

We are calling upon both local and national governments to develop a strategy for technology in the care workplace that meets local needs and advances long-term care as whole.

Conclusion

Any workforce-related call to action aimed at local, regional, and national governments starts with the premise that workers are the heart and soul of any long-term care for older adults. If we cannot attract and retain, nurture and develop, and innovate and progress with this workforce, then we will continue to suffer major challenges in the quality and delivery of long-term care.

Many insights and successful models are available, and disseminating models and approaches that work is appropriate. But ultimately, the role and value of care requires consistent advancement alongside an international emphasis on the value and centrality of care support as “everybody’s business.”



KEY CHALLENGES DIGITALIZATION AND LONG-TERM CARE

Explore the ways that technology can improve quality of life, given proper infrastructure and investments.

As the number of older people grows world-wide, our long-term care systems are ill-equipped to provide needed services, particularly to the vast majority of older adults who will be living in their homes and communities. In addition, workforce shortages tied, in part, to demographic shifts, will strain existing systems of care and support.

Technology can play a critical role in supporting new models of care and support that enable older adults to live as independently as possible, support family caregivers, and give long-term care providers the tools they need to deliver high-quality care. Technology is a key ingredient in any long-term care system in the 21st century.

Improved Quality of Life through Wellness Technologies

Imagine homes of the future—whether individuals' homes or long-term care settings—as places equipped with a variety of technology devices that work together to support older residents. They might feature health and wellness technologies that allow caregivers to monitor function. They might collect important health information that could prevent a health incident and enable older adults to

take proactive steps to enhance their health and well-being. They may allow professional caregivers to work more efficiently and focus more time on the psychosocial needs of residents. These technologies exist today.

To some extent, technology can mitigate many of the challenges associated with later life.

Driven by necessity, the coronavirus pandemic found providers of long-term care, family caregivers, and health professionals turning to technology at an accelerated pace to, for example, provide social interaction, maintain health checkups, create workplace efficiencies, and enhance safety. But even long before COVID-19, there were technology solutions to address functional or cognitive impairment, manage chronic diseases, and address diminished physical activity.

In fact, many of the challenges associated with later life can be mitigated to some extent by using technology. The use of sensor-based networks, for example, for activity monitoring, fall prevention, and wandering detection can

prevent injury or the need for a hospital visit and save health care dollars. Wearables allow for more personalized care and a focus on wellness. Digital technologies were a promising alternative to face-to-face contact during COVID, allowing families to interact virtually.

Technology to Increase Engagement among Older Adults

Beyond COVID, technology is becoming more prevalent in long-term care. Take the Netherlands, for example, where it is becoming more common to see robotic pets, such as dogs, that provide companionship for older adults without the need for physical pet care. In addition, residents are able to access games and music from their past through interactive systems. These innovations have not yet been fully adopted nationally, or indeed globally, but the examples give some insight into the potential for technology in long-term care beyond technology used purely for care needs or safety monitoring.

The Challenges with Technology Adoption

A number of challenges are associated with technology adoption and, depending on the country or region of the world, some are more pronounced than others.

Digital Literacy and Inclusion

The American Library Association defines digital literacy as “the ability to use information and communication technologies to find, evaluate, create and communicate information, requiring both cognitive and technical skills.” It is well documented that accelerated digitalization, brought by the COVID-19 pandemic, amplified the inequalities between generations. To fully achieve digital inclusion, governments must support access, affordability, and accessibility to information and communications technology (ICT).





Investment in technology can ultimately lighten the workload of staff, reducing labor costs.

Cost and Value

Too few studies have been done to evaluate the cost savings that using technology brings, and therefore adopting technologies is more often viewed as an expense than a saving. The initial cost of technology implementation seems high, but investment in such goods can ultimately lighten the workload of staff, reducing labor costs. In addition, the use of technology can reduce staff task burdens, allowing more actual contact time with care receivers, adding value to both the caregiver and care receiver.

There will always be an immediate comparison of the short-term costs of technology implementation over labor costs, but it is important to look at the long-term savings in both cost and time. Governments must incentivize individuals and providers to adopt technologies that will, ultimately, save health care dollars, improve quality of life, and foster efficiencies in care and service delivery.

Inadequate Infrastructures

The opportunity to scale technology is diminished by the lack of critical infrastructures that are the foundation of the effective use of technology. Examples include lack of internet access, systems that are not integrated, or being without any digital systems. Many countries rely on paper records and have unreliable electric grids.

Until we invest in our infrastructures, we will not meet the promise of technology. Where such basic infrastructures exist, incentives to integrate systems are essential. As their needs change, older adults use a variety of services with little transfer of key information between service providers. Interoperability will greatly improve the experience of providers, clinicians, and older adults themselves.

Until we invest in our infrastructures, we will not meet the promise of technology.

Data

Digitalization provides the promise of greater understanding of the socio-economic and well-being status of older adults. At present, there are no common data sets, measures, or metrics across countries. Accurate and up-to-date data will facilitate integrated planning and monitoring of the well-being of older adults and the use of long-term care services.

As part of the Decade of Healthy Ageing, the World Health Organization has identified information systems as a key building block for an effective long-term-care system. In particular, they cite the importance of timely and reliable information and sound analysis, dissemination, and use. The difficulty is that data protection

laws and requirements vary in different countries. For this approach to work successfully, common ground on data protection would need to be reached in data sharing to protect older adults' privacy.

Concerns about Security and Privacy

As technologies improve, greater and greater attention is paid to protecting users' privacy and security, typically through laws and regulations. As we build digital literacy skills, it is critical to provide assurances about privacy and security concerns.

As we build digital literacy skills, it is critical to provide assurances about privacy and security concerns.

Conclusion

The Asian Development Bank wrote this in a recent report: "Much of LTC revolves around person-to-person care, but there is a key role for technology. Many assistive technologies can enhance the lives of older people and enable them to age in place. However, the current lack of access to assistive technology and lack of widespread coverage are key impediments for older persons and care. Information systems are another important aspect of the role of technology. Thailand and Indonesia are leading the way in this regard. Indonesia's Elderly Information System, SILANI, is an example of harnessing information and communication technology to support better care. ...Breaking away from paper-based re-

cord-keeping and switching to digital records are the first steps toward a seamless flow of information about elderly care between different sectors, including health and social welfare."^{xlvii}

KEY CHALLENGES LONG-TERM CARE SECTOR AND LESSONS FROM COVID-19 IMPACT

Consider ways to ensure the long-term care sector is not overlooked again.

The COVID-19 pandemic has put the long-term care sector to a test. It was not only a test of preparedness for a pandemic and for a serious crisis situation. It was also a test of how seriously governments, public bodies, and politicians prioritize the long-term care sector.

We failed at all aspects. The pre-COVID-19 facts like underfunding, understaffing, low attention of governments, etc., revealed how urgently the long-term care sector does need attention, reforms, changes, and support. It also showed us how generally the sector was overlooked and underappreciated. This is not a subjective feeling or even feedback from a few long-term care settings or countries.

Global Agreement: Pandemic Response Left Long-Term Care Behind

From the very beginning of the pandemic in March 2020, country, regional and continental peak associations initiated virtual meetings to share experiences and to learn from other countries' best practices and mistakes. Maybe

for the first time in our sector, the evaluation and feedback were the same across countries. We shared a common experience.

From more than 50 countries across continents that were small, large, poor, wealthy, with or without great social policies, they all reported the same feelings, experiences, and frustrations. Very often we heard at those meetings "they left us behind." After the first COVID wave in March and April 2020, the first studies, surveys, and position papers appeared, bringing more or less the same conclusion and summary. Highlights appear below.

- **The European Ageing Network together with the Global Ageing Network, LeadingAge introduced "COVID-19**

Reflections: 12 key statements." Below are statements No. 7 and 11:

"Politicians and the general public do not generally hold nursing professionals in high esteem. State funds are opened to companies whose raison d'être is to make profits, yet people who devote their lives to caring for others merely receive applause and a

thank you. As such, attempts to pay tributes to carers remain mere political lip service and are a mockery for those concerned.

“COVID-19 has highlighted the global prevalence of ageism as well as a lack of planning in elderly care. As a result, the elderly population receiving care, as well as those providing it, have been let down during the COVID-19 pandemic. It is important to recognise this and apologise as well as giving thanks. In addition, changes must be made going forward. The elderly population must be valued equally, and planning should be put in place for every type of elderly care.”

- **The FORBA Report “Impact of the Covid-19 pandemic on the social services and the role of social dialogue” from 2021 states the following:**

“The main consensus among all interview partners is that the challenges that have pre-existed before the onset of COVID-19 have further intensified during the pandemic (insufficient funding, additional costs due to the pandemic, lack of qualified personnel, workers leaving the sector). In addition, new challenges appeared (shortage of personal protective equipment, unclear regulations and insufficient information, challenges regarding digital modes of work and staff management).”

- **The Federation of European Social Employers joined together with EPSU in their position paper “Preparing the social services sector for the COVID-19 resurgence and increasing its resilience”:**

“It has been argued that a key lesson of the pandemic is the need to better recognise and value social services’ contribution to the well-being of millions of Europeans,

and to consider investment in them to be investment in the future rather than a mere cost.”

- **EUROFOUND published the report “COVID-19 and older people: Impact on their lives, support and care.” The Policy pointers chapter stated the following:**

“Ensure well-developed, flexible welfare systems, health and social services and civil society to enable rapid responses when needs emerge. The pandemic has shown that most support is built on pre-existing structures.”

“Governments should consider scaling up initiatives introduced during the pandemic to better understand older people’s care needs and the support needs of their carers (also among non-service users), making such initiatives permanent and learning from those carried out elsewhere. Improve working conditions for care workers to enable sustainable staffing and provide reliable and high-quality services.”

- **The European Commission released the report “The Organisation of Resilient Health and Social Care Following the COVID-19 Pandemic”:**

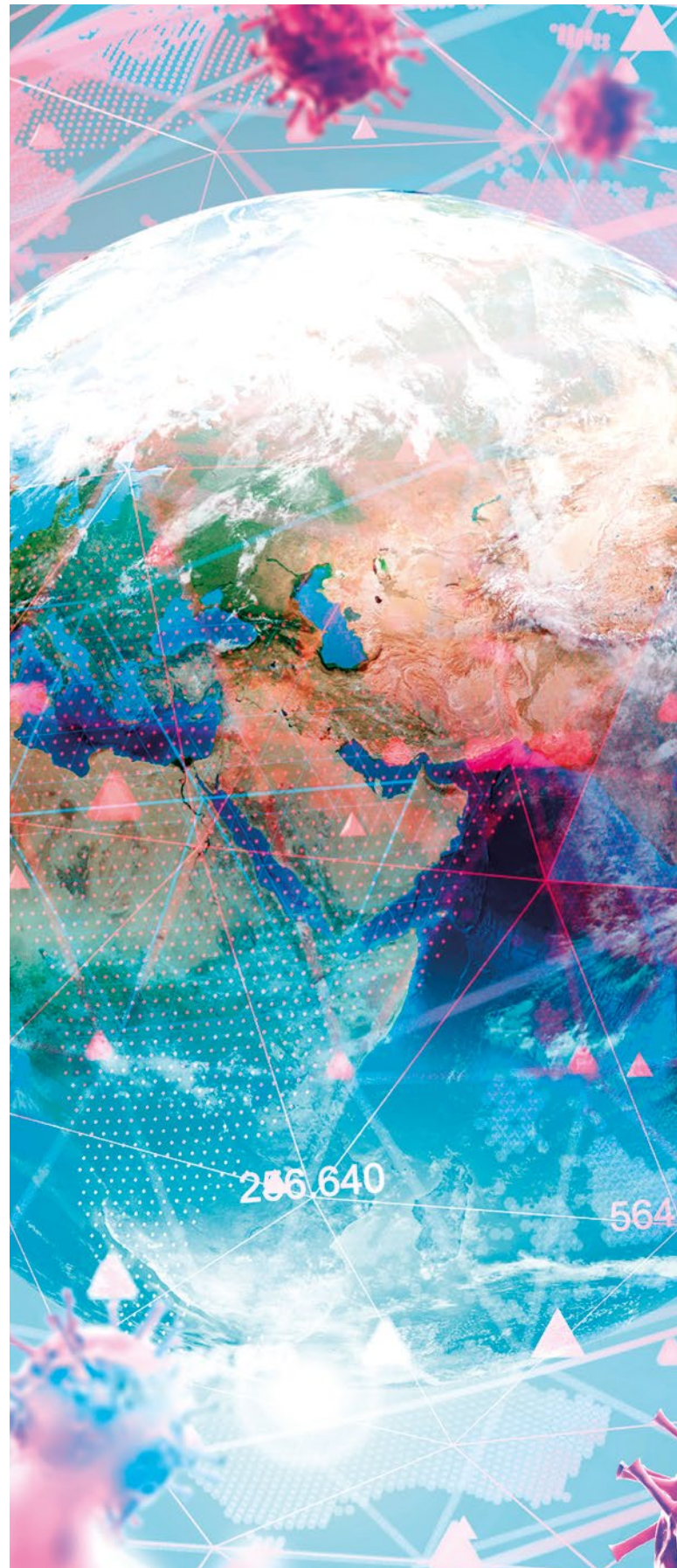
“In most countries, the needs of the elderly were overlooked within a context of already existing institutional and geographical fragmentation of long-term care provision in most European countries (Spasova, Baeten et al. 2018). Prevention of illness and care for elderly and other vulnerable people, and primary care (e.g. for chronic patients) was often de-prioritized in favour of hospital-based treatment. This contributed to the quick, and initially unrecognised but rapidly fatal, spread of the virus in residential and domiciliary settings (Coote 2020).”

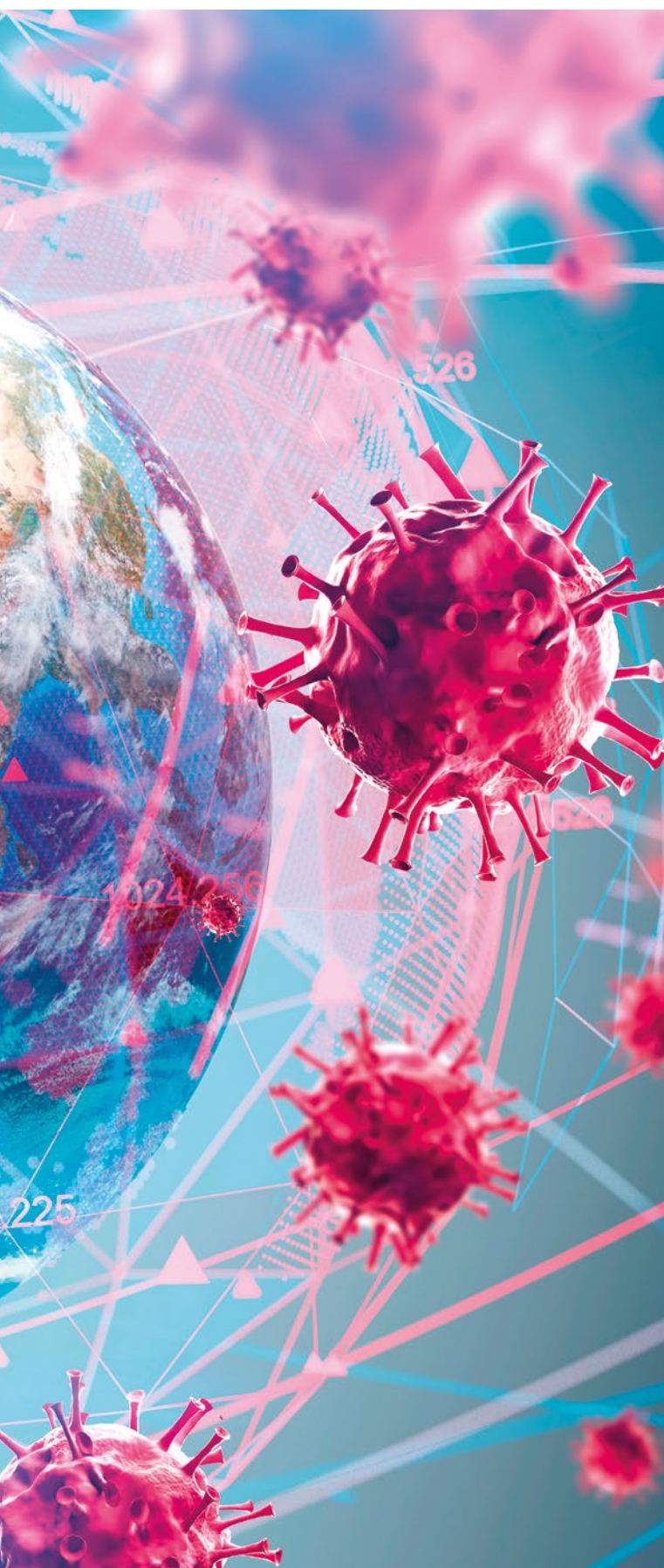
"This fragmentation has contributed substantially to the high mortality experienced in some countries, in particular in long-term care facilities that, in effect, fell outside the formal system with no one in authority having a comprehensive view of what was happening."

- **The OECD introduced a report "COVID-19 in long term care: Impact, policy response and challenges."** At the end of this report, its authors indicate a way forward:

"The pandemic has put LTC in the spotlight because of the high number of deaths among older adults who are more at risk of dying from COVID-19. Lack of prioritisation of containment and mitigation measures in the sector generated delays in the provision of PPE, and delays in testing of LTC workers and recipients. Staff shortages also affected the capacity to meet infection control protocols and provide adequate care. On the other hand, those in LTC institutions, as well as the elderly more broadly, have been prioritised in the ongoing COVID-19 vaccinations rollout in many countries. Vaccine effectiveness in real-world conditions is reassuring and has already made a clear impact in LTC. Such positive developments should not dampen the urgency for ensuring that LTC is better prepared to face future emergencies."

"First, the pandemic has revealed the lack of standardised, comprehensive and timely data collection and use in the LTC sector. In a large number of the countries most severely affected by the pandemic in 2020, information on the number of infected cases and deaths in LTC was not available on a daily or weekly basis. In many of those countries, data availability has improved and is leading to regular standardised reporting."





At the same time, much data on LTC is still missing to provide a complete and accurate picture on staffing (e.g. hours worked by category of worker, sickness absence) and job quality, care quality and outcomes. In that respect, ensuring that quality standards are appropriately measured and enforced to guarantee minimum standards of care appears to be more needed now than ever before. Good data will be a first step to generate a stronger culture of evaluation and evidence-based policy-making in LTC. Overall, there is insufficient evidence of the impact of policies on the sector.

“Second, the sector was ill-prepared to tackle a health emergency. While many measures are being taken during the pandemic to improve the performance of the sector, more needs to be done. Some countries are now recommending that LTC preparedness for health emergencies requires regular, granular assessments of preparedness at the facility level, as well as in home-care settings. Such assessments would include assessment of infrastructure, resident characteristics, human resources, material resources (such as stock of PPE), protocols for different scenarios, as well as assessment for the revision and actualisations of protocols. The recommendations include having a specific response or contingency plan for each facility or adapting the plan. Clear responsibilities and follow-up mechanisms with appropriate metrics need to be in place.

“Third, recent events have resurfaced the discussion on workforce, care quality and safety. Several countries have highlighted concerns about staff ratios, shortages and skill mismatches prior to the pandemic. Ensuring avenues for rapid replacement

of individuals on sick leave, and training of new personnel, need to be found. Rapid recruitment and retention of staff will remain challenging without addressing adequate pay and improving job quality. Previous research showed the high physical and psychosocial risks associated with LTC jobs. Efforts to support mental well-being have been mostly focused on helplines, while a broader mental health approach and more intensive support is required. Lack of sufficient, qualified medical staff with skills to deal with complex cases; as well as structural problems involving insufficient co-ordination with the rest of the health care system, also need to be addressed. Promoting social dialogue and collective bargaining can be an avenue to improve job quality in the sector and provide solutions for professional development."

Conclusion

There are many more COVID-19 related studies, reports, and analyses. In fact, more studies and reports of the long-term care sector were completed in 2020 and 2021 than ever before. But their assessments, analyses, conclusions, and recommendations are all the same. The long-term care sector has been neglected, overseen, and not prioritized, or it was seen as a burden or a less-important part of health and social systems.

Having learned from those lessons, we have to change the long-term care setting and systems.

Having learned from those lessons, having accepted the critical feedback and analyses and having listened to all the feedback from the grassroots level, we have to change the long-term care setting and systems. We must deal with all the problems that the many reports, surveys, and studies identified.

The COVID-19 pandemic has shown us many things. Speaking for the long-term care sector, all of these findings and conclusions and our own experiences are leading us to only one outcome. We must change, reshape, reform, modify, adapt, and in some countries, integrate to make the long-term systems and settings work effectively and protect older adults. This direction means addressing funding, sustainability models, workforce, and quality assurance. We must adopt person-centered care and deliver care that respects human rights. We must facilitate digitalization, consider ethical issues, and revamp long-term care systems to recognize the essential role of family caregivers and develop new living and service delivery models.

KEY CHALLENGES HUMAN RIGHTS AND LONG-TERM CARE

Consider the issues around personal autonomy, specific care needs, technology, and more.

Why Human Rights?

Over the last few decades, the role and significance of human rights has grown considerably within the world of long-term care. Long-term care was often conceived of in terms of institutional settings, but the influence of the disability civil rights movement and the emphasis on independent living has encouraged nations to move away from large-scale, often de-personalized models of long-term care. Now, they are moving toward enabling people to be supported to remain independent in their own home for as long as possible.

The drive toward independent living, whether in one's own home or in a home-like setting such as a long-term care facility, has been deeply influenced by the desire of citizens across many countries to be able to exercise the maximum degree of choice and control over their care and support.

In human rights terms, the key document is the 1948 Universal Declaration of Human Rights (UDHR) with its regional articulations such as the European Convention of Human Rights. All of these documents placed the dignity of the

human individual as an inherent quality and characteristic of all human relationships. The Convention on the Rights of Persons with Disabilities further describes what human rights means in practice and has real significance for the delivery of long-term care across all age groups and conditions.

The long-term care sector has continuously sought to put individuals' rights and autonomy at the forefront.

The long-term care sector has continuously sought to ensure that the rights and autonomy of individuals are at the forefront of the delivery of care support services. As we move toward an increasingly consumerist and personalized approach to care, there are challenges to ensuring the sector responds to developing situations in a way that continues to embed and enhance the human rights of individuals. Those who resource and fund long-term care provision need to be aware of and to meet additional challenges.

Personal Autonomy and Shared Environment

The Western approach to embedding the UDHR has always articulated the rights of the individual in relation to others. My right to privacy, to family, psychological and personal integrity (Article 8) or my right to freedom (Article 5) and my right to freedom of thought, conscience, and religion are all individual and personal in nature. Any care provider has to ensure that the personal human rights of an individual are upheld, advanced, and realized to the best of their abilities. National care standards and regulatory bodies expect no less.

However, one of the challenges of such an approach is where long-term care services are delivered in a shared or collective environment. The question of how an individual's rights are upheld in relation to others has been and remains one of real significance for long-term care organizations.

Equality, Diversity, and Inclusion

These challenges are further enhanced when you consider the requirement of long-term care providers to meet the equality, diversity, and inclusion outcomes of those receiving support and to make any necessary adjustments to ensure equal treatment and access.

In recent times, this approach has meant an increased emphasis on issues of human sexuality and identity, ensuring that those who are lesbian, gay, bisexual, transgender, and intersex (LGBTI) do not experience discrimination or that the religious and belief rights of individuals are respected in the way in which they are supported. Other challenges relate to race and ethnicity, respecting those who use supports and the whole care workforce.

The Nature of Care

Given the diversity of individuals who receive long-term care, there are ongoing challenges in meeting the human rights needs of individuals. As many older persons are living with dementia and with aural and visual impairments, the nature of their care support continually has to meet their distinctive communication and neurological needs.

For people living with dementia or on an end-of-life pathway, care support must meet their distinctive needs.

Again, as many who are using long-term care support are individuals who are either on a palliative and end-of-life care pathway, long-term care providers face very real human rights challenges in relation to individual choice and personal decision-making in countries that have or are intending to introduce legislation to support assisted dying.

Technology and Its Use

As we will see elsewhere in this report, one of the major challenges and yet opportunities the long-term care sector is facing now is the increased use of technology and digital supports in the care support of citizens, regardless of age. The sector will face that issue with real magnitude in the years to come.

Clear human rights issues impact the sector in the use of technology.

Clear human rights issues impact the sector in the use of technology. For instance, how does an organization ensure an individual's privacy when sharing data with other stakeholders and in using personal health data? How does an organization ensure personal autonomy and choice remains with the individual resident or user of long-term care services? As robotics develops as a support for care delivery, how does its use together with wider artificial intelligence (AI) systems and the Internet of Things pay due regard to the individual human rights of all who use long-term care services and supports?

Human Rights Resource Budgeting

Overarching all the above is the fundamental issue that faces all nations and local administrations, namely the way in which they choose to allocate limited and often scarce resources. To ensure that a human-rights-based approach is evident in the direct delivery of care support, there needs to be a robust human-rights-based process when allocating resources and finance to services and in the relative prioritization criteria that are used at that stage.

Conclusion

Much work of a positive nature is already happening in this sphere, and at a very basic level long-term care is meeting the human rights

needs of privacy, health, safety, and housing for many citizens across the world. The very nature of long-term care support helps individuals to potentially achieve and realize their basic human rights, not least through its accessibility. More progress needs to be made, for instance in realizing the role of long-term care in current projects such as the European Pillar of Social Rights and the United Nations Office of the Commission on Human Rights.

Human rights, especially as a framework for ethical conduct, offers some very real practice challenges for the delivery of long-term care.

Human rights, in terms of legislation but more significantly as a framework for ethical conduct, offers some very real practice challenges for the delivery of long-term care support. This is especially true in ensuring that individual rights are upheld in the delivery of care support. Regardless of these challenges, there are very real opportunities for each nation at local and national government levels in ensuring that long-term care support services, and older adult care in particular, directly address discriminatory practice and ensure the gradual realization of the human rights of all citizens.

OPPORTUNITIES, CHALLENGES AND THINGS TO DO SUSTAINABLE FUNDING MODELS

Explore sustainable models that provide affordable, accessible care.

A lot of countries are either changing, reforming, modifying, or adjusting their funding systems of long-term care or are having expert discussions about these changes. In Europe in the second half of 2022, a CARE STRATEGY¹ was introduced to help Member States in such reforming efforts.

In addition to many other countries, Australia is struggling with the sustainability of its funding model:

“The residential aged care system is already in crisis with 64 per cent of homes operating at a loss in 2020, compared to 56 per cent the previous year, making the entire system unsustainable. Australia’s aged care system needs a secure and sustainable source of funding now and into the future.”^{xlix}

Funding models of long-term care should meet some of the following key principles.

Sustainable

The funding models must be projected and functioning in a mid-term or preferably long-term period. All the basic facts like independence ratio, demographic changes, economics changes and development, migration and work migration, insurance, taxation and social policy, digitalization, and other facts must be taken into account.

**Sustainable financing
for long-term care is needed
to ensure adequate long-term
care for current and future
generations.**

Public spending on long-term care is projected as the fastest-rising social public expenditure item compared to healthcare and pen-

¹ The action plan announced that the Commission will propose an initiative on long-term care in 2022, designed to set a framework for policy reforms that will guide the development of sustainable long-term care and ensure better access to high-quality services for those in need.

Human rights and dignity principles must be reflected in every country, regardless of the level of their long-term care systems.

sions on average across the EU-27. In order to sustain long-term care spending in the future, many Member States face the challenge of developing sustainable financing systems for long-term care.¹ Sustainable financing for long-term care is, therefore, necessary to ensure adequate long-term care for current and future generations.

Affordable and Accessible

Social services, thus long-term care for older adults, should be reachable, accessible, and affordable. Services must be available in regions—not only in bigger cities where the private for-profit sector is building new capacities, but also in other locations and rural areas. The long-term care services should be to some extent² affordable, with the out-of-the-pocket payments set at an affordable level.

Different levels of quality of services should be considered, starting at a baseline with so-called “hotel services/housing and diner.” We all have different quality levels of housing and catering during our lives, mainly in relation to our incomes and economic situation. It is not necessary to unify that to some universal level at the end of people’s lives in care facilities.

To have accessible and affordable long-term care services was also defined in principle No. 18 of the European Pillar of Social Rights. Everyone has the right to affordable long-term care

services of good quality, in particular home care and community-based services.

Reflecting Human Rights and Dignity

Any funding system of long-term care services should respect the Charter of Fundamental Rights and must enable older adults and their informal caregivers to live dignified lives. The quality of the services could be different in different countries, reflecting the history, tradition, social and cultural life, etc. – especially with housing, accommodations, food service, leisure time activities, daily life structure, etc. However, the human rights and dignity principles must be reflected in every country, regardless of the level of their LTC systems.

These principles should be reflected while ensuring fiscally sustainable foundations for long-term care systems, to enable them to meet older people’s needs today and in the future.

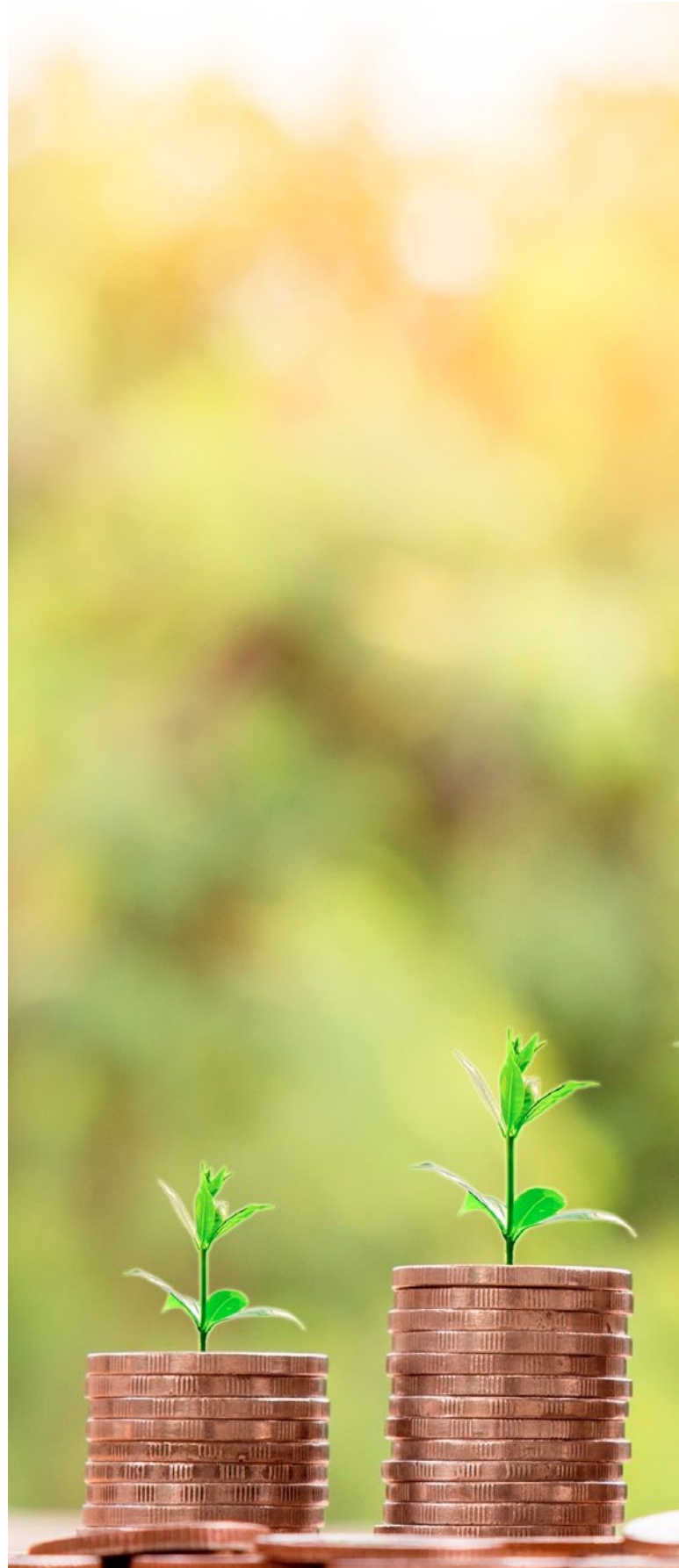
Social Policy Settings / Welfare States

The long-term care funding models are part of national social policy and social protection systems and/or health care systems. Any reforms always need to meet the social policy settings in the given country. Europe has four to five basic social policy models, with different approaches in defining and describing them. Even though this is a “European description,” it fits most of the social policy settings in the developed countries.

² To some extent means to ensure a life in dignity to fulfill the basic human rights as we describe the Human Rights chapter. Nevertheless that does not exclude possible different levels of housing and dinner services according to the out-of-pocket payments.

- In the Scandinavian (welfare state) model, the state assumes a high responsibility for the entire population and provides a high level of benefits in kind. They are usually tax-based models of a universalistic nature that promote an equality of high standards.
- In the Mediterranean model that prevails in southern Member States, by comparison, the primary responsibility and financing for care lies within the family, to which the state is only subsidiary. Mediterranean Member States may be either insurance-based or tax-based, but benefits are usually means-tested with relatively low levels of benefits.
- The continental models are typically insurance-based, and they sit between the Scandinavian and Mediterranean models. They are based on the Bismarck insurance system.
- In the Anglo-Saxon model, benefits are tax-based; however, the responsibility lies with the individual, and the state only supports in exceptional cases and with a relatively low level of benefits. Strict entitlement rules are often associated with stigma. They are based on the Beveridge insurance system.
- Eastern Member States seem to be developing into hybrid welfare states, with strong reliance on family support and a tradition of residential care. However, that model is changing.

Such a diversity of welfare state models shows on the one hand that there is no unique structure in the Member States, but on the other hand that there will also be no one-size-fits-all solution.

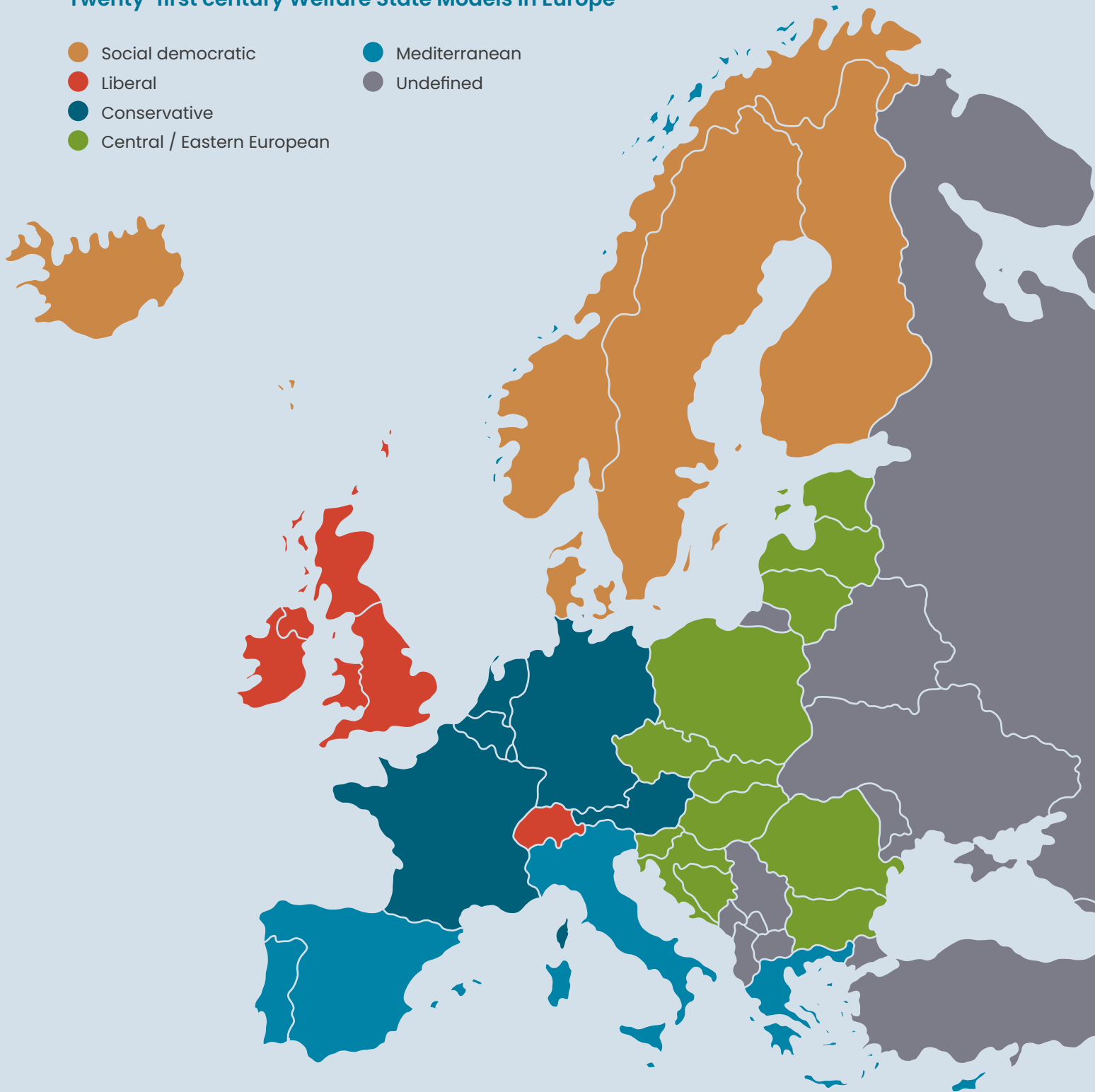




Twenty-first century Welfare State Models in Europe

- Social democratic
- Liberal
- Conservative
- Central / Eastern European

- Mediterranean
- Undefined



Ensuring sustainable long-term care systems requires efficient organization of risk-sharing and financing arrangements. This scenario could be achieved via different models for financing formal long-term care, which Member States often combine within hybrid approaches. These models pool risks within and across generations, as current cohorts of working-age people finance the benefits of current cohorts of older people, with the expectation of receiving the same treatment from future generations. The three main models of financing are as follows:

1. Tax-based (which may imply universal but also means-tested access).
2. Social Insurance.
3. Private Insurance (voluntary or compulsory).

The main financing models broadly reflect the typology of different welfare states in Europe. Nevertheless, not all Member States fit purely in this theoretical typology, and recent reforms imply that approaches may be in flux. Over recent decades, academic literature has identified four main types of welfare state models.ⁱⁱ

Key Questions and Decisions

Long-term care provision includes different stakeholders:

- Care Recipients
- Family/informal Caregivers, Live-in Carers
- State
- Regions, Provinces, Departments
- Municipalities

Key questions revolve around the division of responsibilities and competencies: who is responsible for what, who should pay what part of the LTC provision, how all the key stakeholders cooperate, who is regulating the system, who is planning the capacities, who is monitoring the quality, etc.

Other key questions are how much the country wants to rely on the informal care pillars, how the out-of-pocket payments should be regulated (social protection), and/or how private insurance products in LTC will be supported. Finally, all the digitalization processes, movements, and developments should be taken into account while changing the national long-term care systems.

**While defining new structures,
we have to be aware of lack and
scarcity of resources.**

While defining new structures, defining and/or shifting the responsibilities and competencies, we have to be aware of lack and scarcity of resources. This challenge is significant with the deinstitutionalization movements and tendencies with residential social services for older adults and for people living with dementia.

Community-based services and very small-scale care facilities that often serve older adults with the last stage of dementia, older adults with high dependency of care and with comorbidities, etc. require more funding and more staff. As a result, they have higher financial and human resources needs. We have to be aware of these limits when some countries are struggling to sustain the current LTC capacities.

The school system provides a strong parallel. It would be great to have only 10 or fewer students in a classroom and one teacher. Nobody can doubt that it would be great for the students' development, knowledge potential, and careers. The problem is that no country in the world could afford that because of the limited resources of money and teachers.

OPPORTUNITIES, CHALLENGES AND THINGS TO DO RESHAPING LONG-TERM CARE SYSTEMS

Consider ways to find the ideal mixture for your country.

What is the ideal mixture of programs and services within an integrated long-term care system? How can communities and countries of different infrastructure and resources have and sustain a long-term care system best suited and proportionate to their region?

The goal of support, care, and housing for older adults is to ensure individuals who have or are at risk for significant decline in physical or mental capacity maintain the best possible quality of life, with the greatest possible degree of independence, autonomy, participation, personal fulfilment, and human dignity.

As populations age, the provision of comfort and well-being for people at the end of life and their families should also increase. Going forward, a principle-based integrated continuum of long-term care should uphold the following values for older people and their caregivers.

Be Person-Centered and Aligned with the Person's Values and Preferences

For Older Adults

Long-term care activities should be adapted and tailored to the level of capacity of each individual and their values and preferences in a person-centered manner. Doing so provides older adults (or their trusted caregiver, in cases of severe cognitive impairment that prevents independent decision-making), with the education and support they need to make informed decisions in relation to their care.

Older adults and their caregivers have the right to and deserve the freedom to realize their continuing aspirations to well-being, meaning and dignity, and a good life. This is true even in the event of significant loss in intrinsic capacity or the risk of such a loss.

For Caregivers

The values and preferences of caregivers and others who are involved in care provision also need to be considered. To successfully do so within a designated care environment, it is important that caregivers take the time to get to know their care recipients to fully understand who they are and what they prefer. At the same time, they must also consider the new needs and preferences of the older adult in present day, to balance the person they were before and the person they have become moving into a long-term care environment.^{lii}

Optimize Functional Ability over Time and Compensate for Loss of Intrinsic Capacity

Along with addressing physical and basic needs such as nutrition and hygiene, long-term care systems should promote older adults' ability to move around, build and maintain relationships, learn, grow, decide, and contribute to their communities as much as possible.

Long-term care should aim to keep people's intrinsic capacity and functional ability as optimal as possible.

Long-term care should aim to keep the trajectories of people's intrinsic capacity and functional ability as optimal as possible over time. Care should optimize and rehabilitate temporary functional loss, as well as compensate for permanent losses, to achieve healthy ageing. This process should be done after discussions with the older adult, so that their goals/wishes can be incorporated into rehabilitation plans.^{liii} In short, to the maximum extent possible, emphasis should be on *ability*, not *disability*.

Provide Care in the Community

Older adults and their caregivers value services and interventions that enhance their daily lives and allow them to age in their preferred place of living, while participating in and contributing to their families and their community for as long as possible. The overwhelming majority of people prefer to remain in the community, receiving care and services as may be necessary at home.

Services that increase social interactions and physical support, such as at-home rehabilitation or assistance with daily living activities, can improve the chances of an older adult remaining in their own home while providing relief to informal caregivers.^{liv}

Provide Integrated Services in a Continuum

Formal long-term care involves a package of services that includes aspects of prevention, promotion, treatment, rehabilitation, palliation, assistive care, and social support to varying degrees, depending on the older adult's needs and choices. To maximize older adults' mental and physical capacities and functional ability and to support their caregivers, these service components should be delivered seamlessly in a systemic, integrated continuum with service packages that respond to changes in the older adult's functional ability.

Include Services that Empower the Older Adult

Long-term care should empower and enable older adults to do as much as they wish to do themselves, rather than replace their existing or potential ability with a social service that may ultimately decrease their function and increase care dependency. Instead, services should provide only necessary support that complements the current level of independence.^{lv}

Long-term care should empower and enable older adults to do as much as they wish to do themselves.

Emphasize Support for Caregivers and Care Workers

Support should ensure that caregivers and care workers do not endure the negative impact of caring on their physical, emotional, social, and financial well-being. Both paid and unpaid caregivers should be provided with the appropriate education and skills training to ensure physical and emotional advancement of older peoples' optimal abilities.

Long-term care upholds the basic approach provided by the Integrated Care for Older People (ICOPE) implementation framework, which is applicable throughout long-term care. Appropriate support for informal caregivers at home is essential to reduce the risk of caregiver burden. Support should include wellness checks to ensure caregivers' own mental and physical health is not suffering, plus respite care for the care receiver where necessary.

In cases of concern for the caregiver's well-being, there should be some intervention to explain and discuss options for additional support with both the caregiver and care receiver.^[vi]

Service Delivery

The delivery of an integrated continuum of long-term care includes various programs and services, with the following elements being essential to accelerate efforts to improve care for older adults.



The integration of health care and social care services is essential to creating programs for older people who need both types of services. Social determinants of health such as economic stability, environment, food, transportation, health and technology literacy, and social context play an important role in pre-



vention, quality, and health care cost reduction, particularly for older people.

Many countries and jurisdictions face a series of functional divisions, such as different eligibility criteria and timing, geographical boundaries, legal frameworks, staff training, com-

prehensiveness of coverage, and resource limitations. As such, professionals sometimes known as care navigators or care managers, who are experts in matching jurisdictional programs with older adults' needs, can play an important role in maximizing supports regardless of resource availability.

Separate budgets and a fragmented patchwork of funding sources contribute to insufficient and inefficient care coordination. Moreover, professionals from social and health care usually have different values and cultures and are unfamiliar with each other's ways of working, which creates additional barriers to integration.

There needs to be a concerted effort to integrate essential long-term care services related to health or social well-being.

There needs to be a concerted effort to realize a continuum of care that integrates essential long-term care services related to health or social well-being. To do this, it is necessary to analyze and revise the factors that contribute to fragmentation—such as aspects of fragmented governance, disjointed funding sources, and ~~parallel workforce training~~. The solution will vary according to each country's geographical, political, social, and cultural situation. This crossover of training and knowledge should start from the top and reach all levels of caregivers to ensure successful knowledge transfer.^{lvii}

Long-term care systems should clearly define the types of services that are included, as well as the settings where such services are provided. Service delivery should be based on needs

assessment, and there should be an established quality management plan in place to ensure good-quality service provision to all those who need it, when they need it (promoting choice and person-centeredness), and where they need it (promoting ageing in place).

At the same time, service delivery should ensure access to and coverage of equitable, evidence-based, and sustainable long-term care. The measure of success should focus more on meeting the needs and preferences of the person receiving care than on health and safety tick boxes.

Minimal Services Defined

When defining the types of services, the continuum of care includes preventive, promotive, rehabilitative, curative, palliative, and bereavement. The specific types of care include personal assistance, medical or clinical, support with self-management, and social support. Increasingly, technology considerations are impacting positively on care and care coordination and should be included in the continuum's development.

Services are also defined by their target audience: older adults with various degrees of functional ability and their choices, those who live alone versus those who are accompanied, and caregiver needs—working versus retired caregivers, older versus younger caregivers, cohabiting versus long-distance caregivers.

Services should be provided in line with the needs, choices, and preferences of each older person and their caregivers: for example, via co-designed individual care plans. Services should also respond in a timely manner to rapid changes in intrinsic capacity, which could be facilitated by introducing some degree of flexibility along the various care pathways.

Older people should be able to choose where they wish to live, and this place should allow them to age with well-being.

Settings for Long-Term Care Provision

Long-term care can be provided in several settings. Older people should be able to choose where they wish to live, and this place should allow them to age with well-being. The various settings where long-term care is provided need to be mapped out and defined, and both rural and urban areas should benefit from long-term care services to enable universal coverage.

Supportive Services that Enable Successful Long-Term Care

Equal distribution of services should be targeted in large cities where normally there is a concentration of services around the city center or in more wealthy areas. City outskirts are commonly not covered by a range of services, resulting in poor service provision and unmet needs.

Transportation should be provided to services that cannot be delivered at home or near home. Home- and community-based services, such as outreach programs, day care services, home care, and support services in primary care facilities and respite care are often useful for older people who have chosen to live at home and who are at any point of their trajectory of functional capacity. Community-based services and assisted living facilities, in particular, are more suitable for those whose intrinsic capacities are more preserved.

Long-term Residential Care

Long-term residential care—care homes, nursing homes, and hospices—can be an option in cases where the older person’s intrinsic capacity has severely deteriorated and these are their preferred choice. These options may also be best when there are no family members nearby for support, or when caregivers are no longer able or willing to provide care and support at home. A permanent transition into long-term residential care is less distressing for an older adult who understands and accepts the decision to move. Therefore, this decision should, where possible, be made with the older adult, and the reasons for the move should be explained.^{lviii}

Countries should ensure adequate infrastructure to support community-delivered long-term care.

Long-Term Care in the Community

Additionally, countries should ensure progressive but sustainable availability of adequate infrastructure to support community-delivered long-term care aiming at supporting safe and effective care delivery in the community: physical space, transportation, telecommunications, and access to assistive devices.

The physical infrastructure of many health and social care settings is far from prepared to attend to older adults’ needs. Many share a lack of adequate community care centers; no universal design, such as provision of accessible toilets in buildings; physical barriers to access; and communication barriers resulting from a lack of accessible information for people with hearing loss and visual impairment.

Long-Term Care at Home

In the home, poor home accessibility, lack of services for home modification, difficult access to assistive products, and violent neighborhoods can significantly impact the care that care workers and caregivers can offer. In addition, there is a shortage of affordable transportation, particularly for those living in rural areas where the concentration of services is further reduced. A lack of coordinated referral systems and transition of care services that link acute care to long-term care services compounds the issue.

Multisectoral action to strengthen environmental infrastructure will contribute to ageing in place and enhancing the quality of life for all, as environments play a fundamental role in the maintenance of functional ability.

Looking Ahead

The need to reshape long-term care systems with the ideal mixture of programs and services will only increase as populations age globally. A more value-based and adaptive process, particularly in leadership, is needed to bring about the transformation.

Frameworks are needed that assess the readiness for change.

Above all, frameworks are needed that assess the readiness for change, shifting the focus from the “why” and the “what” to the “how” to meet the growing demand and expectations for quality of life and care. Decisions about how to change these processes should be made in collaboration with formal and informal caregivers, as well as older adults, to ensure needs are being appropriately met.

OPPORTUNITIES, CHALLENGES AND THINGS TO DO NEW APPROACHES AND PARADIGM SHIFTS

Understand that supporting ageing is supporting life,
and consider new models to do so.

To make the future of long-term care sustainable, the current approaches need to change. With rising costs, workforce shortages, and lower quality, governments and providers face immense challenges. Paradigm shifts and changing approaches for governments and providers will provide solutions.

In 2019, The European Ageing Network published a report, “The Future of Long Term Care 2030.”^{lix} This report, which described needed paradigm shifts, received a lot of attention and was translated in different languages. This chapter addresses some proposed paradigm shifts, while others are addressed in other chapters. This section also highlights the role of the private sector and the public-private partnership. The paradigm that long-term care for older persons is exclusively a public sector is more and more challenged.

Governments’ Current Approach

Governments’ current approach to meet the challenges of long-term care is finding solutions to optimize the long-term care sector.

They do so by promoting ageing in place, using technology, and increasing budgets, which are not in pace with the rising demand. This approach is a dead-end road, because the unsustainable system itself stays the same. Optimizing a current system is not a transformation. More actions need to be taken that are impacting the current system.

**The current approach
is a dead-end road,
because the unsustainable
system itself stays the same.**

The following recommendations suggest shifts that would improve long-term care and raise the quality of life for older adults and their caregivers.

Recognize that Ageing Is A Society Matter

The first action governments should take is to recognize that the consequences of an age-

ing society matter not only for the social care sector, but also for the whole society. It cannot only be the domain of long-term care providers to find solutions. A department of ageing should be present in all governments as a project department that goes through all departments to develop an integral approach for solutions for the ageing society and rising demand. This department must coordinate collaboration among different departments, such as Economy, Finance, Labor, Social Affairs, and Education.

Recognize that Ageing is a Stage of Life

Ageing itself is not a disease, but a stage of life. Ageing comes with age-related inconveniences, like problems with mobility and vision and hearing loss. But ageing is not a medical condition.

Therefore, long-term care should not be part of health care but rather the domain of the social care, with a focus on older adults and their families. Supporting ageing means supporting people with living.

**Supporting ageing means
supporting people with living.**

Transform the Public Finance to Co-payments and Public/Private Partnerships

Transition of Public Coverage: We expect that public coverage of long-term care will be limited in the future. As inevitably more co-payments emerge, the client/family provider relationship becomes far more important, because they are the ones who then pay a higher share of the costs. Also, as noted above, private for-profit companies will emerge more and more on the long-term care and services market.

This transition can lead to more diversity, which is a positive development. More diversity increases the possibility of fulfilling the lifestyle needs of older people, but it is critical that we not overlook those who have fewer resources. Governments must not shield the long-term care sector for older adults as exclusively in the public sector. In countries like the Netherlands, all providers are private, with the majority not-for-profit.

Changes in the Private Sector: The private sector is a growing presence in residential care and serviced apartments, and it is often seen as a partner to fill the gap between public services and social needs.^{lx} There are concerns about privatization and residents' security.^{lxi} But there are positive experiences in transforming the residential long-term care sector into a private sector neo-liberalistic concept that is used "precisely and securely."^{lxii}

In the private sector, innovation is important in a competitive market. Therefore, collaborations between the public and private sector are seen as productive.^{lxiii} But it is important to evaluate not only the economic component of a public-private partnership, but also the impact on society and the environment.^{lxiv}

Create Staff Mobility by Offering More Flexibility

Staff mobility throughout the world must be made more possible—not only because of staff shortages, but also because of older people moving to warmer regions.

There are still barriers to staff mobility, such as the recognition of diplomas and credentials. Having the United Nations, WHO, and other organizations recognize diplomas worldwide can increase staff mobility. However, this must be done with two considera-

tions. The first is an ethical one: Most countries in the world also need workers in this sector because of their own ageing populations. We need to be as aware of the needs of the country from which workers may be migrating and the needs of the recipient country. The second one is a quality consideration. Language and socio-cultural practices can form a barrier to providing a good quality of care and services, despite the professional quality of immigrant workers. The ability to communicate well is key in interacting with older people.

Recognizing diplomas worldwide can increase staff mobility.

The brief conclusion is that governments have not prioritized effective approaches to respond to their ageing societies. The steps they are taking are incremental and do not address the transformation that the long-term care sector needs. People of all ages and professions need to be involved in changing the perception of aging—it is a stage of life that impacts every family in the world at some time. We must invest in the systems and supports that will enable older adults to live their later years to the fullest, with quality care, accessible services, respect, and purpose. To make this vision a reality, we need adequate, quality staff in every setting.

Providers

As mentioned above, in 2019, the European Ageing Network published “Long Term Care 2030,” which gives the provider’s perspective on the paradigm shifts needed to make long-term care sustainable in the coming decade. These paradigm shifts are not only European; they are universal. Therefore, they are part of this Call for Governments report and are described below.





From Care to Prevention and “Inclusion”

Care providers need to aim more for prevention and inclusion. Be active in a stage of life where the need for care and services is not present. Pay visits to older people and, for example, check the refrigerator.

Activate communities; include older vulnerable people in the neighborhood and even residents of nursing homes and care homes in community activities. Keep people socially involved and let them feel useful.

Shift from Quality of Care to Quality of Life

There is currently too much emphasis on the quality of care or the care activities (technical quality) and far too little attention on the way the care is provided (functional quality). The impact of quality of care on quality of life also deserves more attention. New concepts like positive health and service quality need to be implemented to get more client focus on older adult care and services.

The impact of quality of care on quality of life deserves more attention.

Shift “Institutional” to “Home”

Ageing in place is a term that is often understood to mean remaining in one’s home as one ages. In fact, ageing in place is ageing in whatever place you call home, which could include a wide range of housing options.

Current care homes where people get 24-7 care and support with activities of daily living (ADLs) are a concept that we will still need in the future. It is possible to provide such care in less institutional settings. For example, apartments might be able to support residents’

choice of extensive services, including support with ADLs and light nursing care, enabling residents to create their own highly individualized arrangements.

In one scenario, family members are the first responders and have control over the professional caregivers, not the other way around.

Shift Focus from Professional Care to Co-creation with Family

Providing care is no longer the sole domain of the “care professional.” For too long, institutional settings were closed systems. When one of your loved ones enters a nursing home, you would have to leave them, and the world outside the nursing home is suddenly a world in which your loved one is separated from you. Now, it is far more common for families to be part of the care team, providing practical and emotional support.

Shift from a Medical Focus to a “Social and Service Approach”

The medical model is still dominant in long-term care. (See Governments’ Current Approach in this chapter.) As a result, the care approach may give less emphasis on the social, emotional, and spiritual dimensions of care. A social and service approach built around quality of life should be dominant, without denying that medical care plays an important role when the client has health challenges.

Most older people live in an institutional setting because of social problems. As an example, dementia is caused by a disease, but in this stage of life, no 24-hour medical care is

needed. Palliative care needs also to refocus toward quality of life. It seems contradictory, but the quality of life also includes the quality of dying.

Refocus from One Size Fits All to Recognizing Individuality

Everyone's identity is unique. "One size fits all"—or a single approach to long-term care, denies the uniqueness of each person's life, their experiences, circumstances, family situation and, most importantly, their preferences. Ensuring a focus on individuals within a system rather than simply the system itself is essential.

Currently, care and services are organized based on the most efficient way and according to sometimes irrelevant regulations. This approach negatively affects a resident's daily rhythm and lowers their experienced quality of life. For example, if the resident wishes to sleep in one day, then the organization of care must be organized according to that wish and not the other way around.

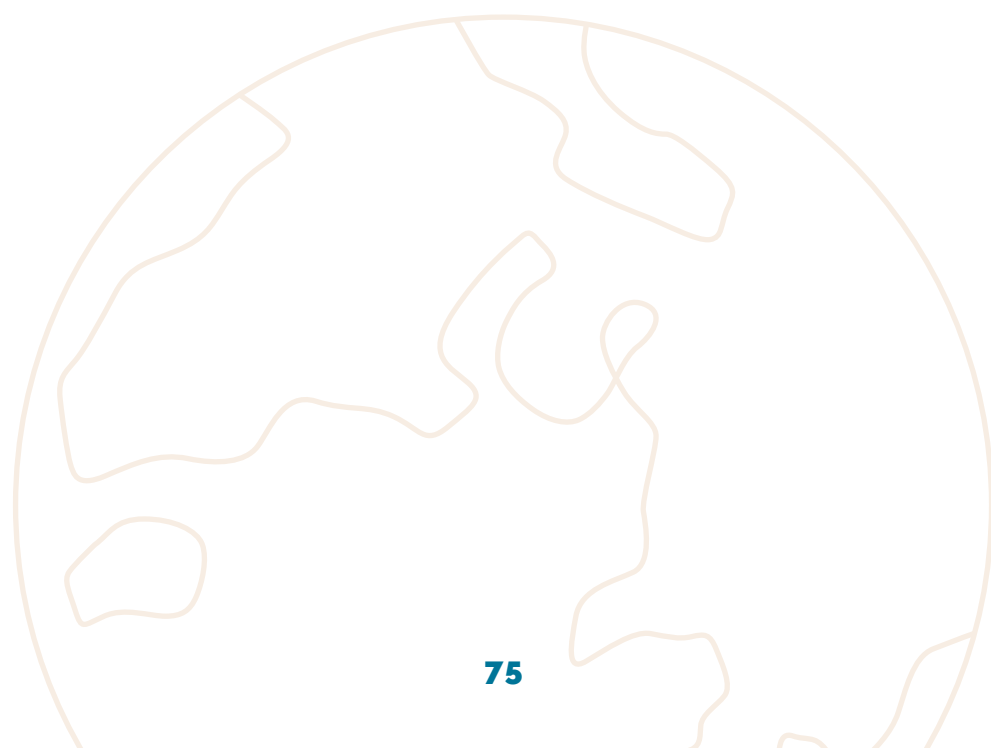
Use Common Sense instead of Critical Performance Indicators

Most long-term care is not highly complex but actually very familiar to everyone: at its core, it is about love, companionship, support and care, as needed. Professional caregivers in long-term care have the opportunity to develop relationships with residents and get to know them as individuals. While there are core competencies needed to provide quality care, above all else is the need for compassion.

Conclusion

There is much that long-term care providers can do to change their practices to be person-centered. But, ultimately, they need the support of governments to support, through regulation and funding, a philosophy that reshapes long-term care from a care- and institutional-driven sector to a service and support sector that helps people with living in a home-like and inclusive environment.

The private sector becomes an important partner. Therefore, public-private partnerships are important to keep the long-term sector for older adults sustainable and person-centered in the future.



DIALOGUE, COOPERATION AND COLLABORATION

Take Action

As described in the previous chapters, most if not all national governments need to reform, reshape, modify, change, or integrate their long-term care systems. Developing countries may need to create them. That way, in the years to come, long-term care will become or stay accessible, available, and affordable to ensure that older adults live with dignity and respect.

System changes often require cuts, reductions, and/or higher public expenditure and pension reforms. As a result, they are not politically popular, but hesitating and postponing these changes only create higher costs and more-painful changes in the future.

Key Points for Key Changes

When reforming, changing, or setting up long-term care systems, a few key points and views must be taken into account. Sometimes they contradict each other (like quality versus sustainable funding models, etc.), and finding the ideal mixture or compromise is the high political task. It is critical that cultural norms, values, and traditions be considered when designing a reform agenda.

Consider these key points:

- **Financial Resources, thus Funding Models**
 - Who is going to pay for what, what should be the participation rates, what should be the social protection settings and tools, what funding models should be used, etc.
- **Competencies and Responsibilities**
 - Who is responsible for what and who possesses the right competences to do what is expected (state, regions, municipalities, individuals, family members, insurance companies, health care providers, social services providers, domestic workers, and others).
- **Human Resources**
 - Workforce/staff are the biggest issue and challenge of long-term care today. How to recruit and retain the staff, how to train them, where to find them. Is the staff skilled enough (not under or over skilled), what staff key/structure do we need, etc.
- **Quality**
 - Quality of life is paramount, superceding quality of care. Quality of life is not only for care recipients but also for family caregivers and domestic workers (live-in caregivers). Quality is often linked with financial resources, but it should be a universal expectation.
- **Structure of Long-term Care**
 - What capacities do we need: residential care, respite care, community-based services. Which type of long-term care services is suitable for whom, what are the links with quality and sustainability.

• Digitalization

- How much to invest and coordinate and promote digitalization of long-term care services (digitalization is linked with general digitalization of health care systems). Digitalization brings rational and more-efficient approaches yet tackles it with high investment costs and must consider ethical and data protection issues. Digitalization is not only digital data and digital communication. It is also future usage of artificial intelligence and robotics in long-term care.

The European Commission calls the EU Member States to take the following actions in order to reform, reshape, and change their long-term care settings:

"Encourages Member States to strengthen social protection for long-term care and improve the adequacy, availability, and accessibility of long-term care services;

"puts forward a set of quality principles and quality assurance guidance, building on previous work of the Social Protection Committee in this area;

"calls for action to improve working conditions and upskilling and reskilling opportunities in the care sector, while highlighting the significant contribution made by informal carers and their need for support;

"sets out several principles of sound policy governance and sustainable financing."^{xv}

Key Stakeholders and Partners with Different Levels of Cooperation

Quite a few partners are involved in long-term care provision, and there two extreme examples on how to involve them. First is to involve

all of them in the "working groups" tasked with advancing any reform. Because reforms and system changes are always difficult, there will always be differences of opinion. The second approach, which is less appealing, is to omit them and make all the changes within the state administration.

Key partners may include the following:

- State administration (ministries, government)
- Regions, federal states
- Municipalities
- Social partners (employers and Trade Unions)
- Civic society (including providers not being involved in social dialogue)
- Clients/patients' associations/councils
- Family caregivers (associations)
- Health insurance companies
- Health care providers
- Advocacy organizations (not being providers)
- Others

Make Long-Term Care Change a Priority and Consider All Options

Especially in developed countries that already have relatively longer traditions in long-term care provision, some polarizing discussions are happening about the future of long-term care settings. Does the future of long-term care lie in residential or community-based services? Does it lie with public or private providers? If private, then with for-profit or not for profit? Or with low out-of-pocket payments/participation in paying for full costs? Is care provided by informal caregivers (family members, domestic providers, live-in caregivers, etc.) or secured by mainly professional providers, etc.?





We are spending too much time on these discussions, sometimes advocating for one or the other solution. Yet the future of long-term care lies in all of the above: public and private providers, not-for-profit and for-profit providers, community-based and residential services, informal care and professional care provision, public and private spendings, and so on. One very important note: There is no ideal or perfect solution that would fit all or even the majority of countries.

There is no ideal or perfect solution that would fit all or even most countries.

The only way to be successful in anything is to really want it, to strive for it, and to make it a priority. The problem of an integrated long-term care system is that it lies squarely between social and health, and most of the countries have separate Health and Social (Labor) ministries. In those cases, only a strong governmental priority that claims a space that recognizes both dimensions has a chance to be successful.

To succeed, transforming long-term care must be a priority and then (or maybe because of that), change will happen.

ANNEX 1 KEY DEFINITIONS AND ABBREVIATIONS – EUROPE^{lxvi}

Keyword	Definition
Access (to long-term care)	Possibility of using long-term care services, encompassing the dimensions of cost/affordability, availability, awareness (about the existence of a particular service), and physical accessibility.
Accessibility (of long-term care) on an equal basis with others.	Degree to which people with limitations in (instrumental) activities of daily living have access to products, services, and infrastructure on an equal basis with others.
Activities of daily living (ADLs)	Personal care activities such as bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet, and/or controlling bladder and bowel functions.
Affordability (of long-term care)	Degree to which people in need of long-term care are able to meet the out-of-pocket costs (after social protection or security) associated with the use of long-term care.
Availability (of long-term care)	Degree to which long-term care goods or services are available for purchase or reach people in need of them.
Cash benefits for long-term care	Monetary transfers to a person in need of long-term care and/or their family to buy long-term care services (as opposed to in-kind benefits).
Community-based care	Long-term care provided and organized at the community level: for example, in the form of adult day services or respite care.
Formal home care	Long-term care provided in an individual recipient's home, by a professional long-term care worker.
Informal carer	Person providing informal long-term care to someone in their social environment—most often a partner, parent or other relative—who is not hired as a care professional.
Informal long-term care	Long-term care provided by an informal carer.
In-kind benefits	Social transfers in kind from government or other authorities, including goods and services purchased on behalf of individuals. The goods and services may be the output of these institutions as non-market producers, or may have been purchased by these institutions from market producers for onward transmission to households for free or at prices that are not economically significant. These benefits may also take the form of reimbursement of the cost of goods or services purchased by individuals.
Instrumental activities of daily living (IADLs)	Household activities such as preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone.

Live-in carer	Long-term care worker who lives in the care recipient's household and provides long-term care.
Long-term care	A range of healthcare and social care services and assistance for people who, as a result of mental and/or physical frailty and/or disability and/or old age, over an extended period of time depend on help with daily living activities, and/or need some permanent nursing care.
Long-term care recipient	A person in need of long-term care who receives any kind of long-term care (formal and/or informal long-term care).
Out-of-pocket payment	Direct payment for long-term care goods and services from primary income or savings, where the payment is made by the user at the time of the purchase of goods or use of services; or the part not reimbursed by a third party.
Residential care	Long-term care provided to people staying in a residential long-term care setting.
Semi-residential care	Intermediate cases of long-term care combining formal home care with specific elements of residential care: for instance, day or night care, respite care, and short-stay services.
Social protection	<p>All interventions from public or private bodies intended to relieve households and individuals of the burden of a defined set of risks or needs, provided that there is neither a simultaneous reciprocal nor an individual arrangement involved. The list of risks or needs that may give rise to social protection is, by convention, as follows:</p> <ol style="list-style-type: none"> 1. Sickness/healthcare 2. Disability 3. Old age 4. Survivors 5. Family/children 6. Unemployment 7. Housing 8. Social exclusion not elsewhere classified

RESOURCES

Ageing Population

- OECD. <https://data.oecd.org/pop/elderly-population.htm>

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