

SHORT VERSION

BAY OF BISCAY BAY OF CARE REPORT

DEVELOPING THE LONG-TERM CARE EMPOWERMENT MODEL



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WHY OUR REPORT?

European countries have aged continuously over recent decades, seeing an increase in the percentage of those aged over 60 years, and a decrease in those under 15. By 2030 Europe will have 43% of its population aged over 50, around one quarter over 65, and over 10% over 75. This has arisen though both falling mortality and childbearing rates. Life expectancy at birth is now over age 80, with women at 83.2 years, and men at 77.5 years. Indeed, Biscay in the Basque Country has slightly higher life expectancy than the European average, at 86.3 years for women and 80.7 years for men, and 23% of the residents are over 65 years old.

However, healthy life expectancy remains well below, with women experiencing 64.5 years of healthy life, and men 63.5. Thus women are more vulnerable to spending a portion of their older years in dependency. Falling mortality, and in particular falling late life-mortality, results in the growth in the number and proportion of oldest-old, increasing demands for health and social care. By the middle of the century, there will be over 30 million people aged over 85 within the European region. And around three-quarters of these report at least one long standing illness. In addition, around 40% of those over 90 are living with dementia.

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

The ability of older adults to maintain good health, and a high quality of life and independence is often predicated on an enabling environment and access to support, be it from families and communities. However, the policy discourse surrounding population ageing and the development of adequate support infrastructures has overwhelmingly focused on issues related to the financing, organisation and sustainability of long-term care systems. While these topics are important, we believe that a human rights-based approach focusing on the older adult and their families and wider community should be the main focus, highlighting the wide diversity of needs and abilities should be central to the design of any model of long-term care.

Both the Government of Biscay, and Age Platform Europe are committed to developing tools for common action of mutual interest. On the eve of the publication of the EU Care Strategy, this a unique moment to influence policy makers, services providers and us, the societies and local communities to implement a new, empowering, accessible and quality care that respects our human rights – the kind of care we all would like to receive at any moment of our lives when we may need it.



THE IMPACT OF THE COVID-19 PANDEMIC

The question of appropriate long-term care for Europe's ageing population has become more pressing in the light of the devastating mortality rates caused by the Coronavirus Pandemic. The World Health Organisation estimates that up to 50% of all European COVID-19 deaths in 2020 occurred among care home residents. Around 100,000 older adults died in care homes, hundreds of care workers have also died, and tens of thousands of older people and their carers were infected. This did decrease in the 2021 second wave, but primarily due to the vaccination programme. There is now widespread acknowledgement that despite predisposing risks, such as physical frailty or multi-morbidity, across Europe long-term care homes were both underprepared and underequipped to protect their residents. A variety of causes have been identified including refusal to take older adults with COVID-19 into hospital, discharge of those with COVID-19 to care homes, movement between homes and between the community and care homes of care workers, a lack of training and equipment.

Alongside this, older adults in the community faced widespread shielding. During the pandemic, most governments warned older adults that they were at a higher risk of both severe illness and death with COVID-19. Early mortality data, on which much of this advice quickly emerged, indicated rising mortality rates with age, leading to a general recommendation in many countries that older adults should stay at home and avoid social contact. This was despite the fact that there was widespread evidence from our understanding of other later life illness that gender, ethnicity, socio-economic status, co-morbidities and obesity would discriminate between members of these age groups. And emerging evidence of the huge mental and physical toll this was taking on older adults.

The pandemic and subsequent containment measures implemented in all European countries thus highlighted the vulnerabilities within our long-term care systems. The high mortality rates, especially in long-term care settings, and the high death rates among care workers, have brought many concerns to the fore. Of particular concern was that long-term care homes were both underprepared and underequipped to protect their residents. Over reliance on residential care services, under-development, under-recognition and undervaluing of community-based care alternatives, lack of informal carer support programmes, dominant focus on physical health, and the difficulties of ensuring safe working conditions for a strained long-term care workforce were clear issues. The pandemic also highlighted the deepening of both gender and socio-economic inequalities. Women, low-income individuals and marginalised groups were identified as being more exposed to the risk of contracting the virus and more vulnerable to the negative economic and mental health consequences of the subsequent containment measures.

HOW WE PERCEIVE LONG-TERM CARE

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

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

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

- To support older adults to lead meaningful lives, to promote quality of life; and to empower older adults until the end of their lives;
- To ensure dignity, autonomy and self-determination, as well as equality and non-discrimination, for all older adults;
- To promote healthy ageing, defined as the process of developing and maintaining the functional ability that enables wellbeing in older age¹;
- To enable the inclusion and social participation of older adults, allowing them to remain active and engaged members of their communities should they so desire.

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

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



A NEW MODEL OF LONG-TERM CARE EMPOWERMENT

Our report aligns itself with and argues for strengthening the commitment to a rights-based approach to care in Europe, calling for a Long-Term Care Empowerment Model, which brings long-term care for older adults in line with the recognised health care empowerment approach. We also recognise the recent WHO Framework (2022) for care to be person centred and aligned with the person's values and preferences; optimize functional ability over time and compensate for loss of intrinsic capacity; be provided in the community; provide integrated services in a continuum; include services that empower the older person; and emphasize support for carers and care workers.

In developing our Long-Term Care Empowerment Model we took into account a variety of *contextual factors* which structure the experience and needs of older adult and their families, and *key framings* of the model.

CONTEXTUAL FACTORS

Social and environmental factors include gender, age, socio-economic and educational status, and income. In particular there is a clear gender imbalance in the older population, particularly among the oldest-old, reaching 2.1 women for every man among the very old (85+). In addition, older women are more vulnerable to poor health, poverty, marginalization, social isolation and violence. Poverty rates tend to increase in later life, leading to a situation where the risk of poverty among those aged 75 and over is higher than in the general population in the majority of EU countries. Understanding the living conditions of older adults is key here. European countries have experienced a significant increase in the share of nuclear families and individuals living alone, particularly among older age groups. Even though such patterns differ across countries and regions, older adults in Northern and Western Europe are more likely to live alone, while co-residence with adult children remains a common household living arrangement for older adults in Southern and Eastern Europe. And the quality of housing varies considerably, with many oldest-old living in inadequate housing in terms of heating, damp and home adaptations.

Alongside these factors sit **cultural backgrounds, gender and generational norms**. In particular the generations may have very different expectations of the relationships and obligations between generations, and the role different family members should play. This has become especially acute following the emancipation of women in European countries. In addition it is important to recognise the heterogeneity of the ageing experience. Thus individual characteristics - personality, negative life experiences, such as trauma and psychosomatic disease, anxiety, and physical and mental health status all need to be acknowledged and addressed.



KEY FRAMING

Our thinking also stressed key framings: **combating ageism, person-centred approach, universal access to and continuity of care**

In considering the **contesting of ageism**, elder abuse and mistreatment, we argue that legislation to combat ageism is particularly important as mounting evidence suggests ageist attitudes and practices are widespread in health and long-term care settings. This includes anti-age discrimination and equality legislation at international and national level, as well as policies at any governance level that promote dignity and equality of status for all individuals, irrespective of their age. The UN Global Report on Ageism highlights the importance of strengthening policies and legislation that address age discrimination and human rights laws; introducing educational interventions in both formal and non-formal educational contexts; promoting intergenerational contact through interventions that foster interaction and cooperation between people of different ages; and raising awareness about the scale and impact of elder abuse and mistreatment and recognize it as a public health problem.

A **person-centred approach** has long been integrated in to thinking around long-term care. It is argued that governance arrangements should be participatory and inclusive, creating opportunities for older adults and their carers to be fully involved in long-term care policy and service development. This should include establishing care systems which empower older adults through placing them, their families and communities, at the centre of system design and organization, rather than a focus on diseases and disabilities; enabling those receiving care and support to express their own needs and decide on their own priorities through a process of information-sharing, shared decisionmaking and action planning; placing the development of collaborative relationships between older adults and care professionals at the heart of service delivery; and supporting people with long-term conditions to have the knowledge, skills and confidence to manage their condition effectively in the context of their everyday life.

It is also important to ensure **universal access to and continuity of care**. This should include ensuring care is available where and when it is needed, in particular improving coverage in small, rural isolated communities, and ensuring individuals can access care without undue financial burden to themselves and their families. Many individuals in receipt of long-term care will have complex or frequently changing needs, requiring care pathways that ensure continuity and coordination of care. It is also important that those who have advanced dementia or frailty or are approaching a palliative or end of life care stage are able to access appropriate specialist services and these are well integrated with the provision of long-term care.



CHALLENGES AND CHANGES FOR LONG-TERM CARE EMPOWERMENT

Our report draws on the WHO Europe Country assessment framework ICOPE - the integrated delivery of long-term care and the implementation framework for integrated care for older adults. We thus consider our system enablers at three levels: the *Macro level* particularly focusing on governance, financing and collaborative leadership; the *Meso level*: formal and informal care provision, considering the role of families, communities and migrant workers and how they may be supported through education and training and working conditions; and the *Micro level*, recognising the importance of the digital infrastructure in the facilitation of effective care planning and assistive technologies.

Integrated governance arrangements are essential for the planning and delivery of long-term care as a continuum of health and social care services including protection, prevention, treatment, care and support, rehabilitation, reablement, and palliative and end of life care. Yet these services have traditionally had separate, often complex, governance arrangements distributed between health and social care sectors at national, regional and local government levels. Care and support may be provided by a mix of health and social care professionals from the public sector, private for-profit providers, NGOs and independent not-for-profit providers, as well as informal carers and personal care assistants. The health system is responsible for the care provided by health professionals, while care services are usually organised by the social sector. COVID-19 has raised awareness of the need to break down barriers between services, between formal and informal providers, and to promote collaboration between fragmented services.

Integrated governance thus requires clarity of roles and effective relationships, and both vertical integration between local, regional and national governments and horizontal integration across sectors and with the community and civil society. In addition, governance arrangements should be participatory, creating opportunities for older adults and informal carers to be fully involved in long-term care policy and service development, and inclusive, addressing the inequities frequently experienced by women, migrant carers and underserved communities. This should include developing care pathways that ensure long-term care services are well integrated with primary and specialist care provision; improving intermediate care arrangements that allow individuals to seamlessly transition between care levels and care settings as their needs change; and creating the conditions in which informal carers can collaborate as equal partners with formal care teams.

Ensuring **sustainable funding** is a crucial component of successful long-term care. Financing long-term care systems encompasses a spectrum of activities that include designing policies and eligibility for cash or in-kind benefits and out of pocket contributions, raising and pooling finances, and commissioning and purchasing long-term care services. Funding for long-term care is generally a mix of public, private and citizen funding variably generated at national, regional or municipal levels through general taxation, mandatory



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

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

Supporting **the relationship between formal and informal care** is a key component of long-term care. Informal care remains the main source of support for older adults across Europe, with the contribution of families, friends and communities at around 80% of all long-term care provided and a monetary value that far exceeds public expenditure on long-term care services and cash benefits combined. Women are significantly more likely to provide informal care. Workforce mobility and migration patterns, increased female and older worker participation in the labour market, alongside changes in cultural norms are leading to a crisis in the availability of informal care. These family carers are supported by a network of volunteers, local faith communities, schools and community organisations. However across Europe, there are varying levels of cash benefits and in-kind support for informal carers. These variously include flexible working arrangements paid and/or unpaid carer leave; day and residential respite care; information, advice and training; peer to peer and professional emotional and psychological support; and cash benefits or carer allowances.

Governments need to tackle the insufficient development of formal care services which are creating pressure for communities and families to compensate for gaps in formal capacity and provision. They should provide financial and practical support for these families, households and communities. This should include ensuring well-developed and readily available support for informal caregivers which addresses their health and well-being; combating gendered care stereotypes and thereby encouraging equitable distribution of care tasks within families, and between formal and informal caregivers; ensuring that older adults, their families and communities are meaningfully engaged in the design of care services and empowered to shape them; supporting grassroots, socially innovative initiatives to develop care models and solutions that build on local community strengths.

There exist requirements to assure that the quality of long-term care is supported by **regulatory frameworks** and standards, including accreditation and licensing or



registration of professionals and providers. These should also include developing quality criteria, in collaboration with older adults themselves and their informal carers; registering and monitoring the activities of service providers; reporting by providers against nationally / regionally agreed standards; and strengthening surveillance capacity and infection prevention in long-term care settings.

We need to reassess the situation of the **professional or paid workforce**. In many countries, recruiting and retaining sufficient long-term care workers is a challenge driven by negative perceptions of the role, poor pay and reward, high workload and often stressful working conditions. The long-term care workforce is predominantly female and it is common for care workers to have zero-hour contracts and to work for multiple care providers. The lack of integration between providers makes it difficult for the workforce to move flexibly across the system as demands change, or to take up opportunities for professional development and career progression in the sector. This is an issue especially for migrant workers, who often face difficulties in having their previous qualifications recognised. High quality learning and clearly defined qualifications, accreditation and professional development pathways are required to raise the status and attractiveness of long-term care work. Training, supervision, feedback and support should be available for both paid and unpaid carers. Interdisciplinary training should include topics such as dementia, palliative care, nutrition, safeguarding, communication and emotional and psychological support.

In particular there is a need to improve **workforce planning**, considering redesigning professional roles, adopting technology enabled care, and exploring new ways of providing support and care at home. These should include reforming the regulation of the long-term care workforce sector so as to improve working conditions and increase financial remuneration and status; developing access to training to enable both the current and future long-term care workforce to have the knowledge, skills and confidence to deliver holistic assessments and care planning, to provide safe, effective and person-centred care and thereby enhancing the dignity and functional ability of older adults, both at home and in care homes; promoting sustainable and fair management of cross-border mobility of the care workforce, thereby enabling opportunities for professional development and career progression for migrant workers in the sector. The long-term care workforce should thus be managed in a fair, transparent and equitable manner and supported to stay safe and well in their working lives

In the 21st century, it is essential to establish an **effective digital infrastructure**, and to fully recognise the importance of this infrastructure in the facilitation of effective care planning and distribution, and the use of assistive technologies. Continuity and coordination of care and monitoring of quality are enabled by interoperable ICT systems and processes to store, exchange and communicate information between different health and social care providers. Yet currently, few countries have information and monitoring systems that include individual-level data about the characteristics, needs and outcomes of people who use formal long-term care services, and about the type and quality of care that they are receiving.

They may include information on chronic disease prevalence and medications, but less often include granular information on functional ability and levels of care dependence and carer support, which are required for effective population health planning and targeting of resources. The ICT infrastructure should enable long-term care to be integrated with strong, community-oriented primary care and with risk prediction tools to target health promotion, self-management and proactive preventative interventions that aim to improve population health and health equity. It also needs to ensure high-level ethical and integrity safeguards around data confidentiality.

In terms of **assistive technologies**, COVID-19 has accelerated the adoption, uptake and normalisation of digital solutions to support health such as protection messaging, contact tracing, self-care, remote and mobile monitoring of symptoms and chronic disease, video enabled triage and consultations, remote working and enhanced information sharing. It is important that adoption of such technologies are extended and are available and sympathetically managed for those who are digitally excluded or need to be upskilled.



LONG-TERM CARE EMPOWERMENT MODEL

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

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

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

There is a need to raise awareness of and promote the immeasurable value of care work and of family care for social cohesion as well as for the economic sustainability across Europe.

There is a need to place equity at the very core of care systems and prioritize fairness and user-empowerment in all systemic reform efforts.

The European Pillar of Social Rights supports the principle of deinstitutionalisation -the move to home based care. Underpinned by a shared understanding that home and community- based care provision reflects user preferences, this is aligned with a rights-based approach to care and is economically more sustainable. This should be supported by good quality residential care where home care is not viable due to the complexity or intensity of long-term care needs. Progress however has been very uneven, with southern and eastern European countries lagging far behind those in the north and west.

Clearly, however, families and social networks remain the backbone of care provision throughout Europe. The sustainability of long-term care systems therefore



requires families and communities to continue to provide the care that is needed. Long-term care services should thus include a systematic approach to identify and value informal carers as equal partners, and support them to access information, advice, benefits and services. Informal carers should be offered emotional support, advocacy, respite opportunities and, when needed, financial support to enable them to stay well and continue their caring responsibilities.

In addressing these challenges, our model has four conceptual pillars: autonomy, independence, co-production and empowerment (choice, control and legal capacity). This aims to ensure the full, effective and meaningful participation and co-production by older adults in the social, cultural, economic, public and political of their countries and beyond.

WHAT DO WE MEAN BY AUTONOMY, INDEPENDENCE, CO-PRODUCTION AND EMPOWERMENT?

Autonomy is the ability to live according to one's choice on an equal basis with others. It includes the ability to make one's own decisions in all aspects of life and to have them respected. It also includes the ability to maintain their legal capacity to exercise those choices and decisions.

Independence is the ability to keep the control over one's life, and to exercise one's own choices and decisions in all spheres of life, including personal lifestyle and daily activities.

Co-production is about an equal and reciprocal relationship between clinical and non-clinical professionals and the individuals using care services, their families, carers and communities. Co-production implies a long-term relationship between people, providers and health systems where information, decision-making and delivery are shared.

Empowerment is about supporting people and communities to take control of their own lives and the decisions required. In terms of health this includes decisions over health behaviours, self-management of illnesses and decisions about living environments. It sits alongside full engagement whereby people and communities are involved in the design, planning and delivery of health services, enabling them to make choices about care and treatment options or to participate in strategic decision-making on how, where and on what health resources should be spent.

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



though older adults are indirectly covered by general provisions where those exist. In the few cases where secondary national law refers to autonomy and independence in old age, these are primarily related to health and care law or mental capacity acts.

Our report proposes that long-term care systems should pursue the following core goals, outlining the challenges and the changes needed to achieve this. Long-term care should:

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

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