This report is a summary of the Report “Bay of Biscay Report – Developing the Long-Term Care Empowerment Model” commissioned by the Government of Biscay. The full report with supporting references, tables and figures will be available during the second quarter of 2022

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

1. Introduction

21st century long-term care is a range of services and assistance for people who, as a result of frailty or disability, both mental and physical need help with daily living activities or nursing care.

This is a combination of health, social and care services, and financial compensation – generally wholly or partially funded through a social protection system at a local, regional or national level.

The World Health Organisation (WHO) defines this as a means to ensure that older people with a significant loss of capacity can still experience healthy ageing. In particular, they argue that it is essential to realign health systems to the needs of older adults, requiring a shift from systems designed around curing acute disease, to systems that can provide ongoing care for the chronic conditions that are more prevalent in older age.

Governments, it argues, also need to develop long-term care systems to ensure people live their last years with good quality of life and dignity. Other framings call for person-centred orientation, rights-based approaches, and most recently empowerment of older adults through long-term care.

We also note that the question of appropriate long-term care for ageing populations has become more pressing in the light of the overwhelming morbidity and mortality rates among older adults caused by the SARS-CoV-2 virus. The deaths in 2020 in residential long-term care settings was particularly devastating. The WHO estimates that around half of all European COVID-19 deaths by mid-2020 occurred among care home residents, hundreds of care workers died and tens of thousands of older people and their carers were affected by coronavirus and by related restrictions. A review of care home mortality in 20 countries reported that while the average share of the population in care homes is 0.73%, the average share of all COVID-19 related deaths that were care home residents was 46%. In addition, disruptions of primary health care and community-based care services have disproportionally affected older people and other vulnerable groups, limiting access to essential care services and significantly increasing the pressure on informal caregivers.

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

The goals of 21st Century long-term care

We propose long-term care systems should pursue four core goals:
● To support older people to continue leading meaningful lives and promote their quality of life;

● To ensure dignity, autonomy and self-determination, as well as equality and non-discrimination for all older people;

● To promote healthy ageing, defined as the process of developing and maintaining the functional ability that enables wellbeing in older age (WHO, 2020 – Decade of Healthy Ageing baseline report);

● To enable the inclusion and social participation of older people, allowing them to remain active and engaged members of their communities.

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 for a change in the way we think about and approach ageing. They emphasize the societal responsibility to protect and work towards realizing older people’s human rights.

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

2. Contemporary long-term care systems

Formal long-term care services are provided in a range of settings. Most common among them are:

- social care support provided at the older person’s or family’s home;
- community based day centers and non-residential facilities;
- dedicated housing with care services;
- residential and nursing care facilities;

combined with assistive services and provisions:

- telecare and assistive technology services;
- day centre services;
- cash benefits;
- services to support informal carers.

Care should be delivered with a focus on prevention and enablement, promoting physical activity, maintaining social networks, enhancing wellbeing and independence, and reducing isolation, depression and anxiety.

The emphasis is increasingly on prevention to ensure that older adults are able to continue living in their own homes for as long as possible. Similarly, following an acute illness or event, safe but quick return of the older adult to their own homes is seen as a priority in many systems. Intermediate care, including transitional care, reablement and hospital at home, ensures continuity and quality of care, promote recovery and restore independence and confidence.

There is also growing recognition of the role of informal carers, with a variety of state sponsored schemes: flexible working including paid and/or unpaid carer leave; day and residential respite care; information, advice and training; cash benefits or carer allowances; pension benefits or credits for the time spent caring.

3. Integrated Care Pathways

The range of long-term care services is a complex landscape that is often difficult for older persons, families and professionals to navigate. Many individuals in receipt of long-term care will have complex or frequently changing needs that benefit greatly from proactive assessment and care pathways that ensure continuity and coordination of care.
It is important that local care pathways ensure that primary care and specialist services are well integrated with the provision of long-term care.

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

- **Macro level**: development and improvement of long-term care through appropriate legislation and governance, sustainable financing and collaborative leadership for improvement;
- **Meso level**: building capacity in both the paid and unpaid workforce through training, support, working conditions and opportunities for career development;
- **Micro level**: establishing an effective digital infrastructure to enable effective care planning and monitoring, sharing of information between providers and use of assistive technologies.

### 4. Governance

Healthcare and social care services have traditionally had separate, often complex, governance arrangements distributed between health and social care sectors at national, regional and local government levels. The health system is responsible for the care provided by health professionals, while services related to supporting the care-dependent person in the activities of daily life are usually organised by the social sector. COVID-19 has raised awareness of the need to break down barriers between services and between formal and informal providers, and to promote collaboration between fragmented services and cooperation rather than competition.

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

This requires clarity of roles, balanced financial responsibilities, effective relationships and both vertical integration between local, regional and national governments and horizontal integration across sectors and with the community and civil society. Governance arrangements should be participatory, creating opportunities for older people and informal carers to be fully involved in long-term care policy and service development, and inclusive, addressing the inequities frequently experienced by women, migrant carers and underserved communities.

Arrangements to assure the quality of long-term care should be supported by regulatory frameworks and standards, requirements for accreditation, licensing or registration of professionals and providers.
Legislation to combat ageism is particularly important in this context, as mounting evidence suggests ageist attitudes and practices are widespread in health and long-term care settings. This includes anti-age discrimination and equality legislation at international and national level, as well as policies at any governance level that promote dignity and equality of status for all individuals, irrespective of their age.

The Global Report on Ageism highlights the importance of promoting policies that aim to change attitudes and perceptions of older people and strengthening human rights legislation and the enforceability of those rights.

5. Sustainable Funding

Financing long-term care systems encompasses a spectrum of activities:

- designing policies and eligibility for cash or in-kind benefits and out of pocket contributions;
- raising and pooling finances;
- 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.

More needs to be done to adequately to reward long-term care providers for quality, collaboration, continuity and coordination of care.

6. Long-term care coverage: capacity and availability

Deinstitutionalization, the shift of care service provision from residential care institutions towards community-based settings has occurred across Europe in recent decades. Progress however has been uneven, with southern and eastern European countries lagging behind those in the north and west. Although community-based care has considerably expanded over the last decades, it remains under-sized with respect to needs and unequally distributed across localities.

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

The use of informal care is particularly skewed towards lower income groups in the majority of European countries. Recent and projected changes in population structure, workforce mobility and migration patterns, female employment rates, increases of retirement age, are threatening the availability of familial care.
Governments must both address the insufficient development of formal care services which generates significant pressure on communities and families to compensate for capacity gaps through informal care provision, and provide financial and practical support for these families, households and communities.

7. Workforce capacity

Robust assessments of the demand for care and the intensity and acuity of needs are required to plan sufficient workforce capacity that guarantees safety and positive outcomes for individuals and their carers.

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

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

These must include consideration of:

- domestic workers and personal care assistants. There is an urgent need for reform to regulate this sector of the long-term care workforce and to improve their working conditions;
- migrant workers. The lack of integration between providers makes it difficult for the workforce to move flexibly across the system as demands change, or to exploit opportunities for professional development and career progression in the sector. This is a particular issue for migrant workers who often face difficulties in having their previous qualifications recognized;
- improvement of working conditions and financial remuneration;
- sustainable and fair management of cross-border mobility of the care workforce.

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

Training is required to support the current and future long-term care workforce to have the knowledge, skills and confidence to deliver holistic assessments and care planning and to provide safe, effective and person-centred care and support that enhance the dignity and functional ability of older persons at home and in care homes.

Access to high quality learning and clearly defined qualification, accreditation and career development pathways have the potential to raise the status and attractiveness of long-term care work. Training, supervision, feedback, and support to improve performance in their role should be available for all paid staff and for unpaid carers.
8. Technology

Age and dementia friendly design and use of assistive technology should be used to increase choice, improve quality of life, reduce physical and emotional burden on carers and ensure that the provision of care is as unobtrusive as possible. A variety of technological aids are available and growing as the private market sees the economic potential in these systems: personal alarms; medication dispensers; motion sensors; fall detectors; temperature, GPS monitoring devices, mobile apps and other similar tools.

New technologies must be integrated into long-term care systems, making sure they are accessible and affordable for all users. These technologies include:

- **Digital communication and information systems.** Continuity and coordination of care and monitoring of quality are enabled by interoperable information and communications technology (ICT) systems and processes to store, exchange and communicate information between different health and social care providers. 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;

- **Assistive technologies.** COVID-19 has accelerated the adoption, uptake and normalisation of digital solutions to support health protection messaging, contact tracing, self-care, remote and mobile monitoring of symptoms and chronic disease, video enabled triage and consultations, remote working and enhanced information sharing. Adoption of these technologies may pose specific challenges for many formal and informal carers who are digitally excluded or need to be upskilled to ensure they can fully exploit the potential of these new technologies for the benefit of the people they support.
SECTION THREE: New Model

9. A new model of long-term care empowerment

A post-pandemic world should aim to address the challenges and gaps faced by long-term care systems, through the lens of a human rights-based approach. Important considerations are:

Person-centeredness:

- Establish a core principle of care systems, which empowers older adults through placing them, their families and communities, at the centre of system design and organization, rather than diseases and disabilities
- Enable those receiving care and support, supported by family, friends and health and social care professionals, to express their own needs and decide on their own priorities through a process of information-sharing, shared decision-making and action planning, and plan and deliver the support accordingly
- Place the development of collaborative relationships between older people and care professionals at the heart of service delivery. People with long-term conditions should have the knowledge, skills and confidence to manage their condition effectively in the context of their everyday life

Universal access to care:

- Revise and review eligibility assessments to consider only care needs, decoupling entitlements to care and support from the socio-economic characteristic of users and their families
- Ensure individuals can access and use needed care without undue financial burden to themselves and their families
- Ensure care is available where and when it is needed and improve coverage in small, rural and remote communities

Integration and continuity of care:

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

Multi-dimensional assessment:
- Blend in elements from comprehensive individual needs assessment, needs assessment for informal caregivers and family members and something akin to community needs assessment

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

Support families and local communities to provide care:
- Ensure support for informal caregivers is well-developed, readily available and geared towards protecting their health and well-being
- Combat gendered care stereotypes and encourage an equitable distribution of care tasks within families and between formal and informal caregivers
- Ensure older people, their families and communities are meaningfully engaged in the design of care services and system and empowered to shape them
- Support grassroots, socially innovative initiatives to develop care models and solutions that build on local community strengths

Assure the Quality of care:
- Development of quality criteria, in collaboration with older people and their informal carers
- Registration and monitoring of service providers’ activity
- Regular reports by providers against nationally / regionally agreed standards
- Inspection of service facilities and delivery of care.