



World Health  
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Rebuilding for sustainability and resilience:  
**STRENGTHENING THE INTEGRATED  
DELIVERY OF LONG-TERM CARE  
IN THE EUROPEAN REGION**





REBUILDING FOR SUSTAINABILITY  
AND RESILIENCE:  
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## Abstract

The pandemic of coronavirus disease 2019 (COVID-19) has revealed and accentuated important gaps in the provision of appropriate, community-based, long-term care services for a rapidly growing number of people experiencing decline in functional ability, across the WHO European Region. As countries work to rebuild and strengthen health and long-term care systems, it is essential to support broad dialogue, a common vision for change and focused interventions to bridge existing divides. This policy brief proposes a conceptual framework that maps long-term care actions within the health and social policy landscape and highlights the need and potential for deeper integration and coordination across systems.

## Keywords

LONG-TERM CARE, INTEGRATED DELIVERY OF CARE, HEALTH SYSTEMS, SOCIAL PROTECTION, EUROPE

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# GLOSSARY

<b>Activities of daily living (ADL)</b>	The basic activities necessary for daily life, such as bathing or showering, dressing, eating, getting in or out of bed or chairs, using the toilet and getting around inside the home. Together with the instrumental activities of daily living (see below), they represent key life tasks that each individual needs to be able to manage without support, in order to live independently.
<b>Assistive care</b>	Assistance provided to help a person perform a particular task to maintain functional ability and preserve independence.
<b>Care coordination</b>	Proactive approach that brings care professionals and providers together around the needs of care users to ensure that people receive integrated and person-focused care across various settings.
<b>Clinical integration</b>	The integration of care into a single and coherent process across the different functions, activities and operating units within and between care systems. Clinical integration includes horizontal and vertical integration.
<b>Functional ability</b>	The health-related attributes that enable people to be and to do what they have reason to value.
<b>Functional integration</b>	The extent to which key support functions and activities, such as financing, human resources, strategic planning, information management, marketing and quality assurance and improvement, are coordinated within and across care systems.
<b>Informal caregivers (carers)</b>	Are usually members of the family or community who provide support in the context of a personal/social relationship or a formal or an informal agreement with the family or the State. They are not professionally trained, or have received only sporadic training for care work.
<b>Instrumental activities of daily living (IADL)</b>	Activities that facilitate independent living in the community, e.g. using the telephone, taking medications, managing money, shopping for groceries, preparing meals and using a map.
<b>Integrated care</b>	A system and process in which services are managed and delivered such that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and assistive and palliative care, coordinated across the different levels and sites of care within and beyond the health sector, and provided according to their needs throughout the life course.
<b>Intrinsic capacity</b>	The sum of all the physical and mental capacities on which an individual can draw. Through constant interaction with all the factors in the extrinsic environment (i.e. all the factors that form the context of a person's life), intrinsic capacity determines an individual's functional ability (!).
<b>Long-term care</b>	A broad range of personal, social and medical services and support that ensure people with, or at risk of, a significant loss of intrinsic capacity (due to mental or physical illness and disability), can maintain a level of functional ability consistent with their basic rights and human dignity.
<b>Palliative care</b>	An approach that improves the quality of life of patients (adults and children) and their families facing the problems associated with life-threatening and progressive life-limiting illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.
<b>Transitional care / intermediate care</b>	Care that occurs during the transitions between care states, care settings or care providers – for example, from illness or injury to recovery and independence, from hospital to home, and from acute to palliative care provider.

*Reference:* Cesari M, Sadana R, Sumi Y, Amuthavalli Thiyagarajan J, Banerjee A. What is intrinsic capacity and why should nutrition be included in the vitality domain? *J Gerontol. (Ser. A)*. 2022;77(1):91–93 (<https://doi.org/10.1093/gerona/glab318>, accessed 2 April 2022).

# EXECUTIVE SUMMARY

The COVID-19 pandemic has revealed and accentuated important gaps in the provision of appropriate, community-based, long-term care services for a rapidly growing number of people experiencing decline in functional ability across the WHO European Region. As countries work to rebuild and strengthen health and long-term care systems, it is essential to support broad dialogue, a common vision for change, and focused interventions to bridge existing divides.

This policy brief proposes a conceptual framework that maps long-term care actions within the health and social policy landscape and highlights the need and potential for deeper integration and coordination across systems.

# BACKGROUND

A profound transformation of health and social care systems is required to secure the right of all Europeans to universal access to quality care and ensure they can enjoy better health and well-being at all ages. To achieve these core priorities of the WHO European Programme of Work, 2020–2025 (1), it is essential to bridge the gaps between health, long-term care and social care systems, putting people at the centre of a seamless, coordinated continuum of care across the life course. Considering the lessons of the COVID-19 pandemic, the Pan-European Commission on Health and Sustainable Development places integration at the centre of its vision for investing in strong, resilient and inclusive national health systems, recommending that European countries “prioritize the integration of health and social care services, ensuring patient-centred care and building on strong primary care” (2).

At global level, the same call to action has been echoed in the WHO Global Strategy and Action Plan on Ageing and Health and the WHO-led United Nations Decade of Healthy Ageing (3, 4). Delivering person-centred, integrated care and primary health services responsive to older people, and providing access to long-term care for older people who need it, are two of the action areas identified as crucial to improving the health and well-being of older people (4). Objectives, interventions and actions in these areas will be operationalized in the upcoming roadmap for a decade of healthy ageing in Europe, 2021–2030.

Considering these recommendations, this policy brief proposes a conceptual framework that maps long-term care actions within the health and social policy landscape and emphasizes the porous boundaries between them. At these intersection points, there is both need and scope for further integration and coordination. The framework emphasizes community-based services and actions, focusing on primary care provision as the centrepiece of people-centred service delivery, and the system-level and service-level recommendations for providing integrated care, as described in the Integrated Care for Older People (ICOPE) framework (5). It is intended to support decision-makers in the health and social care sectors, at all governance levels, as they jointly define coherent development plans for community-based, person-centred, integrated, long-term care services.



# INTRODUCTION

An estimated 135 million people across the WHO European Region live with a disability, experiencing limitations on their independence and often needing support to maximize functioning. In European Union countries, 7% of the adult population report severe long-standing limitations on their usual activities, usually associated with the need for regular care and support. The prevalence of long-term limitations increases with age and is considerably higher among women (6).

Europe, which is already the world region with the highest median age, will continue to experience accelerated population ageing, with the fastest increase among people aged 80 years and older, a significant proportion of whom live with illness and disability and are increasingly dependent on access to affordable, quality long-term care to maintain their health, well-being and social participation (7).

Long-term care and support for people living with functional limitations, traditionally provided by families (in particular, women) and local social networks, has been increasingly formalized through care service provision in health and long-term care settings. However, the pace of service development has not been sufficient to compensate for the eroding availability of informal and family support, at the same time as the demand for care has been increasing. As a result, there is an urgent need to strengthen and diversify the provision of long-term care in response to growing care needs. Reform and investment in long-term care has become even more pressing in the aftermath of the COVID-19 pandemic, which has revealed fragmentation, wide capacity gaps, deep inequalities and structural vulnerabilities in care systems (8, 9). Rebuilding for quality, effectiveness and sustainability requires an integrative approach to long-term care service provision, focused on improving coordination across sectoral boundaries and governance levels and between formal and informal caregivers (10, 11).

# WHAT IS LONG-TERM CARE?

Long-term care refers to a broad range of personal, social and medical services and support that ensure people, with or at risk of a significant loss of intrinsic capacity (due to mental or physical illness and disability), can maintain a level of functional ability consistent with their basic rights and human dignity (5, 12, 13). Long-term care is provided over extended periods of time, although not necessarily continuously or at constant frequency and intensity (12). While some care users recover function (at least partly) and require less support as they regain (some) independence, others experience a sustained and irreversible decline in functional ability and thus rely on broader and more frequent care to maintain well-being and dignity.

## Principles and aims of long-term care provision

Long-term care services support individuals with limited and declining functional ability to continue leading meaningful lives, as independently and safely as possible, and promote their quality of life, while respecting their rights to autonomy and self-determination, as well as equality and non-discrimination (14, 15, 16).

To achieve these goals, long-term care should be:

- delivered in a continuum and integrated into health and social support service packages to effectively respond to the needs of care users and their communities (12);
- closely aligned with the values and preferences of care users, their informal caregivers, families and communities; and
- organized in care settings that allow users to remain as active and as engaged as possible with local social networks (16, 17).

## Who needs long-term care?

The need for long-term care arises when individuals experience a decline in their intrinsic capacity and require assistance with performing basic daily activities. Such needs can be present from birth; they can arise suddenly at any point during the life course; or they can develop gradually as people are affected by illness, disability or frailty with advanced age. Long-term care needs increase considerably with age, and are more common among women, people living alone and those with lower health and socioeconomic status (18).

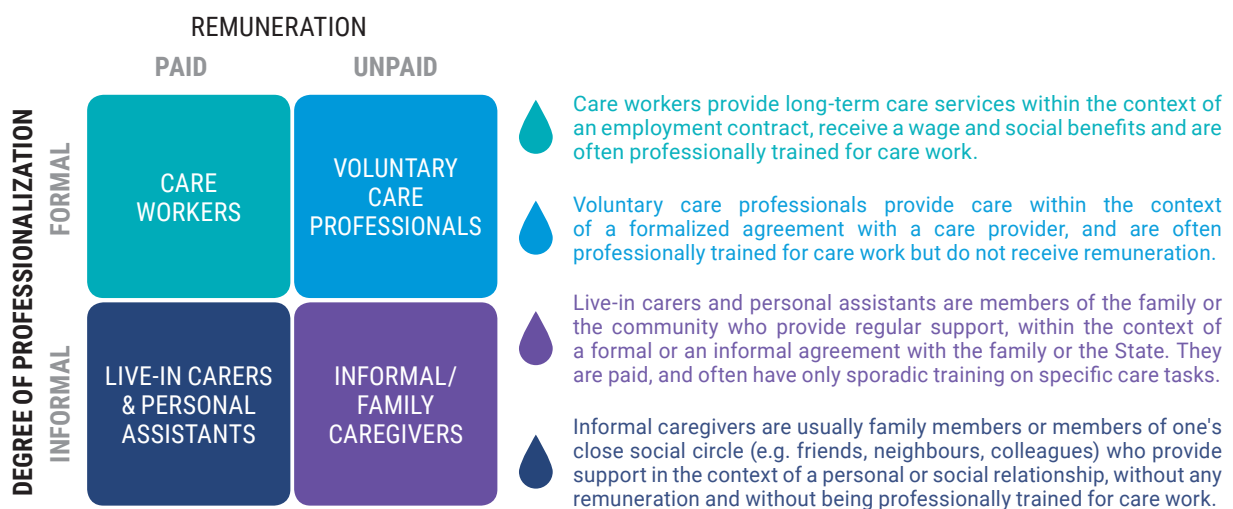
Individuals of all ages can develop long-term care needs, but as the world population ages, older people (aged 60 years or above) account for a larger share of long-term care users. Globally, an estimated 142 million older people are unable to meet their basic needs independently (19) and two out of every three older people are likely to need care and support at some point during their lives.

The need for long-term support can extend beyond the individual with care needs to their informal caregivers (20). Informal caregivers, often older and experiencing declines in functional ability themselves, and particularly those who provide intensive and frequent care, suffer the detrimental mental and physical health effects associated with a chronic stress experience and are exposed to increased risk of social isolation and poverty (21, 22, 23). Access to caregiver support services helps to protect the health and well-being of informal carers and allows them to continue to provide care.

## Who provides long-term care?

Long-term care includes care organized and provided by paid and unpaid caregivers, mainly women (5). These can be specialized care professionals in the context of formal employment regulation, as well as close relatives or other members of the community outside the bounds of a formalized employment or care arrangement, usually described as informal or family care (11). By and large, formal care is provided by a variety of care workers, with different levels of training and different skill levels, who are paid for their work (11). Conversely, many informal caregivers provide support within the context of a social relationship and generally without pay. Nonetheless, exceptions exist and are becoming increasingly more common (24). Fig. 1 depicts a two-dimensional typology that captures the most typical examples.

**Fig. 1. Distinguishing caregiver type by level of professionalization and remuneration**



Across the world, long-term care is overwhelmingly provided informally and mostly without pay (22). Estimates suggest that informal care, both paid and unpaid, accounts for as much as 80% of all long-term care provided (25), a share that is likely to be higher in countries with less well developed long-term care service provision.

Across the formal/informal divide, the vast majority of carers are women. This gender imbalance characterizes both the long-term care workforce and the health workforce but is more pronounced in the case of the former. Women account for as much as 80% to 90% of the formal long-term care workforce, although they represent fewer than half of the total workforce in the European Region (26). Women are also heavily overrepresented among informal caregivers, representing close to two thirds of the total, and more likely than men carers to perform high-intensity care tasks and provide frequent care (26).

# WHAT ARE LONG-TERM CARE SERVICES?

Formal long-term care includes a package of services aimed at preventing, mitigating and rehabilitating functional decline, delivered in a variety of settings, ranging from support at home to community-based, acute or residential care facilities. It covers aspects of health promotion, prevention, treatment, assistive care and social support, rehabilitation, and palliation (12). Depending on the specific needs of each individual and the underlying conditions which lead to loss of functional ability, a mix of all or some of these services will be needed.

**Assistive care** forms the core of the basic package of formal long-term care services and includes the provision of services and adequate assistive products for individuals who require support with activities of daily living (ADL), instrumental activities of daily living (IADL) or well-being and social participation.

**Assistive care services** refer to:

- personal care, including support with limitations in ADL, such as bathing or showering, dressing, eating, getting into and out of bed or chairs, using the toilet and walking short distances;
- nutrition and household management, referring to support with limitations in IADL, such as shopping, preparing and serving meals, managing medication, house cleaning and maintenance, and managing money and bills; and
- support for well-being and social participation, referring to transportation, psychological counselling, facilitated peer-to-peer support, creative, cultural and sport activities and any other activities that support well-being and encourage social and community engagement.

Assistive care services are functionally separate from preventive, curative and rehabilitative care and distinct in their purpose, which emphasizes support and assistance. It is also important to recognize that, while a significant part of formal long-term care provision is accounted for by assistive care services, the majority of assistive care is still provided informally by family, friends, local communities or live-in carers and personal assistants, even in countries with well developed long-term care systems.

While long-term care service packages are commonly centred around assistive care, they include a mix of care services. Prevention, promotion, care coordination, disease management, rehabilitation and palliative services, while often delivered by primary health care providers, are also among the care services regularly provided by long-term care workers, both in long-term care facilities and in community-based settings.

## COUNTRY SPOTLIGHT: DENMARK PREVENTION AND REABLEMENT IN LONG-TERM CARE

Denmark's long-term care system is considered one of the most comprehensive and universal in the world and is characterized by a high level of decentralization, with 98 municipalities responsible for regulating, financing and organizing long-term care services, within a broad national legislative framework. Access to care is needs-based and funded primarily through general taxation, with free home care and some copayments for other care types. A front-runner in the deinstitutionalization movement, Denmark emphasizes a community-based and proactive approach to care. Its orientation towards prevention, health promotion and reablement helps ensure that functional decline and care needs are avoided or delayed to the extent possible, improving the user's quality of life and reducing the pressure on the care system (27, 28).

**Preventive home visits** for older people living in the community have been mandated in Denmark since 1998, although participation is voluntary. Each municipality must offer this service to individuals turning 70 (if they live alone), 75 and 80 years of age, and on a yearly basis for those older than 82. Individuals at risk of suffering from social, psychological or physical disability can access the service from age 65. Preventive visits aim to assess the general health status and functioning of older, community-dwelling individuals, to provide advice about sustaining one's health and functional ability for as long as possible and to guide older people towards available support services (29). Considered highly successful, the programme was expanded to cover all those aged above 70 and to include assessments and advice on social isolation and loneliness, from 2019.

Launched as a medium-sized pilot project in the Fredericia municipality (2007) and adopted at national level in 2015, the **reablement model** makes it mandatory for all Danish municipalities to assess whether a person with care needs could benefit from a short-term intervention aimed at regaining physical or social functionality, before being offered a home care service package. Reablement is a time-limited rehabilitation programme, focused on user-defined, regularly adjusted goals, and an adaptive approach to care provision that reflects the user's evolving care needs and engages a multidisciplinary care team (30). Reablement programmes are person-centred and goal-based, taking into consideration the motivation and resources of each individual, and may include measures such as physical exercise, training in activities for daily living, physical aids and environment adaptations, as well as social activities and measures to address loneliness. The aim of reablement programmes is to give people with care needs a possibility of recovering or improving their functional ability, thereby contributing to increased independence, safety and autonomy.

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**Caregiver support services:** long-term care provision also includes a range of formal services organized and provided by care professionals with the aim of supporting informal caregivers of people who experience functional decline. Such services attempt to transmit useful information and skills, reduce caregivers' burden – for example, through respite care – and mitigate any detrimental health and well-being effects on informal caregivers – for example, through psychological support, training and support for self-care (20, 31).

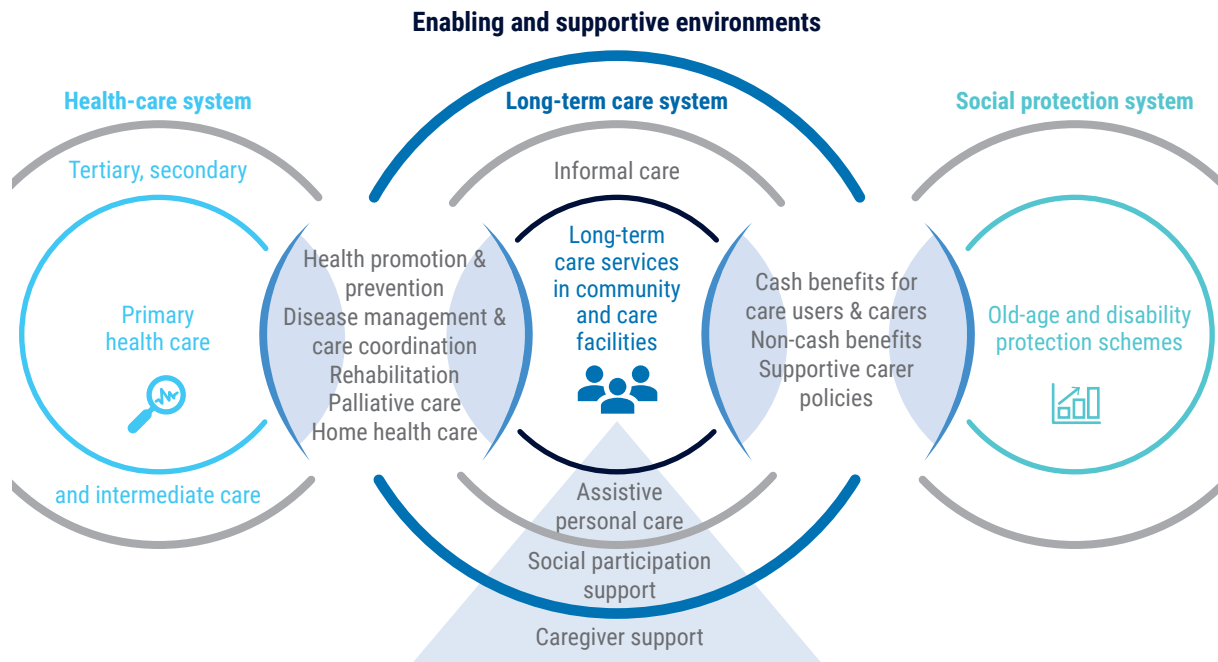
Caregiver support packages also include a series of cash benefits aimed at income replacement, as well as non-cash benefits and supportive policies – for example, care leave schemes, entitlements to social benefits (e.g. pension rights) and flexible working arrangements. These aim to acknowledge informal caregiving by compensating for loss of economic opportunities and allowing caregivers to reconcile caregiving obligations with work.

# TRACING THE POROUS BOUNDARIES OF LONG-TERM CARE SYSTEMS

A long-term care system encompasses all organizations, people and actions aiming to promote, maintain or improve well-being, health and functional ability for individuals with limitations in intrinsic capacity (12). Such actions often span the boundaries between health, long-term care and social protection systems (represented in Fig. 2 as partly overlapping, horizontally aligned circles), as well as the boundary between formalized service delivery and informal care provision (represented in the centre of Fig. 2 as concentric circles that build up the long-term care system).

The joint or complementary provision of care by both formal and informal caregivers is the determining characteristic and the core of long-term care systems, with informally provided care accounting for the vast majority of support (32). At the same time, enabling, age-friendly and inclusive local environments contribute to ensuring that people who experience declines in intrinsic capacity can function independently for longer periods of time, thereby reducing and delaying the need for assistive care (33, 34). Therefore, formal care services, informal care and enabling environments should be considered the three key components of a long-term care system.

Although these three components are common to all long-term care systems, their relative importance can vary – whereas, in some countries, formal care services are well developed, in others they are mostly lacking, or organized primarily within the remits of the health-care system or the social protection system (as shown in Fig. 2). Primary health care has a central role in the provision of long-term services in the community, particularly through its focus on providing promotive, preventive, curative and rehabilitative services and palliative care, accessible to all (35). Similarly, old age and disability social protection schemes contribute greatly to the sustainability and accessibility of care, ensuring that individuals with care needs and their families have the necessary resources to manage the effects of functional decline.

**Fig. 2. A mapping of long-term care systems – porous boundaries and community grounding**

Since the health, long-term care and social protection systems have intersecting and overlapping functions, it is often difficult to draw clear distinctions. The boundaries that separate them are best described as porous, generating a growing need but also a large potential for joint working and collaboration.

A long-term care system may include all, or only some, of the actions and care services described in Fig. 2 and its structure and organization can take very different forms. In the WHO European Region, we observe high variability across a spectrum measuring the degree of formalization, consolidation and centralization of long-term care systems, each with relevant implications for the integrated delivery of care (9, 18).

## Formalization of long-term care systems

The degree of formalization of long-term care refers to the balance between informally and formally provided care. A higher degree of formalization is characteristic of long-term care systems in Nordic and western European countries, such as Denmark, the Netherlands and Sweden, whereas countries in southern and eastern Europe and central Asia predominantly rely on informal care, with limited availability of professionally provided care (18). Lower levels of formalization of long-term care provision stand in contrast with the organization of health care delivery and can act as an important barrier to integrated delivery of care, in the absence of structured processes for interprofessional and interorganizational collaboration.

As population ageing, migration and family trends contribute to increasing the mismatch between the demand for care and the availability of paid and unpaid informal caregivers, the need to invest in developing and formalizing the provision of long-term care services is growing throughout the Region. While the entirely formalized provision of assistive care is neither financially sustainable nor aligned with the preferences of care users, overreliance on unpaid informal caregivers has detrimental effects on economic and social progress, contributes to perpetuating social and gender inequalities and hinders integrated delivery of care (20, 36). In line with a rights-based and universal health coverage approach to

long-term care service development, formal care provision should be sufficiently developed to respond to long-term care needs across the population, complemented and facilitated by informal caregiving enjoying adequate support.

## **COUNTRY SPOTLIGHT: ITALY SUPPORTING INFORMAL CARERS DURING THE COVID-19 PANDEMIC**

The Italian long-term care system is nationally funded, but primarily organized for delivering interventions at regional level. The emphasis on cash benefits over the provision of publicly funded care services, in combination with a strong cultural orientation towards seeing care primarily as a family responsibility, have contributed to the underdevelopment of formally provided care services compared with informal care, which accounts for a considerable majority of all care provided (37). Estimates place the number of informal family caregivers at 7.3 million, accounting for 14% of the population (38). In addition, many households hire care workers privately, mostly workers with a migrant background and an irregular contractual status (39).

Informal caregivers, already facing considerable challenges, have been particularly vulnerable to the effects of the COVID-19 pandemic, which has exacerbated their care burden. In response to the emergency situation, the Italian national Government allocated €68 million in 2020 to the Fund for Supporting Family Caregivers, aiming to alleviate the burden caused by disruptions to residential care provision, through interventions to be implemented by the regions during the year 2021.

In the Marche region, where support for informal caregivers has traditionally been limited, the urgency of providing support led to the decision to allocate funds as a cash benefit of €1200 to family caregivers of persons with very severe disability – the first time that caregivers in the region had received a direct cash benefit for this purpose. The funding also prompted the launch of an evaluation and experimentation programme, collecting data on the needs and preferences of informal caregivers, with the aim of informing the development of a structured support system at regional level (40).

In contrast, in Emilia Romagna, the first region in Italy to have legally recognized the role of informal caregivers as part of the formal support network (Law No. 2/2014), support services already included information, training, psychological support, respite care and economic support through care allowances. Here, the resources allocated by the national fund have been integrated with regional resources, allowing for the expansion of all support services, but primarily focused on increasing availability of respite care and home-based formal care, to reduce informal caregivers' burden.

The national Fund for Supporting Family Caregivers represents an important recognition of the crucial role they play in the sustainability of the Italian long-term care system, and facilitates the development of support structures, despite large regional differences. It aligns with an ongoing national reform plan that recognizes as a priority the integration of formal and informal care.

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## **Consolidation of long-term care systems**

The extent of consolidation of long-term care systems refers to the recognition of long-term care action and organizations as separate structures, with clearly defined and independent functions from those of the health and social protection systems. In countries such as Austria and the Netherlands, long-term care is explicitly recognized as a distinct policy field, while most countries in the Region organize long-term care as interlinked with, or as part of, policies for health, social support, housing and inclusion.

Importantly, while consolidation can help reduce fragmentation in responsibilities and policies for long-term care and facilitate change processes, it does not remove the challenges of coordinating across sectors or across governance levels.



## COUNTRY SPOTLIGHT: RUSSIAN FEDERATION LONG-TERM CARE REFORM AND PROACTIVE OUTREACH

The long-term care reform in the Russian Federation started in 2018, with the launch of the national project “Demography” and its subsidiary federal project “Old Generation”. The reform overhauled the existing care system, envisioning profound changes that would promote proactive responses to demographic change, coordination across health and social care and inbuilt flexibility to respond to the requirements of a decentralized and highly diverse regional structure.

The national long-term care reform follows a series of transformations of the Russian welfare system over recent decades, which started with the consolidation of the Ministry of Health and the Ministry of Welfare (with responsibility for social policy) into a single national agency, with a very broad portfolio (2004 to 2012). As this experiment was considered unsuccessful, corrections going in the opposite direction increased the separation of medical and social policies and service provision, which peaked in 2018. Care fragmentation quickly led to overloading of health institutions, reduced the accessibility and affordability of community-based social care and triggered the development of a “grey market” to fill service capacity gaps in residential and community-based care services.

The emerging long-term care reform attempts to correct this imbalance by emphasizing coordination and joint working rather than consolidation. Its core principles are:

- proactive outreach to those in need of care
- implementation of a standardized needs assessment system (five grades)
- development of a cross-sectoral coordination model, linking health and social care
- introduction of a quality control system for residential-based care and
- expansion and development of formal community-based care services.

Responsibilities for the reform are shared between two “project offices” representing the Ministry of Welfare, which takes the leading role, and the Ministry of Health, coordinating the development of an integrated data sharing and “patient-routing” system and supporting multidisciplinary work between doctors and social workers.

Gradual implementation of the reform started in six pilot regions and is expected to be fully scaled up to include all 85 regions by 2024. A decentralized approach to implementation allows every region to define a customized reform plan, which reflects local characteristics and preferences. This bottom-up process has revealed multiple stumbling-blocks, among them the variability of experience and expertise at regional level and regulatory inconsistencies. At the same time, the rich evidence generated in pilot and early-adopter regions is constantly being analysed to identify problems and emerging solutions to inform subsequent phases of the national roll-out.

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### Centralization of long-term care systems

The degree of centralization refers to the distribution of responsibilities for long-term care organization, provision and funding between local, regional and national administrative levels. Due to the rooting in social protection systems of many long-term care actions, decentralization is common to most long-term care systems in the WHO European Region (18). This stands in contrast with the higher level of centralization in regulation, financing and service delivery characteristic of health care systems. For example, home health care provided by health professionals in the home of individuals with long-term care needs is generally regulated and organized at national level (notable exceptions are Denmark and Italy, where responsibilities are held at regional level). At the same time, home-based assistive care can be funded and regulated at national level – for example in Ireland, Malta and Slovenia – or at regional and local level – for example in Denmark, Finland and the United Kingdom. In the majority of European countries, funding and regulatory responsibilities are split between all three levels of governance – for example in Austria, Belgium, Turkey

and Romania (41). Despite the complexity of governance of regulatory and funding structures, provision of long-term care remains primarily locally driven and organized. The benefits of decentralized care provision are most apparent in higher responsiveness and in the ability to leverage existing community resources and strengths. At the same time, decentralization can lead to considerable distortions and care gaps, particularly with respect to geographical inequalities in access to care and the lack of a coherent strategic vision and coordinated planning between governance levels.

**The wide range of national experiences across the spectra of formalization, consolidation and centralization of long-term care systems highlights the marked trade-offs that need to be carefully weighed against one another as countries approach the more extreme ends of either spectrum, often with considerable impact on overall care system performance. Taken together, the main lesson from these experiences is that, while there is no one-size-fits-all solution, it is essential that levels of formalization, consolidation and centralization are considered in the context of and well aligned with the national goals and vision for long-term care provision and system development.**

## Integration at the core of coherent, post-pandemic long-term care policies

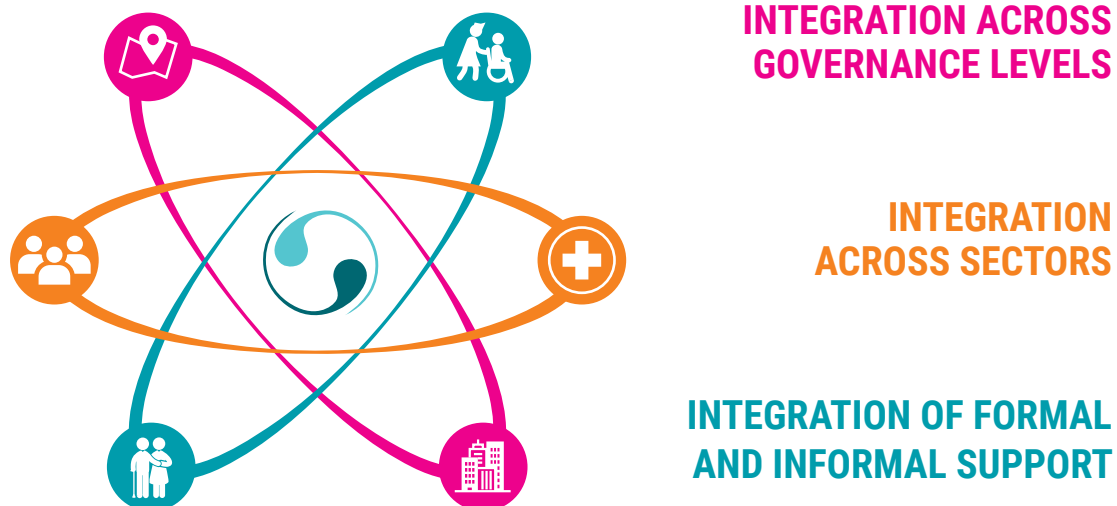
Despite the large variability in care system organization, structure and functioning in the WHO European Region, the shared vulnerability of underresourced, fragmented and poorly monitored long-term care systems has become acutely apparent in many European countries as the COVID-19 pandemic has swept through the Region (12). National strategies and emergency response plans have rarely included an integrated perspective on care provision, prioritizing health system sustainability and leaving long-term care systems limited in their capacity to react. Uncontrolled spread of infection and devastating mortality rates in care facilities have had significant consequences for the well-being and health of residents, care workers, their families and communities, despite sustained efforts in many European countries to stop or slow the spread of infection and to find innovative ways to limit the negative effects of contact restrictions or social distancing measures. The pandemic has raised public awareness of the segregating and isolating nature of care in institutional settings, of difficulties in ensuring care quality, and of the need to uphold the rights and dignity of people who receive care. At the same time, it revealed pre-existing and glaring capacity gaps in community-based care and a pronounced overreliance on informal caregivers, with a host of negative health, social and economic consequences.

Acting as a common wake-up call, the COVID-19 pandemic has also given rise to a common opportunity for accelerating progress and building better, more resilient long-term care systems (8, 42). A key lesson of the pandemic is that countries in the Region must strengthen care systems through better integration. Notwithstanding the crucial role of increasing the availability of transitional and intermediate care to ensure continuity along care pathways (43), the pandemic has highlighted the need to develop and diversify community-based care provision, both in primary care and long-term care settings, as an alternative to facility-based care (18).

Integrated provision of community-based care is key to the resilience of care systems because every sectoral boundary represents a change in incentives, values and culture, processes and regulatory structures. Furthermore, each misalignment increases the potential for costly duplication of care provision, inefficient allocation of scarce resources and suboptimal care outcomes due to gaps and delays in care provision. If they are to achieve their goals of providing timely, affordable and equitable support across the continuum of care, long-term care systems must minimize such misalignments and ensure coherent processes and policies along three integration axes (see Fig. 3):

- between the health, long-term care and social protection sectors
- between governance levels – local, regional and national – and
- between formal and informal care provision.

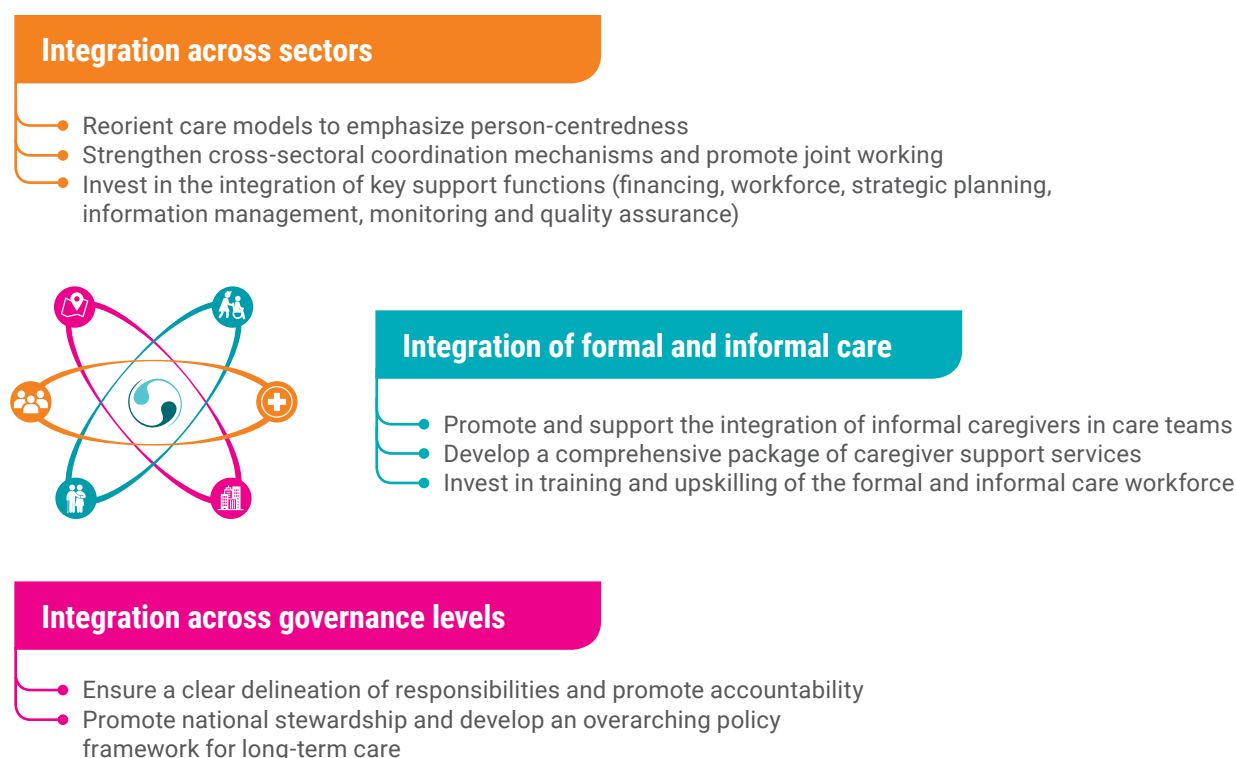
**Fig. 3. Three axes of integration for long-term care provision**



# STRATEGIES FOR PROMOTING INTEGRATED LONG-TERM CARE PROVISION

Because no two long-term care systems are alike, successfully addressing a common problem may require different solutions, which account for the characteristics of each setting (44). At the same time, decades of reform and experimentation with long-term care models in the WHO European Region have led to the clarification of principles and strategies that can promote integration of long-term care delivery along all three axes of integration and improve system performance in a variety of contexts. These strategies (summarized in Fig. 4) should guide and inform national efforts to strengthen long-term care provision, promote resilience and sustainability of long-term care systems and ensure equitable access to care and support for all those who need it.

**Fig. 4. Strategies for promoting integrated long-term care provision**



To reduce capacity gaps and improve the efficiency of community-based health and long-term care, countries should prioritize investment in the development of integrated delivery models, bridging the boundary between primary care and community-based long-term care services. Investments in the formalization of community-based long-term care provision and the development of harmonized standards, procedures and care pathways for primary and long-term care providers, with special emphasis on aligning needs assessment standards and instruments and entitlements to care across the health and long-term sectors are crucial facilitators for joint working and coordination. Care and case

management programmes, training of community-based care coordinators and the creation of specialist multidisciplinary teams in the provision of care in both primary and long-term care settings have been successfully implemented in many European countries and should be scaled up and mainstreamed in community-based care provision. Additionally, including long-term care service packages in universal health coverage programmes and increasing investment in strengthening data infrastructure and information-sharing mechanisms between different community-based health and long-term care providers are key systemic facilitators for integrated delivery of care, as well as for promoting high quality and equity achievements of care systems.

## **COUNTRY SPOTLIGHT: ROMANIA COMMUNITY CARE AND INTEGRATED COMMUNITY CENTRES**

The Romanian long-term care system is characterized by pronounced decentralization of financing and organizational responsibilities to the local level and high cross-sectoral fragmentation. The marked emphasis on cash benefits, administered under various social protection schemes, and chronic underfinancing have contributed to the very low coverage and unbalanced geographical distribution of formal care services, especially in community-based settings. As accessibility of care is closely linked with the administrative and financial capacity of each local authority, deprived and vulnerable communities in rural areas are particularly underserved. The parallel underdevelopment and patchy geographical coverage of primary care compounds this problem, leaving many vulnerable individuals unable to access a basic package of health and social support services, to which they are entitled under extant legislation (45).

The community care programme (Asistență medicală comunitară) was first piloted in 2002 with the aim of facilitating access to health and social services for all individuals, and particularly for vulnerable groups, rural and underserved communities. Progressively expanded by subsequent legislation seeking to strengthen continuity and coordination of care through the creation of integrated community centres, the programme was prioritized as part of the 2014–2020 National Health Strategy (46). Community care workers carry out their activities in close collaboration with health mediators and social workers, but also with general practitioners, educational support services and all other relevant health and social structures operating in their areas, including nongovernmental organizations.

In 2021, 1800 community care workers and 500 health mediators were active in Romania, half of whom were concentrated in 11 of the 41 counties. Self-reported data indicates each community care worker supports a median number of 250 adults and older persons living with chronic diseases and up to 50 adults with disabilities, in addition to over 200 neonates, children and adolescents (47). At the end of 2021, the Government announced the allocation of resources from the Recovery and Resilience Plan to opening 200 integrated community centres in rural and marginalized communities across Romania, each staffed by at least one community care worker and one social worker, with additional multidisciplinary support as required in each locality.

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## COUNTRY SPOTLIGHT: AUSTRIA DEVELOPING COMMUNITY NURSING

The Austrian social and long-term care system remains separated from the health care system in terms of legislation, competencies and financing. Whereas the organization and financing of the health-care sector follow the logic of social health insurance, the provision of long-term care services falls under the responsibility of regional governments, resulting in substantial differences regarding coverage, structural quality regulations and quality assurance mechanisms across the country. With the introduction of the care allowance (Pflegegeld) in 1993, the Austrian long-term care system took a shift towards more universalist principles, providing non-means-tested cash benefits for all people in need of care. Yet, the system maintains its strong reliance on informal carers, both unpaid family members and privately paid live-in care assistants, usually with a migration background. The availability of formal care services varies substantially across the country and is facing an increasing shortage of professional care workers, with an expected 75 000 more care workers needed by 2030.

Funded through the Austrian Recovery and Resilience Plan 2020–2026, community nursing is currently being piloted in Austria. Its aim is to improve the health of the Austrian population, especially for at-risk groups and older people, to respond to unmet support needs, improve well-being and strengthen the self-help capabilities of older people and their informal caregivers. In all, 150 community nurses will act as an easy-to-reach local point of access for nursing and health issues and are expected to reach approximately 50 000 individuals per year.

With the implementation of community nursing, a significant contribution is made to the implementation of the Sustainable Development Goals (SDGs) particularly SDG 3, Ensure healthy lives and promote well-being for all at all ages. Community nurses will also play a crucial role in enabling coordination between primary health care, home care and informal caregivers at the local level and facilitating access to information, advice and counselling, with a focus on prevention, health promotion and health literacy.

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Investing in better integration is not equivalent to consolidating care systems. Countries need not, and should not, strive to consolidate all relevant functions within standalone long-term care systems that operate separately from the broader health and social policy fields. Rather, they can invest in cross-sectoral coordination mechanisms which allow care services to be delivered across these sectors in a coordinated, person-centred fashion that responds better to population needs (43). System-wide and organizational-level efforts should focus on the integration of key support functions, such as financing, human resources, strategic planning, information management, monitoring and quality assurance, as well as clinical integration (43, 48). A clear definition of responsibilities reflected in a balanced distribution of resources and the alignment of incentives and data systems able to capture and provide relevant information must underpin effective coordination mechanisms.

The pitfalls of complex governance structures in long-term care cannot be managed through centralization alone. Rather, this can be achieved through a clear delineation of responsibilities between governance levels and by creating coordinating national and subnational bodies. Local control over care provision allows for swifter reactions and the development of better fit-for-purpose solutions, and facilitates bottom-up, participatory decision-making processes that can empower individuals and communities to shape care. At the same time, national stewardship and coherent policy frameworks are necessary for a fair and efficient distribution of resources and investment in the care workforce, data infrastructure and digitalization, system performance and quality assurance (12).

## COUNTRY SPOTLIGHT: GERMANY INVESTMENT IN INTEGRATION AND INNOVATION

The long-term care insurance model introduced by Germany in 1995 operates under the principle “long-term care insurance follows health care insurance”, reproducing the characteristics of social health insurance and securing financing for long-term care via mandatory contributions. In 2021, 73.5 million Germans were covered under the social long-term care insurance scheme and 9.2 million under the private one (both offering the same level of benefits). In the same year, 4.6 million individuals received long-term care benefits, a majority of which were cash benefits (49). The value of benefits varies depending on an assessment of care needs (on a scale of five care grades) and the type of care arrangements needed, but it does not fully cover care costs, especially for facility-based care, and must be supplemented by individual copayments (so-called out-of-pocket costs) or by social grants provided for individuals who cannot meet the additional costs of care (50, 51).

The highly regionalized structure of German health and long-term care and the low degree of control of federal bodies over the specific organization of care at community level make the financial incentives built into the long-term care insurance model one of the most powerful tools to promote integration and innovation. For example, long-term care insurance funds and municipalities cofinance local advisory centres for long-term care (Pflegestützpunkte), with the aim of facilitating coordination across local service providers and across all nursing, medical and social services. They provide counselling for people with care needs and connect them with relevant providers. Long-term care insurance also provides funding for regional care networks, bringing together all relevant actors involved in the delivery of community-based care.

The current legislative structure also includes provisions that facilitate health and long-term care insurance funds in concluding special contracts with care service providers, in order to foster cross-sectoral and integrated delivery of care services. Furthermore, care coordination across settings and sectors is recognized as a key goal for projects funded under the Innovation Fund, which supports testing and evaluation of innovative health care models, including better and integrated health care for persons with long-term-care needs (52).

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Formal and informal care provision should not be seen as substitutes, but rather as complementary types of care, interlocking to cover care needs in an effective manner. The coproduction of care services between care professionals, volunteers and networks of family, friends and neighbours should be nurtured, wherever appropriate and feasible. This requires the integration of informal caregivers in care teams, through a more inclusive approach to care planning, as well as an active investment in the provision of appropriate training, guidance and support for informal caregivers to avoid overburdening. Furthermore, because informal care remains the backbone of long-term care provision and is essential for the sustainability of care systems in all countries in the Region, the development of a well-balanced package of support measures that can ensure the sustainability of informal care resources is a crucial step towards developing stronger and more resilient long-term care systems (53). Policies and interventions supporting informal caregivers should be aligned across sectors with a view to promoting gender equity and the equitable sharing of the burden of care within and between families, communities and generations.

Finally, investment in the care workforce is crucial for the sustainability of long-term care systems and for promoting integration across all three identified dimensions. Integrated care requires care professionals to adapt and adopt new ways of working across sectors, care levels and care types. To this end, sustained investment and innovative approaches to training and upskilling are needed, as well as the development of guidelines for health and long-term care professionals on how to collaborate with and empower care users and informal caregivers to participate in the care process (11).

# CONCLUSION

In order to improve access to quality care and ensure that all individuals can enjoy better health and well-being at all ages, European countries must reorient care models to emphasize person-centredness, user involvement, prevention, healthy ageing and enablement. This will require alignment and coordination across care systems, governance levels and care settings and a customized approach to strengthening the integrated delivery of long-term care, which recognizes and is adapted to the key characteristics of long-term care system organization and functioning in each national setting.



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**World Health  
Organization**

REGIONAL OFFICE FOR **Europe**

## The WHO Regional Office for Europe

The World Health Organization (WHO) is a specialized agency of the United Nations created in 1948 with the primary responsibility for international health matters and public health. The WHO Regional Office for Europe is one of six regional offices throughout the world, each with its own programme geared to the particular health conditions of the countries it serves.

### Member States

Albania  
Andorra  
Armenia  
Austria  
Azerbaijan  
Belarus  
Belgium  
Bosnia and Herzegovina  
Bulgaria  
Croatia  
Cyprus  
Czechia  
Denmark  
Estonia  
Finland  
France  
Georgia  
Germany  
Greece  
Hungary  
Iceland  
Ireland  
Israel  
Italy  
Kazakhstan  
Kyrgyzstan  
Latvia  
Lithuania  
Luxembourg  
Malta  
Monaco  
Montenegro  
Netherlands  
North Macedonia  
Norway  
Poland  
Portugal  
Republic of Moldova  
Romania  
Russian Federation  
San Marino  
Serbia  
Slovakia  
Slovenia  
Spain  
Sweden  
Switzerland  
Tajikistan  
Turkey  
Turkmenistan  
Ukraine  
United Kingdom  
Uzbekistan

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