

# TOWARDS COMMUNITY-BASED PEOPLE-CENTRED INTEGRATED CARE: THE ROLE OF INFORMAL CARE

Despite significant advances in people's health and life expectancy in recent years, relative improvements have been unequal among and within countries. Care is too often fragmented and, as a result, the responsiveness of the health and long-term care (LTC) systems and satisfaction with care services remain low in some EU member states (more than 70% of EU citizens are satisfied with the overall quality of the health and long-term care in their home country, according to a new survey by Eurobarometer. However, there are great differences between member states, with western and northern countries being in general more positive). Many countries still face significant problems of unequal geographical access to care services, shortages of health workers and weak supply chains. The focus on hospital-based, disease-based and self-contained "silo" curative care models further undermines the ability of health and LTC systems to provide universal, equitable, high-quality personalised and financially sustainable care. Service providers are often unaccountable to the populations they serve and therefore have limited incentive to provide the responsive care that matches the needs of their users. People are often unable to make appropriate decisions about their own health, health and long-term care, or exercise control over decisions about their health and that of their communities.

Long-term care encompasses a wide range of care services and supporting activities aimed to meet individuals' personal needs. People who have multiple care needs usually receive health and social care services from different providers and in different care settings. Health and social care providers have experienced that this often happens without appropriate co-ordination or a holistic approach, leading to various issues for the service user, the (in)formal carer and

the family such as gaps in service provision or inadequate support, limited access and information, as well as increased costs to care systems in the form of unnecessary hospital admissions or aggravated health problems.

Integrating care, services and supporting activities means that the design and delivery of care is made in a more effective manner, so that users receive a continuum of preventive, rehabilitative, curative, and support interventions throughout the life course which are suited to their needs over time and seamlessly available across different levels and areas of health and social systems.

Integration is also more efficient, because it fully releases the potential for synergies across services, better allocates resources and avoids overlaps and the negative effects and costs of service disruptions on health status. Establishing and coordinating the full range of services in the continuum of care will also increase the flexibility and responsiveness of resources to meet the changing needs of older persons and people with disabilities and provide more adequate answers. Integration is also the cornerstone of deinstitutionalisation policies, aimed to facilitate the transition from institutional to community-based care, in accordance with the UN Convention on the Rights of Persons with Disabilities.

The European Commission has often underlined the importance of integrated approaches to the provision of social services. Integration of services improves coherence, people-centeredness, empowerment and participation towards care and services. It is nevertheless essential that policy responses geared towards integration deliver from a people-centred services approach

that meets the need for quality, innovative solutions for care and services, while promoting, at the same time, their preventive potential.

**Developing more integrated people-centred care systems has the potential to generate significant benefits to the health and health care of all people, including improved access to care, improved health and clinical outcomes, better health literacy and self-care, increased satisfaction with care, improved job satisfaction for health workers, improved efficiency of services, and reduced overall costs.**

Integration of care, both within and between health and long-term care can offer numerous advantages and yet no EU country seems to have an optimal level of coordinated care. EU Member States should enhance the coordination and continuity of care but there are several challenges in integrating LTC.

- First, with health and social care being traditionally separated, it is a challenge to establish continuity of care.
- Second, traditionally, systems are fragmented in terms of different public payers, types of reimbursement and providers of care, which make it challenging to incentivise care integration.

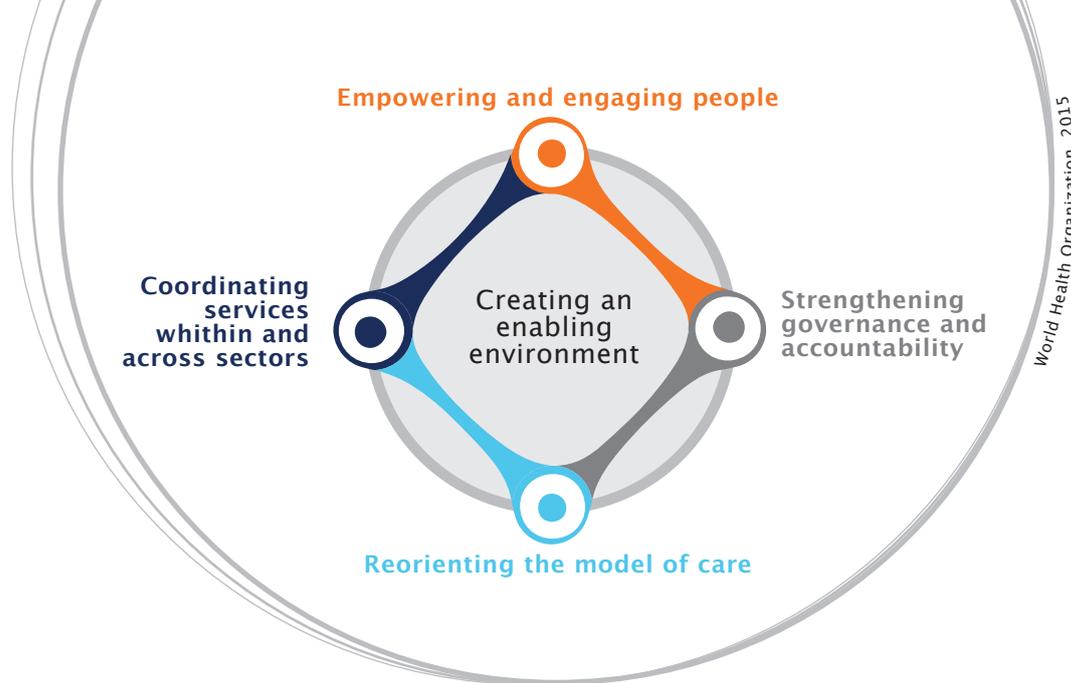
- Third, it is not straightforward how to appropriately mix health and long-term care services. LTC patients have many contacts with both the health and long-term care system. Whereas LTC system provision is often under the responsibility of local governments, the oversight of acute care tends to be at the regional or national level. This creates problems at the interface between acute care and LTC.

One way to reduce cost in LTC is to prevent dependency. Disease prevention, health promotion and rehabilitation are therefore key aspects of integrated care and should have a more central part of LTC systems. The levels and cross-country variations in self-reported dependency suggest considerable scope for fostering healthy and active ageing. Prevention and promotion are preferable to acute and reactive care, enabling the individual to stay healthy for longer, potentially bringing also financial savings. Rehabilitation can also be cost-effective in LTC and thus create cost savings. In some Member States, rehabilitation is clearly identified as a specific service and is an integrated part of comprehensive programmes of health care and health promotion. Countries should invest in evaluating the most promising initiatives targeting health promotion.

All EU Member States provide formal LTC services to their population. There is, however a great deal of variation in the distribution of recipients and expenditure that mainly reflects differences in the coverage of formal systems of home care and institutional care. Home settings typically have lower costs, can reduce dependency, encourage independent living and are most suitable for relatively low levels of dependency. Institutional settings typically have greater unit costs and are more appropriate for high levels of dependency. However, care can be set up at home even in cases of relatively heavy dependency if building on supportive integrated health and long-term services, putting users including informal carers at the core.

Several EU Member States report predominant use of either institutional care or home care. This suggests that there is scope for optimising the provision of care by ensuring the most efficient setting is used for each recipient. In particular, evidence suggests





that in many EU Member States it would be possible to move towards home care rather than in institutional settings, supporting care recipients to remain independent longer and allowing for the provision of informal care.

As a crucial element of the shift towards community care, informal care home-based care is seen as a practical measure to contain the costs of services and help increase the sustainability of LTC systems while also supporting widespread preferences among older people for being cared for in their own home. However, it can have a significant personal impact on the informal carers themselves. EU Member States should ensure that policies to support informal carers are consistently implemented. Member States have set up a number of measures to support informal carers, including carer allowances, increasing giving carers the right to carers leave and flexibility of employment in order to keep them attached to the labour market, respite care, counselling as well as information and training. There is however variation in the breadth and depth of these measures across EU Member States, which emphasises the potential for improving support for informal carers.

Access to information, training opportunities, financial and in-kind support should all form part of the measures to be envisaged in order to improve the quality of life of informal carers, with clear co-benefits for the people in need of care and society as a whole. A combination of targeted and universal approaches should also be used to allow informal carers to reconcile employment and care duties and to help them

mitigate the substantial economic sacrifice they make when forced to cut their working time or leave paid employment altogether.

The foremost component of a successful system transformation towards more coordinated/integrated health services delivery is an agreement between all stakeholders that care should be centred around patient needs. Incidentally, ‘Engaging and Empowering’ people forms part of the five core strategies of the recently-developed WHO Framework on integrated people-centred health services.

Empowering and engaging people is about providing the opportunity, skills and resources that people need to be articulate and empowered users of health and long-term care services. It is also about reaching the underserved and marginalised groups of the population in order to guarantee universal access to services. This goal seeks to unlock community and individual resources for action at all levels. It aims at empowering individuals to make effective decisions about their own health and at enabling communities to become actively engaged in co-producing healthy environments, providing care services in partnership with the health sector and other sectors, and contributing to healthy public policy.

In order to achieve better clinical outcomes through co-production of care, particularly for non-communicable and chronic diseases, individuals and families need to be active participants. This step is fundamental because people themselves will spend the most time living with and responding to their own

health needs and will be the ones making choices regarding healthy behaviours and their ability to self-care. Empowerment is also about care that is delivered in an equal and reciprocal relationship between, on the one hand, clinical and non-clinical professionals and, on the other, the individuals using care services, their families, and communities, thereby improving their care experience. This approach will enable communities to voice their needs and so influence the way in which care is funded, planned and provided. It will help to build confidence, trust, mutual respect and the creation of social networks, because people's physical and mental well-being depends on strong and enduring relationships. It strengthens the capacity of communities to organize themselves and generate changes in their living environments.

Informal carers play a critical role in the provision of health care. Carers must receive adequate training in order to be able to provide high quality interventions, and to serve as advocates for the recipients of care, both within the health system and at the policy level. Additionally, carers have their own needs for personal fulfilment and require emotional and practical support to sustain their role.

As informal carers are vital providers of health services, it is also important to watch for the system being exploitative of them. Particularly when the quest for efficiency may mean increasing the pressure on informal carers by reducing 'formal' health and social services, caution needs to be paid to adequate support and involvement in the care planning of family caregivers. It is necessary that policy makers and health system actors are aware of this effect, as it raises the risk of the carers themselves becoming chronically ill. To counteract this escalation, it is necessary to allow both models to exist in parallel: one where family members are empowered to take care of their loved ones and one where they are provided with adequate support from the formalised health system. The formal and informal service providers need to blend, calling for flexibility from the engaged professionals. Finally, patients should always be seen in the context of their family and care network.

The growing number of EU citizens who call for dignity in care and require quality care and support services, as well as their families, carers and communities, justifies the pressing need to address these issues.

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Eurocarers receives support  
from The European Union through the programme for  
Employment and Social Innovation (EASI Programme 2014–2017)