The Right to affordable, quality long-term care services: Autonomy and Community

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INTRODUCTION

The EUROSHIP project (2020-2023) aims to provide an original and gender-sensitive assessment of the current gaps in social protection against poverty and social exclusion in Europe. Through the involvement of national and European stakeholders, EUROSHIP develops policy recommendations on how to strengthen social citizenship at the national and EU levels. The research results will support the implementation of the European Pillar of Social Rights.

The European Pillar of Social Rights, proclaimed by the European Parliament in 2017, recognizes as principle 18 the right to "affordable long-term care services of good quality, in particular home care and community-based services." In March 2021, the European Commission announced as part of its European Pillar of Social Rights Action Plan, an initiative on long-term care, setting up a framework of policy reforms and evidence, which was provided by the 2021 Long-Term Care Report of the Social Protection Committee. In parallel, as part of the European Care Strategy, the European Council proposed Council Recommendations on long-term care, which was finalized in 2022 as the Council Recommendation on Access to Affordable High-quality Long-term Care. (Council Recommendation).

This policy brief – building on existing international agreements, research in EUROSHIP [1] and the evidence and recommendations of the Council Recommendation – sets out the policy implications and recommendations of the human rights parameters of **autonomy** and **community** implicit in the current European actions on long term care.

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[1] EUROSHIP Working Paper No 6: Long-term Care Regimes in Europe; EUROSHIP Working Paper No 14: Gaps in the Provision of Long-term Care across Europe.

Evidence and Analysis

Need

1) **Long-term care** is "a range of services and assistance for people who, as a result of mental or physical frailty or disability over an extended period of time, depend on help with daily living activities or are in need of some permanent nursing care." (Council Recommendation)
2) The need for long-term care arises when individuals experience a decline in their physical or mental functioning linked to impairments resulting from health conditions or associated with ageing, that affect the capacity to perform basic or instrumental activities of daily living given environmental factors that shape their everyday lives.
3) Such needs can be present from birth or arise suddenly at any time during life; but most frequently, needs for assistance are linked with impairments arising from the ageing process itself and age-related chronic health conditions. Long-term care needs increase with age and are more common among women, people living alone and those with lower health and socioeconomic status.[2]
4) In light of epidemiological trends of population ageing and increase in prevalence of chronic health conditions, the number of individuals potentially in need of long-term care in Europe will rise, at a minimum, from 30.8 million in 2019 to 33.7 million in 2030 and 38.1 million in 2050 (an overall increase of 23.5 %).[3]

Challenges

A resilient, intersectoral and economically sustainable long-term care policy is required to meet the inevitable and dramatic increase in need associated with epidemiological and demographic trends. But there are substantial challenges that each country needs to meet:[4]

1) **Affordability**: Long-term care generally is covered by social protection systems, but, in some countries these public funds are inadequate or only available to a small population, and in nearly every European country there are out-of-pocket costs.
2) **Availability and Accessibility**: Besides geographical and social-economic barriers to access, there are, for both home and residential facilities, physical accessibility barriers as well. The primary barrier, however, is the limited choice between informal care (provided by family members, usually women), residential facilities or, preferably, community-based care.
3) **Quality**: While there are often regulations and quality standards for residential care (although limited to nutrition and hygiene), there are rarely quality controls on home and community-based care. Moreover, the notion of 'quality of care' tends not to be understood to integrate subjective well-being, person-centredness or human rights.
4) **Workforce**: Informal carers account for nearly 80% of the current caring workforce (52 million people or 14.4% of the population aged between 18 and 74); but the pool of informal carers is diminishing because of growing participation of women in the labour market and changing family patterns. Reliance on informal care may not be unsustainable. At the same time, for formal carers, countries report high levels of unfilled vacancies as attracting and retaining care workers is difficult due to often poor working conditions and low wages. The formal workforce may lack skills and training to care for individuals with high functioning needs.
5) **Funding**: Although it is projected that funding for long-term care will increase from 1.7% of GDP in 2019 to 2.5% of GDP in 2050 (with huge variations across countries), these projections do not take into account the 2.4% GDP estimated contribution of current informal carers.[5] As the number of informal carers declines – while long-term care demand dramatically increases – the need for increased funding for formal carers will be inevitable. Most European countries are not prepared – or are unwilling – to increase social protection funding this substantially.

[2] WHO-EURO, 2022 Rebuilding for sustainability and resilience: Strengthening the integrated delivery of long-term care in the European Region.
[3] EC, 2021, The 2021 Ageing Report – Economic and Budgetary Projections for the EU Member States.
[4] Challenges in long-term care in Europe. A study of national policies (2018)
[5] Eurofound, 2020, Long-term care workforce: Employment and working conditions, European Union.

6) **Governance:** A characteristic feature of long-term care provision is its fragmentation, both as the services are provided and financed across healthcare and social care, and are subject to diverse national, regional and local responsibilities. This produces many of the previously mentioned problems of availability, quality-control, inefficiency and cost-ineffectiveness. Fragmentation also limits effective monitoring to identify gaps in services or mutual learning to implement best-practices. Long-term care has diverse stakeholders – from those in need and family carers, to civil society organizations, long-term care providers and relevant national, regional, and local authorities.

Guiding principles for reform

1) **Legal framework**: In the European context, reforms to long-term care are grounded in three authoritative and normative documents: in general, the **Charter of Fundamental Rights of the European Union** (Article 25 and 26), and more concretely **European Pillar of Social Rights** and United Nations **Convention of the Rights of Persons with Disabilities** (**CRPD**) (of which both the European Union and all member states are signatories).
2) The Council Recommendation enumerates the following guiding principles for reform of long-term care that are consistent with this legal framework: **Principles of accessibility**: accessible, available, affordable; **Principles of quality**: respect, prevention, person-centredness, comprehensiveness and continuity, focus on outcomes, transparency, workforce, facilities.

Policy Implications and recommendations

Policy Framework

1) **The disability perspective**: Although the Council Recommendation speaks as if 'persons with disabilities' are a sub-population of long-term care users (and whose human rights are specially guaranteed by the CRPD), in reality every long-term care user is a person with disabilities: A person with a 'long term care need' is a person with functional limitations in activities of daily living; but in the CRPD a 'person with disabilities' is a person with functional limitations that, in interaction with their environment, affect their daily lives. As everyone in need of long-term care is a person with disabilities, the governing normative framework for long-term care is the CRPD (as confirmed by the European Commission's Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030.)
2) From the disability perspective, the core values for long-term care reform are to secure **Autonomy** and **Community**. This is confirmed by the opening remark in the Council Recommendation:

   "Accessible, affordable and high-quality long-term care allows people in need of care to maintain autonomy for as long as possible and live in dignity. It helps to protect human rights, promote social progress and solidarity between generations, combat social exclusion and discrimination and can contribute to the creation of jobs."

Reform Goals

1) Recognizing that disability arises from the interaction between intrinsic incapacities linked to health conditions or ageing and the physical, attitudinal and social environment, long-term care services should respond both to an individual's intrinsic incapacity and eliminating barriers or enabling his or her environment and aim to optimize the individual's level of activity and community participation.
2) From the disability perspective, the primary goals of long-term care reform are to achieve:

   (i) **Accessibility**: removal of physical, organization, financial and informational barriers to full and equal enjoyment of long-term care services (CRPD arts. 9, 28)

   (ii) **Quality**: long-term care services should be person-centred (aligned with wishes, values and goals of the person) and integrated across settings (CRPD arts 24, 25).

(iii) **Independent living and inclusion in community**: the provision of long-term care services should be governed by the individual's freedom of choice among option and ensure that the individual fully participates in his or her community (CRPD art. 19)
(iv) **Workforce**: availability of the service providers the individual chooses, who are fully supported and trained in the specific needs aligned with the independence of the individual included within his or her community.

Reform Recommendations
Every country will have a different array of policies governing long-term care, involving to different degrees health, social and other sectors, with diverse governance structures at national, regional and local levels. The concrete shape of policy reforms, therefore, need to be explicitly tailored for each country. The recommendations that follow reflect the disability perspective and the primary goals of long-term care reform listed above, but are intended as guidelines for achieving alignment between the aims and outcomes of policy reforms and the key values of autonomy and community:

Autonomy: to ensure and sustain respect for individual autonomy, reforms should be guided by:

1) **Person-centered care:** long-term care should offer a choice of services that respect gender, physical, intellectual, cultural, ethnic, linguistic and social diversity of individuals and in particular the aspirations, life goals, and preferences of each individual.
2) **Integrated care:** long-term care services should reflect the needs of the whole person, and should include a choice of informal, formal and community-based care settings, relevant health promotion, illness-prevention, rehabilitative and palliative health services. Integration of care entails seamless transitions between health and social sectors, settings, care types and services to avoid fragmentation, service gaps and delay. At the systems level, integration requires not only cooperation between health, social protection, disability and other policies, between national, regional and local levels of government, but also integration of financing, workforce, planning, information management and monitoring, quality assurance and other governance support functions.
3) **Workforce training**: to ensure that both the specific needs and preferences of the individual are respected, both formal and informal caregivers (in home, community or residential settings) should be skilled in specialised knowledge about the impairments and underlying health conditions that can affect the relevance and quality of care provided.
4) **Choice**: all reforms to long-term care should be premised on the goal of maximizing individual choice in mode of service provision, settings, and type of service.

Community: to ensure and sustain full inclusion and participation in community, reforms should be guided by:

1) **Universalism:** all reforms should recognize that the need for long-term care services is a universal, human need rather than a 'special' need of some discrete minority of individuals, whether it be 'the elderly' or 'persons with disabilities'. The need for support and assistance in activities of daily living is a universal human need of everyone, and as such is governed by the normative principles of universal human rights.
2) **Priority of home- and community-based services:** given the projected decline in informal care, countries will have to find a national policy mix that is sustainable. Nonetheless, the presumption should be made that semi-residential, home- and community-based services take priority. Further investments in residential care or other settings of consolidation of care that removed individuals from their communities of individuals should be made as a last resort.
3) **Voice of stakeholders:** Reforms must recognize and respect the voice and active participation in the reform process of the full range of long-term care stakeholders. These include not only those in need of these services, their families, informal care-givers and organizations that represent them and long-term care providers and relevant national, regional and local authorities, but also social partners and community representatives, and civil society organizations, including those responsibility for promoting social inclusion and protecting fundamental human rights.

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