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Population ageing and family well-being in Europe

Families, ageing, equality and care

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States should safeguard the human rights of all individuals while also implementing targeted measures to ensure the protection, prevention of abuse, inclusion, and access to vital services for people in vulnerable circumstances. These vulnerable groups may include individuals residing in institutions, those living alone, individuals receiving community-based care, those at risk of digital exclusion, and those at risk of neglect and abuse.

Ensuring affordable and easily accessible high-quality care services brings numerous advantages across all age groups. Early childhood education, for instance, positively impacts a child's development and diminishes the risk of social exclusion and poverty throughout their lives. Similarly, long-term care empowers individuals who rely on assistance for daily activities due to old age, illness, or disability, enabling them to maintain autonomy and dignity. Unfortunately, these services remain unaffordable, inaccessible, or insufficient for many individuals even in Europe.

Investing in care is crucial for attracting and retaining talented professionals in the sector, which often faces challenging working conditions and low wages. It also helps address labor shortages and unlocks the economic and job creation potential of the care sector. Furthermore, investing in high-quality care contributes to enhancing women's participation in the labor market and promoting gender equality, specifically by narrowing gender pay and pension gaps. Currently, women bear the primary burden of care responsibilities, with 90% of the formal care workforce consisting of women, and 7.7 million women experiencing unemployment due to caregiving duties.¹

Families, ageing, equality, and care are interconnected issues that have significant relevance in Europe. Here are some key points related to it:

- *Changing family structures:* European societies have experienced shifts in family structures, including an increase in single-parent families, cohabitation, and same-sex partnerships. These changes have implications for care arrangements and support systems.
- *Ageing population:* Europe is experiencing population ageing, with a growing proportion of older adults. This demographic shift poses challenges in terms of providing adequate care and support for older individuals, including healthcare, social care, and addressing issues such as loneliness and isolation.

¹ European Union: *A European Care Strategy for caregivers and care receivers*
https://ec.europa.eu/commission/presscorner/detail/en/ip_22_5169

- *Caregiving and work-life balance*: The responsibility of caregiving, including caring for children and elderly family members, often falls on individuals within families. Balancing caregiving responsibilities with work can be challenging, particularly for women, who tend to take on a larger share of caregiving roles. This can impact career progression and gender equality in the workforce.
- *Long-term care policies*: European countries have adopted various approaches to long-term care, including a mix of formal and informal care arrangements. Policies aim to support caregivers, enhance home-based care options, and ensure the availability and quality of long-term care services for older adults and individuals with disabilities.
- *Gender equality*: Achieving gender equality is an important aspect of care and family policies in Europe. Efforts are being made to promote equal sharing of caregiving responsibilities between men and women, support work-life balance through family-friendly policies, and address gender-based inequalities in access to care services.
- *Social protection and welfare systems*: European countries have social protection and welfare systems that provide financial support and social services to individuals and families. These systems aim to alleviate poverty, provide healthcare, and support families in need, including those with children, older adults, and individuals with disabilities.
- *Intergenerational Solidarity*: Promoting intergenerational solidarity is a key principle in European care and family policies. This involves fostering cooperation and understanding between different generations, encouraging support networks, and recognizing the contributions of older adults to society.

It's important to note that policies and approaches may vary across European countries due to cultural, social, and economic factors. Each country has its strategies and initiatives to address the challenges and promote the well-being of families, ageing populations, equality, and care.

The role of families

The primary role of families in care is to provide support, assistance, and a nurturing environment for their loved ones. Family members are often the first line of support and play a critical role in the well-being and quality of life of individuals in need of care. This justifies their need for support.

Here are some key roles that families often fulfill in the care process:

- *Emotional support*: Families provide emotional support and companionship to individuals in need of care. They offer comfort, empathy, and a sense of belonging, which can have a positive impact on the well-being and mental health of the care recipient.
- *Personal care*: Families often assist with personal care activities such as bathing, grooming, dressing, and feeding. They help maintain the hygiene and physical well-being of their loved ones, ensuring their comfort and dignity.
- *Medication management*: Family members often play a role in managing medications for the care recipient. They may help with organizing and administering medications, ensuring adherence to prescribed treatment plans, and monitoring any potential side effects.
- *Advocacy*: Families act as advocates for the care recipient, ensuring their needs and preferences are respected within the healthcare system. They communicate with healthcare professionals, help navigate complex healthcare processes, and make informed decisions on behalf of their loved ones.
- *Care coordination*: Families often take on the responsibility of coordinating care services, including scheduling appointments, arranging transportation, and communicating with various healthcare providers. They serve as a central point of contact, ensuring continuity and coherence in the care received.

- *Financial and legal support:* Family members may assist with financial matters, such as managing healthcare expenses, insurance claims, and financial planning for long-term care. They may also provide support in navigating legal issues, such as establishing power of attorney or making healthcare decisions in line with the care recipient's wishes.
- *Caregiving:* Family members may take on the role of primary caregivers, providing round-the-clock care and support to their loved ones. This can involve significant physical and emotional demands, requiring them to balance their caregiving responsibilities with other aspects of their lives.

While families often play a vital role in care, it's also crucial to ensure that they receive adequate support, respite, and access to resources to prevent caregiver burnout and promote their well-being. Collaboration between families, healthcare professionals, and community services is essential for holistic and effective care delivery.

Unpaid care work

Unpaid care work is very related to family life, encompasses a crucial aspect of economic activity and plays an indispensable role in the well-being of individuals and societies.² Every day, many citizens dedicate their time to tasks such as cooking, cleaning, and caring for children, the sick, and the elderly. Despite its significance for overall well-being, unpaid care work often remains overlooked in policy agendas due to the perception that it is challenging to measure and less relevant for policy considerations compared to formal market work. However, disregarding unpaid care work leads to inaccurate assessments of individuals' well-being levels, changes over time, and the value of time itself, thereby limiting the effectiveness of policies across various socio-economic domains, particularly gender inequalities in employment and empowerment.

Women, in particular, tend to bear a disproportionately higher burden of unpaid care work compared to men. Gendered social norms that assign unpaid care work as a primarily female responsibility results in women, regardless of their region, socio-economic status, or cultural background, devoting a significant portion of their day to fulfilling domestic and reproductive roles. This additional workload, alongside their paid activities, creates a "double burden" for women. The way society and policymakers address care-related issues holds critical implications for achieving gender equality. It can either expand women's and men's capabilities and choices or confine women to traditional roles associated with femininity and motherhood. The unequal distribution of unpaid care work between women and men represents a violation of women's rights and acts as a barrier to their economic empowerment.

Gender inequality in unpaid care work is the missing link that influences gender gaps in labor outcomes. The disparity in unpaid care work has significant consequences for women's ability to actively participate in the labor market and affects the type and quality of employment opportunities available to them. Time is a finite resource that individuals divide between labor and leisure, productive and reproductive activities, and paid and unpaid work. Every additional minute a woman spends on unpaid care work translates to one minute less that she could potentially allocate to market-related activities or invest in her education and vocational skills.

Target 5.4 of the 2030 Agenda for Sustainable Development focuses on recognizing and valuing unpaid care and promoting shared responsibility within households and families. Achieving this Target contributes to the broader goal of promoting gender equality and women's empowerment, as outlined in Sustainable Development Goal 5. It recognizes the importance of addressing the disproportionate burden of care on women, enabling their full participation in education, employment, and other areas of society. Overall, it calls for policy interventions, social support systems, and changes in societal attitudes to foster a more balanced and fair distribution of care responsibilities.

² OECD: *Unpaid Care Work: The missing link in the analysis of gender gaps in labour outcomes*
https://www.oecd.org/dev/development-gender/Unpaid_care_work.pdf

The European Care Strategy

The European Commission has introduced a European Care Strategy in 2022³ to ensure the provision of quality, affordable, and accessible care services throughout the European Union. This strategy aims to enhance the well-being of both care recipients and their caregivers, whether they are professional or informal. Accompanying the strategy are two recommendations for Member States, focusing on the revision of the Barcelona targets concerning early childhood education and care, as well as access to affordable, high-quality long-term care.

The Commission advises Member States to develop national action plans that enhance the availability, accessibility, and quality of care services across the EU. Furthermore, the Commission encourages Member States to take measures to attract a greater number of individuals, particularly men, to the care sector. These efforts are aimed at improving the overall care landscape and promoting equal opportunities for all.

As emphasized in the initial stages of the Strategy, care is a matter that affects every one of us. It is essential for achieving a better equilibrium between our personal and professional lives, as well as for ageing gracefully and being treated with dignity and respect. In line with the Strategy's apt recognition, the following actions are crucial to ensure that everyone can access suitable care⁴:

- *Provide high-quality care services for all*: inclusion of all people, no matter their age, disability status, nationality, ethnicity, religion, gender identity, sexual orientation, migration or residence status, socioeconomic status, or social conditions. The Strategy is needed to ensure that the most vulnerable individuals in our society are not left behind and have equal access to care, to ensure a continuous approach to care throughout the entire life of everyone, and to properly support and protect formal and informal caregivers.
- *Increase the number of accessible and affordable services*: The European Pillar of Social Rights states that everyone has the right to affordable long-term care services of good quality, in particular homecare and community-based services. This Strategy is urgently needed to reaffirm this and to stand against the privatization and commodification of care while promoting stepped-up public social investment. We need common targets and indicators and a joint monitoring system based on the Social Open Method of Coordination model - of which LTC is a pillar.
- *Strengthen an EU-wide and comprehensive approach*: which offers support to Member States at the starting position in restructuring and reforming their care systems.

The Strategy touches upon all the domains identified as important:

- It affirms the right to care and the role of persons in need of care to be in the driver's seat of how they receive care.
- It underlines that the design, implementation, and evaluation of care systems at all levels must go hand in hand with stakeholders: persons in need of care, informal carers, workers' representatives, and care providers.
- It calls for a social protection model for financing care to make it accessible to all and for more services and options.
- It defines quality principles for long-term care, based on respect for the person in need of care.
- It reminds Member States of their responsibility to better support informal carers with income and services by implementing and upgrading the provisions of the EU Work-Life Balance Directive.

³ European Union: *A European Care Strategy for caregivers and care receivers*
https://ec.europa.eu/commission/presscorner/detail/en/ip_22_5169

⁴ EU Alliance for Investing in Children: *Position paper on the European Care Strategy*
https://eurohealthnet.eu/wp-content/uploads/221012_positionpaper_investinginchildalliance.pdf

- It emphasizes the need to integrate and coordinate health and social care, to invest in innovative digital and non-digital solutions to improve care, to improve working conditions and invest in skills of the care workforce, to attract third-country nationals to tackle the workforce shortage in the field, the importance of prevention to reduce the rate of increase of long-term care needs and other points.

It is important to note that the European Union lacks legislative power in this domain, and therefore, there are no obligatory actions imposed on Member States.

Ageing population

Over the past few decades, significant medical, economic, and social advancements have led to a notable increase in life expectancy worldwide, marking positive improvements in the quality of life for billions of people. This global phenomenon of population ageing poses particular challenges for Europe, where the demand for elder care has become increasingly pressing. Despite people aged 55 and older constituting over one-third of the European Union's population, there is a lack of sufficient social infrastructure to address the escalating needs of the elderly. As a result, the European Union is grappling with the dual challenge of adapting to the social and economic changes brought about by these demographic shifts and providing adequate care for its ageing populations.

After witnessing the violations and disregard for the rights of older persons during the initial waves of the pandemic, and discovering that approximately half of the COVID-19-related deaths in the first year occurred in residential long-term care facilities, it became imperative to advocate for the right of every individual in need of care to have access to services that promote their independence and well-being.⁵

The ageing population in Europe has resulted in an increasing demand for long-term care workers who can provide essential support to the elderly and individuals requiring assistance with daily activities. Presently, approximately six million individuals are employed in this sector. However, projections indicate that the European Union will need an additional 1.6 million care workers by the year 2050 to meet the growing needs of the population.

In European countries, the availability of timely and adequate end-of-life care, known as palliative care, is insufficient. Less than 40% of those in need of palliative care receive it, despite experiencing symptoms associated with terminal illnesses such as pain, breathlessness, and distress. It is noteworthy that although many individuals express a preference to pass away at home, approximately half of the deaths occur in hospitals due to limited in-home and community-based support.

The provision of palliative care, which aims to offer comfort and enhance the quality of life, often occurs late in the process due to a lack of mechanisms ensuring timely access. Shockingly, less than one-third of OECD countries have implemented national programs to monitor the duration between referral and the delivery of end-of-life care services.

Furthermore, the COVID-19 pandemic has exposed the challenges faced by overwhelmed health systems in providing end-of-life care. This crisis has underscored the critical need for healthcare systems to be scalable and adaptable to effectively address emergencies and ensure the provision of adequate end-of-life care.

The delivery of care at the end of life often fails to align with patients' preferences, and the quality of care provided is frequently subpar. Discussions regarding health status and end-of-life care options occur less frequently than they should, and the voices of patients and their families are often disregarded in decision-making processes. Shockingly, only a quarter of patients and professionals document advance directives outlining individuals' wishes.

Holistic care is not consistently available, and individuals do not always receive adequate relief from symptoms. It is disheartening to note that 10% to 25% of individuals aged 65 or older who pass away

⁵ AGE Platform Europe: *The European Care Strategy has come a long way. What does it change?*

<https://www.age-platform.eu/special-briefing/european-care-strategy-has-come-long-way-what-does-it-change>

receive insufficient pain medication, assistance with breathing, or support for anxiety. Moreover, a significant proportion of older patients hospitalized near the end of life undergo aggressive treatments that do not offer comfort, prolong life, or prove cost-effective. This applies to approximately one-third of such patients.

The fragmented nature of healthcare systems undermines the effective delivery of end-of-life care, resulting in patients experiencing multiple transitions across different care settings. Additionally, there is insufficient measurement and benchmarking of the quality of end-of-life care across countries. Surprisingly, more than a quarter of OECD countries lack audit and evaluation programs to monitor end-of-life care quality.

Furthermore, inadequate funding and a lack of evidence-based policies hinder end-of-life care. Public social protection systems only partially cover the expenses associated with alleviating end-of-life symptoms in one-third of OECD countries, leading to high out-of-pocket costs and heavy reliance on family members. Notably, public funding predominantly supports hospital-based services, which likely influences the place of death and contributes to increased public expenditure. Hospital expenditure accounts for 32% to 67% of total end-of-life care expenditures in OECD countries.⁶

Research in the field of end-of-life care is insufficient, and data infrastructure to provide a comprehensive understanding of end-of-life care across various services and settings remains weak. Less than 30% of OECD countries have a national research agenda focused on end-of-life care, and fewer than 16% have a local research agenda dedicated to the subject.⁷

Such shortcomings call for greater policy priority and measures to improve end-of-life care:⁸

- *Addressing staffing shortages:* Expanding knowledge of end-of-life care among different professionals and care settings is crucial for improving access to care. This includes training more health professionals with expertise in managing end-of-life care. Incentivizing end-of-life care in preferred settings can also be beneficial. Examples from Australia and New Zealand demonstrate the effectiveness of nurse-led models and regionally managed clinical networks in enhancing access to care.
- *Implementing time targets and guidelines:* Setting time targets and guidelines can help ensure timely access to care by optimizing care pathways. Ontario, Canada, utilizes automated tools for screening, while the United States establishes timelines for needs assessments.
- *Enhancing training and evaluation:* Providing more information on end-of-life care to healthcare staff and improving evaluation processes are crucial to ensure that patients' wishes are respected and the quality of care improves. Training for healthcare workers can improve communication and involve patients and their families in decision-making. Canada and the United States have developed training and guidance to support healthcare professionals in open communication with individuals at the end of life.
- *Promoting multidisciplinary teams and holistic care:* Multidisciplinary teams that can provide comprehensive care centered on patients' and their families' needs are essential. Encouraging multidisciplinary team collaboration, advance care planning, and electronic records sharing, as seen in England, can improve care coordination.
- *Increasing public discussion and reducing stigma:* Public campaigns and discussions around death and dying can enhance public knowledge and reduce the stigma associated with end-of-life care. France has undertaken public campaigns in this regard.

⁶ OECD: *Time for Better Care at the End of Life*

https://www.oecd-ilibrary.org/social-issues-migration-health/time-for-better-care-at-the-end-of-life_722b927a-en

⁷ *ibidem*

⁸ *ibidem*

- *Improving decision-making processes:* Involving individuals at the end of life and their relatives in decision-making processes is crucial. Additionally, implementing better quality standards and evaluating the quality of life is important. The Palliative Care Outcomes Collaboration in Australia provides a framework for integrating regular clinical assessment.
- *Effective resource distribution:* Prioritizing the distribution of resources in end-of-life care and promoting evidence-based policies is necessary. Improving payment systems to encourage the provision of cost-effective services and early access to palliative care can enhance quality and financial sustainability. Examples from Belgium, Canada, and the United States demonstrate the positive impact of palliative care in reducing intensive care unit usage, medication use, and overall health expenditures.
- *Promoting research and data utilization:* Encouraging funding and building institutional capacity for research projects on end-of-life care is important. Areas where knowledge remains limited, such as timeliness of access, care delivery models, and cost-effectiveness of interventions, require further investigation. Belgium, Ireland, France, and the Netherlands have established organizations to support palliative care research. Access to linked and timely data can facilitate international benchmarking and inform policy-making, as demonstrated by the Swedish Register of Palliative Care in Sweden and accessibility indicators in Ireland.

Recommendations

Improving care in Europe requires a comprehensive approach that addresses various aspects of the healthcare system.

Here are some key recommendations for it:

1. *Support families in their caregiving role:* Acknowledge it is crucial for promoting the well-being of individuals and building resilient communities. Ensure that families have easy access to information, resources, and guidance. Offer financial assistance programs and tax benefits, establish respite care services and promote parenting education.
2. *Recognize and value unpaid care and domestic work:* As established by Target 5.4 of the 2030 Agenda, provision public services, infrastructure, social protection policies and the promotion of shared responsibility within the household and the family.
3. *Invest more in early childhood education and care services:* governments should take into account dimensions beyond the mere availability of places, such as the time-intensity of participation, the share of children at risk of poverty or social exclusion, as well as the accessibility, affordability and quality of the services provided.
4. *Patient-centered approach:* Ensure that people at the end of life and their relatives participate in the care choices. Guarantee that people's wishes are respected when they approach death, especially for those who are affected by dementia or other cognitive diseases, who might not be able to express their wishes in their last period of life.

Other important recommendations with consequences for families are the following:

5. *Strengthen primary healthcare:* Increase the number of professionals, improve access to primary care facilities, and promote comprehensive and coordinated care. This includes investing in preventive care, early detection, and chronic disease management.
6. *Integrated care systems:* Foster greater integration and coordination between primary care, specialized care, and social care services to provide seamless and person-centered care. Encourage collaboration between healthcare providers, social care providers, and community organizations to ensure continuity of care across different settings.
7. *Focus on prevention:* Prioritize preventive healthcare measures by implementing effective public health campaigns, promoting healthy lifestyles, and increasing awareness of disease prevention

strategies. Invest in screenings, vaccinations, and health education programs to reduce the burden of preventable diseases.

8. *Strengthen long-term care*: Develop sustainable and person-centered long-term care systems that address the needs of aging populations. This includes expanding home care services, improving nursing care facilities, and enhancing support for informal caregivers. Ensure adequate funding and staffing for long-term care services.
9. *Embrace digital health solutions*: Embrace digital health technologies to enhance healthcare delivery, improve access to care, and empower patients. Develop robust health information systems, telemedicine platforms, and remote monitoring tools to support remote consultations, health data exchange, and remote patient monitoring.
10. *Promote health equity*: Address health disparities and inequalities by ensuring equal access to healthcare services for all population groups, including vulnerable and marginalized populations. Implement policies to reduce health inequalities and promote equitable distribution of healthcare resources.
11. *Foster Research and Innovation*: Promote research and innovation in healthcare to drive advancements in medical treatments, technologies, and care delivery models. Support collaborations between academia, industry, and healthcare providers to accelerate the translation of research into practice.
12. *Strengthen the health workforce*: Invest in the education, training, and professional development of healthcare professionals to ensure an adequate and skilled workforce. Address workforce shortages and maldistribution by implementing strategies to attract and retain healthcare professionals in underserved areas.
13. *International collaboration*: Foster collaboration and knowledge-sharing among European countries to exchange best practices, benchmark outcomes, and learn from successful healthcare models. Promote cross-border collaboration on research, health policies, and healthcare workforce mobility.