

Long-term Care in Europe: A New Start?

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As COVID-19 swept over Europe, thousands of avoidable deaths — more than half of the fatalities within the first year of the pandemic in some countries — occurred in long-term care settings. These fatalities triggered more awareness and consideration of the shortcomings of this sector, which faces increasing pressure due to rapid population aging. A new EU strategy could be a starting point for change, but governments need to seize the opportunity.

COVID-19: A Meltdown Requiring a Response

The pandemic has shone a spotlight not only on front-line hospital workers but also on the issues faced by long-term care settings. Workers in these settings often had no access to protective gear and testing, and in several EU member states, reports emerged of ambulances never arriving at long-term care facilities as health systems crumbled under the influx of COVID-19 patients. At AGE Platform Europe, we have been denouncing triage and other forms of ageism since the onset of the pandemic, and we emphasize that these tragic events need to be a starting point for rethinking the systems that one in five of us rely on during the final years of our lives. During the first lockdowns, people applauded from their balconies to celebrate those who were struggling to maintain health systems and the economy of necessities as others stayed home. That energy needed to transform into real change.

In 2021, the European institutions drew up an important report on long-term care that paints a bleak picture of the sector: almost half of people in need of some form of care do not access it, primarily for financial reasons. Only one in three people in need of care had access to care services in their homes. In 11 EU member states, 60 percent of people using care services were at risk of poverty even after public support: in many member states, the costs for long-term care exceed the average pension income. The majority of long-term care — an estimated 80 percent — is provided by informal carers (unpaid relatives or friends often taking time from their careers to fill a gap unfilled by formal services). Most of these carers are women. Also, compared with men, women spend more of their lives in poor health and have a higher life expectancy. Consequently, shortcomings in care are primarily hitting women, creating an additional gender inequality. Staff turnover, understaffing, lack of training, and a large part of care relationships in the gray economy

make the picture even bleaker. Adding on this, occasional lack of awareness and tracking of abuse and neglect, overmedication and use of restraints on people in need of care make it look outright dark.

Later on, scandals erupted about the conditions of both state-subsidized and expensive private residential care facilities in France, Belgium, and Germany. Journalists uncovered practices of undernourishment, neglect, shady real estate deals, and the sabotaging of social dialogue. This raised the question of the role of private-equity firms in a sector providing a public good and benefiting from public money.

Moving from Paternalistic Welfare to a Rights-Based Approach to Care

At the United Nations, we advocate for the human rights of older people and for anchoring in an international convention that human rights apply to all people regardless of age. With the experience of the power of taking a rights-based approach to ageing policies, AGE realized that the narrative of a failing system needed to be turned around. Neither people in need of care, nor their families, informal carers, care workers, or even care providers, are finding current care systems suitable because these systems are focusing only on addressing biomedical needs and “managing” patients, rather than empowering them to enjoy all their fundamental rights.

A rights-based approach would call for redesigning a care context: rather than fitting people in need of care into the strictures of a particular care service, each person’s right to live independently and their individual needs and aspirations must be at the center of their long-term care. We developed a vision of care based on the right to independence and autonomy, which would universally empower people in need of care to participate and contribute to society. Rather than being seen as a terminal stage, care must be designed for rehabilitation with a vision of (re) integrating each person into society — even if that goal is not ultimately achievable.

Designing care systems from this standpoint means emphasizing prevention of care needs by promoting healthy habits; adapting environments (in particular housing and urban settings) to the accessibility needs of people with disabilities; and investing in affordable, high-quality home-care services. It should not be the necessity, but rather the informed will of people in need of care that

determines how they will be cared for. It means taking the people in need of care seriously and including them in all decisions that concern them. This also means increasing the training of formal and informal carers, introducing high-quality management, and monitoring them appropriately. Furthermore, long-term care must be funded through social protection to reduce inequities in access and lack of financial ability, that too often have the same root causes as the care need itself.

A rights-based approach to ageing policies, AGE realized that practice does exist. Recently, AGE Platform helped a provincial government from the Spanish region of Biscay (Basque Country) to develop a care model based on empowerment, in a document that can be applied to other logistical, demographic, or legal contexts. Reports of participative care homes, going as far as having residents take part in job interviews for new staff, have emerged as well. These show that the change we are calling for is achievable, desirable, and — not the least important argument — fundable.

Can Europe Steer the Ship Toward a Rights-Based Approach?

Recently, the European Commission presented an EU Care Strategy, adding to other policy frameworks from the UN and the World Health Organization as part of the UN Decade of Healthy Ageing and the Madrid International Plan of Action on Ageing. The Care Strategy is the first formulation of a policy on long-term care, anchoring it as a service of general interest (the EU lingo for public services) based on the fundamental and social rights of a person. The Care Strategy addresses many of the issues outlined: affordability, availability, quality, support for informal carers and working conditions, and training of professional carers. Yet it remains a menu from which member states can choose their priorities and areas for action.

The European Care Strategy is an opportunity for change; however, this change needs to leave the technocratic corridors of discussions between governments and move into European societies. If the COVID-19 pandemic was a wake-up call, it is now important to stay awake and keep the momentum. All of us are aging, so all of us will be in need of care or become informal carers for people close to us — if not both. Therefore, action and investment in these areas are not welfare; rather, they contribute to realizing some of the most fundamental human rights: participation and integrity. ●

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