

## Supporting informal carers in Europe: from recognition to rights

Research has demonstrated that informal carers across the EU play a central role in the provision of care to people with long-lasting needs (age-related dependency, chronic diseases, disability, etc.) According to some estimates, as much as 80% of all care in Europe is indeed provided by relatives, friends and neighbours, outside of a professional context, with women providing the lion's share of care as daughters (in law) and wives/partners.

The estimated economic value of the time spent on informal care is huge since it is estimated at 2.4-2.7 % of EU 27 GDP (between €320 billion and €368 billion in 2018), exceeding in most Member States expenditure on formal long-term care.

Against this backdrop, it will be very difficult to meet the growing care needs of an ageing population without acknowledging the central role played by millions of informal carers across Europe.

But the provision of informal care does not come without a cost for carers themselves and society as a whole. Without proper support, many carers are indeed faced with additional expenditures as a result of the condition of the person they care for, and their caring responsibilities can be a barrier to entering education and paid employment. Working carers often have to perform a difficult balancing act and may be forced to reduce their working hours (involuntary part-timers) or drop out of the labour market, thereby reducing their income and pension entitlements. The gender dimension of this phenomenon is particularly clear.

The correlation between caregiving and physical and mental health is also well established. Research has highlighted the stress and burden associated with informal caregiving, which presents all the features of a chronic stress experience: it creates a physical and psychological strain over extended periods of time, is accompanied by high levels of unpredictability and uncontrollability, it frequently requires high levels of vigilance, and has the capacity to create secondary stress in multiple life domains such as education, work, social inclusion and poverty (as mentioned before).

As a result, the carer may experience psychological distress, such as anxiety and depression, which may – in turn - negatively affect the carer's physical health. For instance, the prevalence of mental health problems among non-working carers is 20% higher than among non-carers. Besides, caregiving often requires physically demanding work over a long duration, which may cause injuries and chronic illnesses. Carers also tend to neglect a healthy lifestyle (e.g., diet and exercise). These adverse consequences are especially prevalent in the context of high-intensity caregiving situations (e.g. dementia care).

The COVID-19 pandemic has been "The Great Revealer" – of pre-existing weakness in long-term care systems. Among the key lessons that can be extracted to make long-term care systems better prepared and more resilient in the future, I would mention the following:

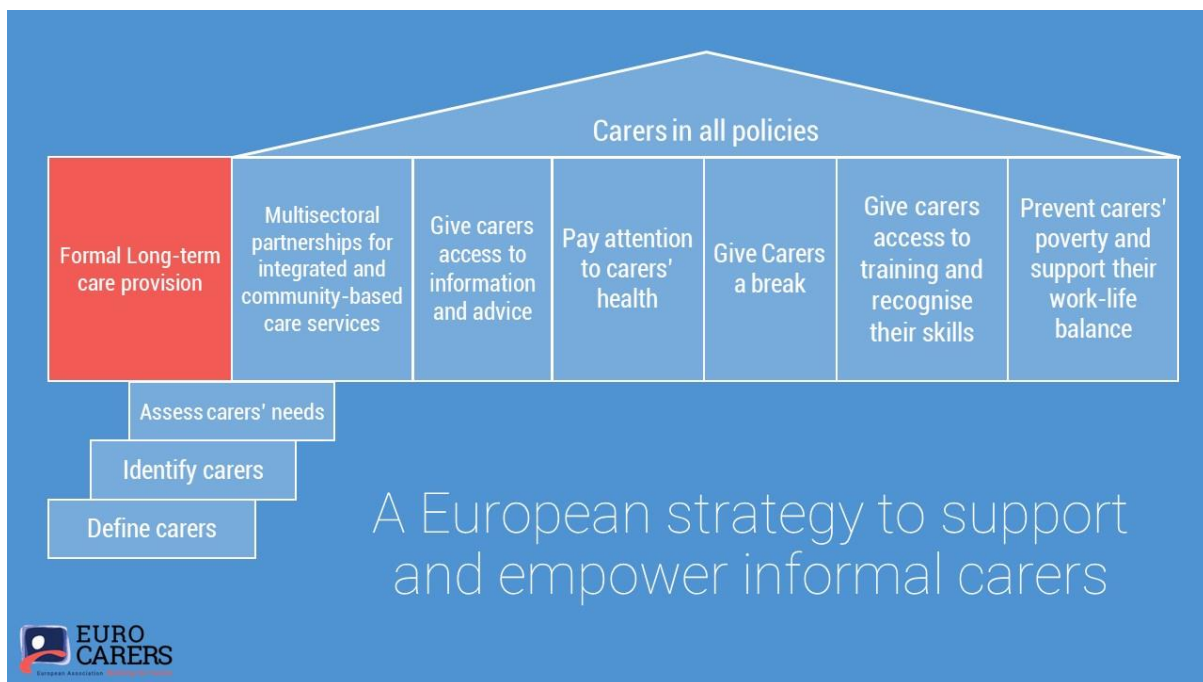
**1. EUROPE WAS BADLY PREPARED FOR A PANDEMIC:** I would argue that, up until COVID at least, future proofing care meant seeking better care outcomes in the context of constrained resources – in other words, doing more with less. While I am not completely naive, I hope that the crisis will

contribute to a change of attitude towards care and caring. There is an urgent need to improve the way the sector is resourced and to boost the integration of health and LTC.

**2. LTC WORKERS WERE IN FIRST LINE DURING THE PANDEMIC, WITHOUT ADEQUATE SUPPORT OR RECOGNITION:** Working conditions in the care sector fundamentally shape the quality of care that care recipients receive. Throughout the pandemic, care workers experienced understaffing, work intensification and dangerous working conditions. They often had limited support (access to tests and PPE, for instance). When it comes to informal carers, our study on the topic showed more care, more intense care and more carers. As you said, these structural problems (with staff shortages, poor job quality and inadequate skills) already existed before the pandemic.

**3. SUPPORT CSO:** The pandemic has proven that civil society organisations play a central role in the provision of LTC and they do not necessarily need a contract to respond to the needs of the community. Many of our member organisations have compensated the interruption or reduction of existing services by providing access to PPE, information (including via new helplines) about COVID, online self-help groups, psychological/emotional support, counselling, help with care coordination and administrative support. Yet, many CSOs are expected to play that role with extremely limited resources.

### What should be done to support carers?



Over the last few years, much has been achieved in taking forward the carers' agenda at international, EU and – to some extent – national and regional level. However, the success of initiatives aiming to address the needs and preference of carers largely depends on the interplay between a broad set of policies in the social, health and employment fields. Yet, policy developments of relevance for carers have often been implemented in a fragmented and uneven manner and have therefore not always resulted in real improvements in carer support, leading - sometimes - to a breakdown in trust between carers and decision-makers and service planners.

It is really important to reduce governments' (over)reliance on informal carers which creates unequal systems because not everyone can rely on the support of an informal carer. So, we need to ensure that alternative solutions to informal care exist and that the provision of informal care occurs out of choice, not necessity. So, first of all, we need to invest in good-quality formal care services and, in particular, home care and community-based care. This means that, we need to make care jobs more appealing, in order to attract and retain staff.

But this is only one side of the coin because, as I said, it is informal carers (relatives, friends and neighbours) – and women in particular – who provide the lion's share of care (in Europe). Moreover, whether we like it or not, informal care is there to stay in the long run. The promotion of a legal status for carers, accompanied by rights (e.g. access to social protection, financial support, pension, respite care, information and training) and obligations (in terms of care quality criteria, for example) is therefore crucial for the future.

Professional services should be the backbone of universal care and informal care should only be there to supplement, not the other way round.

While it is always difficult to pinpoint specific policies I would say that, in our view, all the initiatives that are rooted in transversal, multidimensional approaches to informal care can be seen as innovative. Developing measures to allow informal carers to take a break from time to time (in the form of leaves or respite care) and to remain productive on the labour market is important but it is not sufficient. Informal carers really need to be seen as an essential component of the care architecture and on that basis, they should have access to rights, just like professional carers. These should focus on the time and intensity of care, carers' social protection (pension rights, for instance) and their ability to maintain their health and wellbeing, etc.

So, just to mention a few (imperfect) examples of such transversal approaches, I would highlight:

- The Irish and Scottish policy ecosystem regarding informal care where the emphasis is not only on work-life balance but seeks to enable informal care via various social welfare measures / supports focusing also on carers' health and wellbeing or on financial support.
- The Finnish model is also interesting. In Finland there is no legal obligation to take care of relatives, except for children under 18 and spouses. Yet, for those who want to be recognised as carers, it is possible to access support via a contract with the municipality so, effectively the informal carer becomes an agent of the local care system and has access to an allowance, care leaves, respite care, physical examinations, education and training.
- Finally, I want to mention the ongoing dialogue with civil society that is being held in Spain and led by the Spanish Institute of Women and the Ministry of Equality (with 9 ministries involved). The aim is to not only design and promote gender equality policies but also to make progress in the recognition of the right to both access and provide care, the value of informal care and the fair redistribution of care responsibilities and time between men and women. This dialogue should inform future reforms of the Spanish family law (Ley de dependencia).