



**EURO
CARERS**

European Association Working for Carers

Eurocarers' Position Paper

October 2021

THE EU STRATEGY ON CARE **A new paradigm** **for Carers across Europe?**

On the 15th September 2021, EC President Ursula von der Leyen announced that the European Commission will put forward a new European Care Strategy as part of its Work Programme 2022 in order to “support men and women in finding the best care and the best life balance for them”. Ms. Von der Leyen went on to add that “caring for someone you love is the most precious time of all”, thereby raising hopes that the EU care sector may finally receive the attention and support it deserves.

Building on the lessons of the COVID-19 crisis, this new – and long-awaited - EU Care Strategy will address both carers and care receivers, from childcare to long-term care. It will seek to guarantee access to good-quality and sustainable care services for all throughout the life course¹ by setting a framework for policy reforms. Importantly for our mission, it is expected that the Strategy will cover the provision of both formal and informal long-term care in Europe and be an integral part of the European Pillar of Social Rights’ implementation plan. This very timely EC initiative therefore has the potential to generate very positive developments for an under-resourced and yet overburdened care community.

The Eurocarers network warmly welcomes the EC approach, which perfectly reflects the vision we have been advocating for the last fifteen years: care should be approached as a comprehensive and multi-disciplinary sector, rooted in human rights, choice and dignity for both care recipients and their informal carers. Good quality care indeed cannot be achieved without considering care recipients and carers as equal partners in care. As for integrated care, it requires a comprehensive delivery of quality services across the life-course, designed according to the multidimensional needs of the population/individual and delivered by a coordinated multidisciplinary team of providers working across settings and levels of care². In this context, the essential contribution of informal carers must be recognised via a broad set of policies and measures in the social, health and employment sectors in order to prevent the negative impact of care on carers themselves. We therefore hope that the Strategy will serve to spearhead the development of these much-needed policy developments across the EU.

*“Caring for someone
you love is the most
precious time of all”*

EC President Ursula von der Leyen

Why an EU Strategy on Care is badly needed

The impact of Europe's demographic ageing and increased longevity on the prevalence of chronic/age-related diseases and the demand for care is well documented. Yet, over the last decades, the care sector has suffered from underinvestment, mismanagement, poor job quality (i.e. low pay, difficult working conditions, limited career prospects) and – as a result – from low recruitment and retention rates and shortages in both the health and social care workforce. According to a recent study, the EU-27 will need 11 million newly-trained or imported health and long-term care workers by 2030 to satisfy the rising demand in these sectors³. These trends reveal serious sustainability and quality challenges for our care systems. They are also compounded by the impact of the pandemic as well as by the often-inadequate training of personal care workers (who account for 67% of the EU long-term care workforce, are not qualified or certified as nurses and yet often participate in the implementation of care plans and maintenance of health records). These trends and challenges can be observed across EU member states who must address them as a matter of priority if the principle of universal access to care is to be rigorously pursued in Europe.

As it stands though, the lion's share of all care across the EU is provided by relatives, friends and neighbours – and women in particular - outside of a professional context and with extremely limited recognition or support. The value of these informal carers' contribution to our care systems and the economy as a whole is so substantial that it is virtually impossible to replace by professional care, at least not in the foreseeable future. But the provision of informal care does

not come without a cost for carers themselves. Without proper support, many are faced with additional expenditures as a result of the condition of the person for whom they care, 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 issues is also well established. Research has shown that the pressure associated with informal caregiving presents all the features of a chronic stress experience: it creates a physical and psychological strain over extended periods of time, it is accompanied by high levels of unpredictability and uncontrollability, it frequently requires high levels of vigilance, and it has the capacity to create secondary stress in multiple life domains.

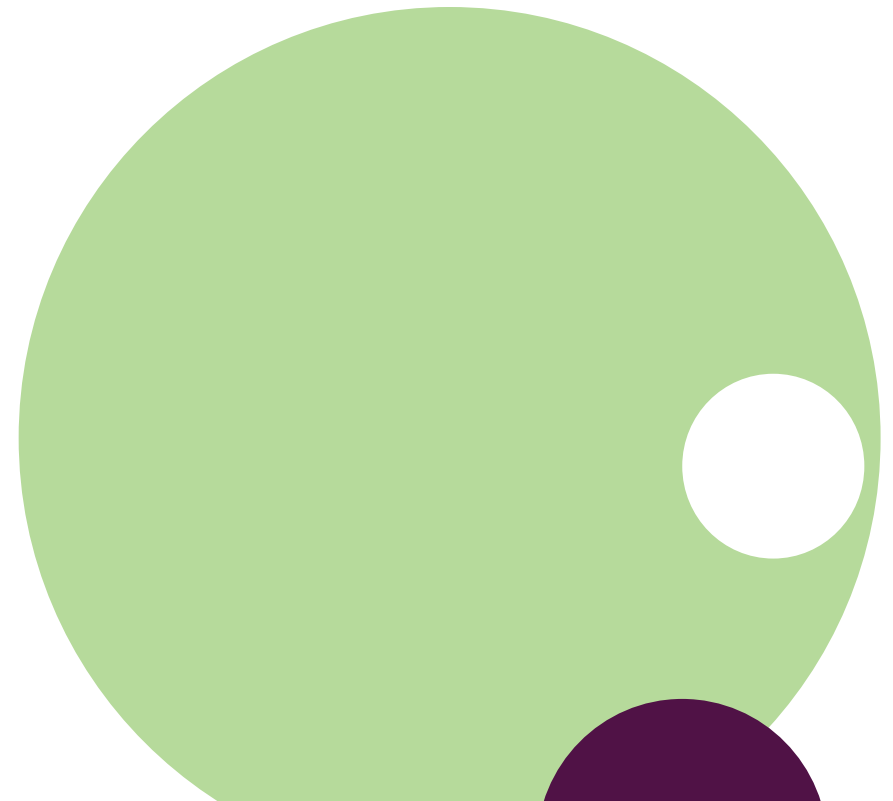
The negative consequences of informal care on carers' living and working conditions can also be observed in all member states and our recent study on the impact of COVID on carers⁴ shows that these pre-existing challenges have been greatly amplified by the pandemic, with carers providing more care, more intense care and with a new population of carers emerging from the crisis. The COVID-19 crisis has emphasised the crucial role played by informal carers on the front line. It has also shone a bright light on the shortcomings of institutional care, by reinforcing the pre-existing predilection for home or community-based care, which frequently relies a combination of informal and formal care.

Against this backdrop, it is very clear that professional and informal care are two sides of the same coin and that the current situation calls for an urgent and vigorous policy response. Unpaid care activities have been left out of policy agendas for too long and our "new normal" shows how this omission has limited policy effectiveness across a range of socio-economic areas. Care should be considered a key driver of our societies' wellbeing and the distribution of caregiving responsibilities between the family and the State as well as between men and women should be revisited in order to foster equality and equity, protect carers and care users' freedom of choice and prevent discrimination for all.

It is imperative for governments to alleviate the reliance on informal carers while recognising and supporting the central role they play, provided that it is based on

choice and free will (i.e. not dictated by necessity). People should indeed have the right to choose whether they want to be – and remain - a carer, and to what extent they want to be involved in caregiving. In contrast, people who do NOT want – or are not able - to be involved in the provision of care to their relatives or who simply want to play a limited role in these activities should be able to access affordable professional care alternatives of good quality, and in particular home-care and community-based services. In other words, informal care should supplement professional care, not the other way round!

While the competence for the design and implementation of policies with an impact on the daily life of informal carers mainly lies at national and sub-national level, **a wide-ranging coordination process at EU level can serve to develop common approaches, define common targets, monitor progress, foster an exchange of information and good practices and complement national efforts. The idea is not to put the exact same support measures in place across the EU but to encourage all member states to define and implement a policy-mix that satisfactorily meets the needs, expectations and resources of the population,** thereby contributing to common EU objectives on both formal and informal care.



What we expect from the EU Strategy on Care

If well designed and resourced, the EU Care Strategy can prove instrumental to a more balanced allocation of caregiving responsibilities between the private and public spheres as well as to achieving EU objectives as regards universal access to (long-term) care, among others. These two aspects are not only closely intertwined, they are crucial to define a comprehensive answer to the European care challenge.

From our standpoint, the aims to be achieved by the Strategy are clear. Governments' overreliance on informal care and the social inequalities it produces must be addressed as a matter of urgency. But caregiving cannot be considered only as a hurdle to a productive life, professionally and economically speaking. It is an intrinsic part of the human experience and an expression of (intergenerational) solidarity and social cohesion that our societies should value and nurture. In President von der Leyen's own words, "caring [...] is the most precious time of all".

The development of a more care(r)-friendly policy environment requires a mix of measures in various areas. While access to good-quality professional care services is - and should remain - the foundation of universal access to care in Europe, informal carers should be recognised and treated as partners in care.

In practical terms, we expect the EU Care Strategy to:

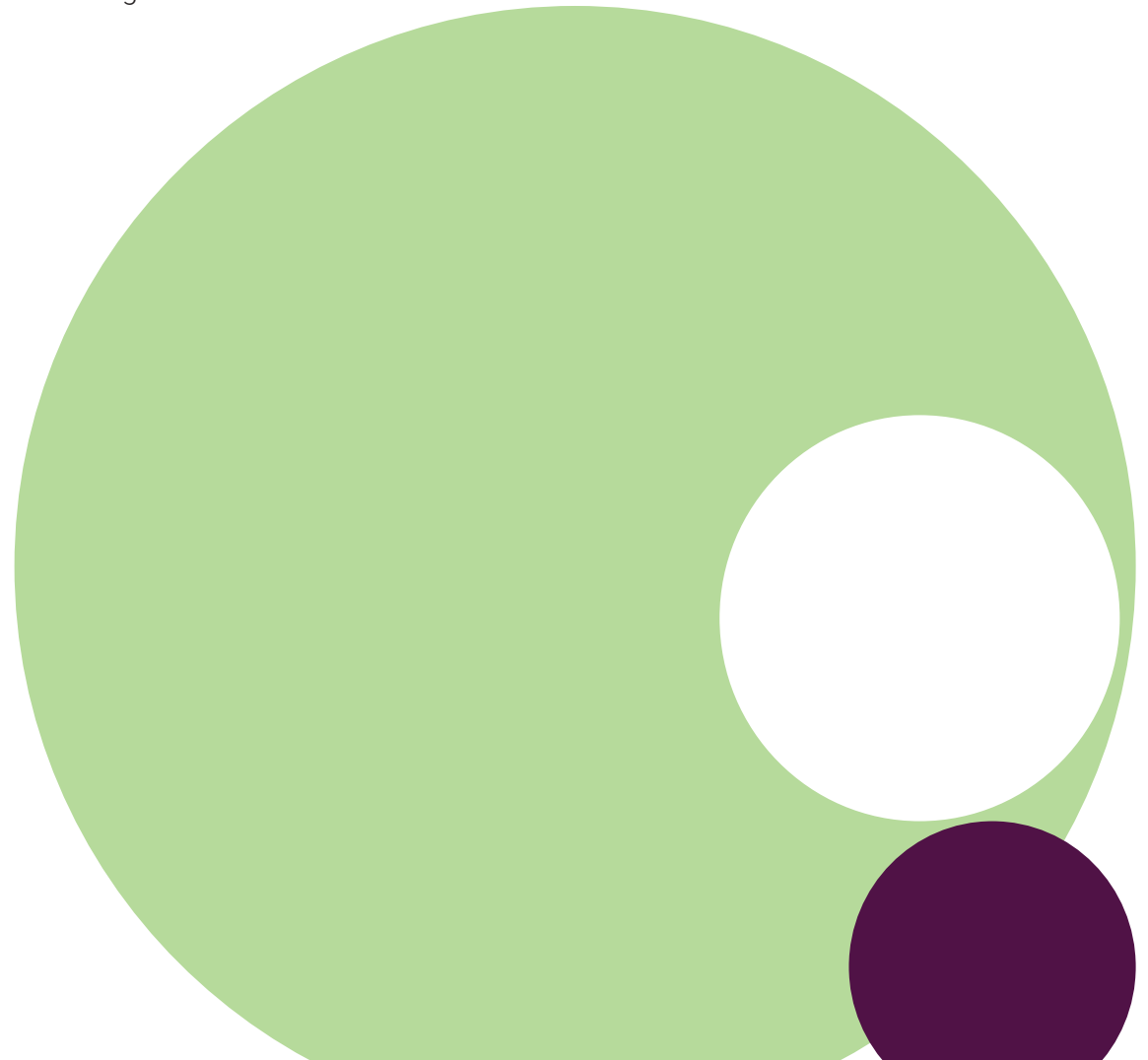


Introduce EU-wide indicators as well as ambitious targets regarding access to long-term care, along the lines of the Barcelona targets⁵ set in 2002 by the European Council in the field of childcare. Ideally, these should be disaggregated by care setting in order to monitor progress – home, community-based and institutional care. The ongoing efforts by the European Commission and Social Protection Committee to develop EU indicators regarding the quality, accessibility and sustainability of long-term care services can be a good starting point for a reflection process on targets.

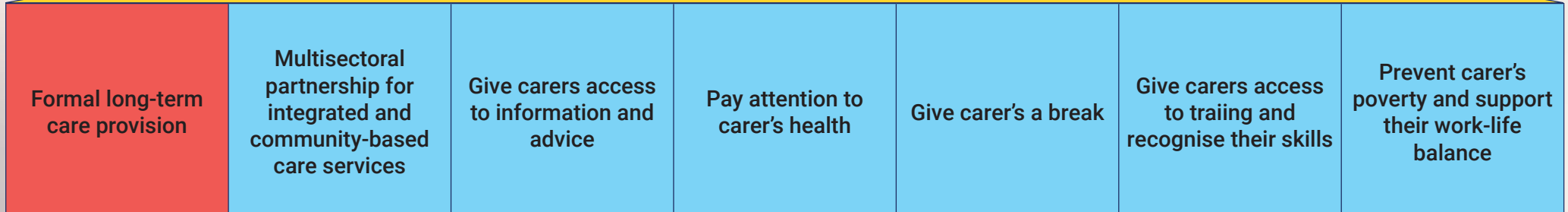
- **Define a quality framework for care services** rooted in human rights and focused on people's preferences, dignity and quality of life. The involvement of users and informal carers in the co-production of people-centred care is crucial in that regard. Quality in care should not be measured only in terms of inputs and process compliance but also in terms of better outcomes for care users and their carers. The conclusions of the WeDo European project regarding the establishment of a quality framework for long-term care services could be used as a starting point⁶.
- **Enhance the development and implementation of integrated community-based care**, which is a root cause of many of the challenges facing member states as regards quality, sustainability and unmet care needs. The lack of alternative solutions is also one of the main predictors of the prevalence of informal care, which is too often seen as the default option for the provision of care in Europe. It is therefore essential to boost investment and developments in the community-based care sector, so as to reinforce care options while making care professions more attractive. EU-funded projects on social innovation in long-term care should help to inform the

process. The WHO and other stakeholders have also developed guidelines on integrated care which should prevent us from reinventing the wheel⁷.

- Encourage EU member states to **develop a legal recognition of informal carers** in order to strengthen their ability to promote their best interest as a group. Informal carers should be able to exercise their rights (e.g. access to social protection, financial support, pension, respite care, information and training) and they should also fulfil obligations (in terms of care quality criteria, for example). This is not only essential to acknowledge carers' role but also to protect them from discrimination. Eurocarers' proposal for an EU Strategy on Carers⁸, re-introduced at the European Parliament in 2018, provides ample details on the dimensions that should be explored through policy and practice in order to properly support carers.



CARERS IN ALL POLICIES



Assess carer's needs

Identify carers

Define carers

A European Strategy to support and empower informal carers



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1

Define and **ACKNOWLEDGE** Carers

Our annual review of member states' legislation shows that the concept of informal care(r) is rarely explicitly defined in the law. When a definition exists, it often fails to overcome traditional boundaries by focusing exclusively on next of kins or cohabitants which overlooking the contribution the broader community (e.g. friends and neighbours). As a result, informal carers still constitute an invisible and unprotected long-term care workforce with no – or limited - rights, or obligations.

We therefore **call on public authorities at all levels of governance to adopt a broad and inclusive definition of informal care and carers in their legislation.** It could be argued that **the transposition of the EU Directive on Work-Life Balance for parents and carers, which introduced the legal concept of 'informal care', nicely paves the way for the development of a legal framework across member states (see STEP 9).** It should nevertheless be mentioned that the definition used in the Directive is still not perfect as it overlooks carers who are not in employment, are self-employed or have atypical working conditions.

2

IDENTIFY Carers

Most carers do not immediately perceive themselves as such and often prefer to consider their caregiving tasks in relation to the care recipient. There is also a widespread view that caring for someone, particularly a family member, is just 'a natural thing to do' - that is until it has detrimental effects on the people involved in the caregiving relationship and society as a whole.

Collecting comparable data about the prevalence of informal care and the negative impact associated with the lack of access to quality professional care and support on both care users and informal carers (in terms of gender equality, negative health impact, loss of income, etc.) **is therefore essential.** The available EU data on care and caring is too limited and does not allow to draw a full picture of the situation. It also affects the ability to devise effective policy initiatives and support measures. For instance, only a (limited) number of national/regional public authorities have introduced questions about care and caring in their population surveys.

(Primary) care professionals could also be better equipped to identify and cooperate with carers. 'Carer-aware' care professionals could indeed play an important signposting role in the implementation of carer support measures.

3

ASSESS THE NEEDS of Carers

Steps should be taken to put in place and – when in existence – enhance the uptake and quality of needs assessments targeted at carers. These allow to define the tasks that carers are prepared to take upon themselves as well as the support required to do this in good conditions for themselves and the care user. The assessment looks at how caring affects the carer's life, including for example, physical, mental and emotional needs, and whether the carer is able or willing to carry on caring.

4

MULTISECTORAL partnerships for INTEGRATED COMMUNITY-BASED CARE services

As mentioned above, care integration helps to improve outcomes by overcoming fragmentation along the continuum of care. The establishment of **multidisciplinary care teams should be fostered across Europe in order to overcome silos and improve coordination between actors of the care pathway.** Given their central role in the provision of care in Europe, **informal carers (or organisations representing them) should form part of these teams.**



5

ACCESS TO INFORMATION and advice

Carers' access to information and advice about care, caring and care-life balance should be ensured. Carers often struggle to access - sometimes basic - information about the condition of the person they care for, the services and support measures available to them and ways of maintaining their own health and wellbeing. Here again, the role of care professionals (and, in particular, the primary care sector) as well as of civil society organisations is important and should be supported. ICT-based solutions offer great potential to give carers access to the information they need.

6

Carers' HEALTH AND PREVENT NEGATIVE HEALTH outcomes

More attention should be paid to carers' health in order to break vicious circles where carers themselves become unwell and in need of care. Caring can impact heavily on a carer's health and wellbeing, when not adequately supported. Access to emotional support (via an NGO or care professional), counselling and training can help to prevent negative health outcomes among carers.



7

Give carers a **BREAK**

Investments should be made to provide innovative breaks, which are adapted to both the care recipient and their carer(s) and which can be delivered in partnership with the voluntary sector. The provision of short breaks or respite is hugely important to alleviate the care burden and stress. Yet, carers are often reluctant to take such breaks because of uncertainties about the quality of respite care and financial difficulties.

8

TRAINING and recognition of **SKILLS**

Investment in carer training should be made in order to improve carers' confidence and enable them to provide better quality care for longer and in better conditions for themselves and the person for whom they care. Adequate training and support have a preventative aspect in avoiding or delaying hospital admission and long-term institutional care.

Moreover, it may also be useful to validate the sometimes very technical skills acquired by carers on the job to prevent their social exclusion and improve their chances of remaining on/re-entering the labour market. Informal carers indeed tend to gain skills in the areas of personal⁹ and medical care¹⁰. They often have to deal with challenging behaviours in the context of demanding care needs (e.g. dementia or other mental illnesses) and therefore acquire important transversal management and communication skills which could be certified.



9

Carers' **POVERTY** and access to an **ACTIVE** professional and educational life

Policies aiming to successfully assist informal carers should include financial support. As the EU seeks to reduce poverty and material deprivation via the introduction of minimum income schemes, the specific situation and needs of informal carers, who often face poverty as a result of their contribution, cannot be overlooked. **A range of financial support options should therefore be made available to them - such as minimum incomes schemes, personal care budgets or care allowances, compensation for care-related costs, in addition to better coordinated social benefits, enabling social services and personalised pathways to employment when possible.**

When in employment, carers should be able to rely on work-life-care reconciliation (or "flexicurity") measures - e.g. teleworking, part-time, flexible working time, awareness raising, etc. **Paid leaves should also be available to them and these should be paid at level that enables the main income earner in a household to take the leave** – thereby fostering a more equal sharing of care-giving responsibilities between women and men.

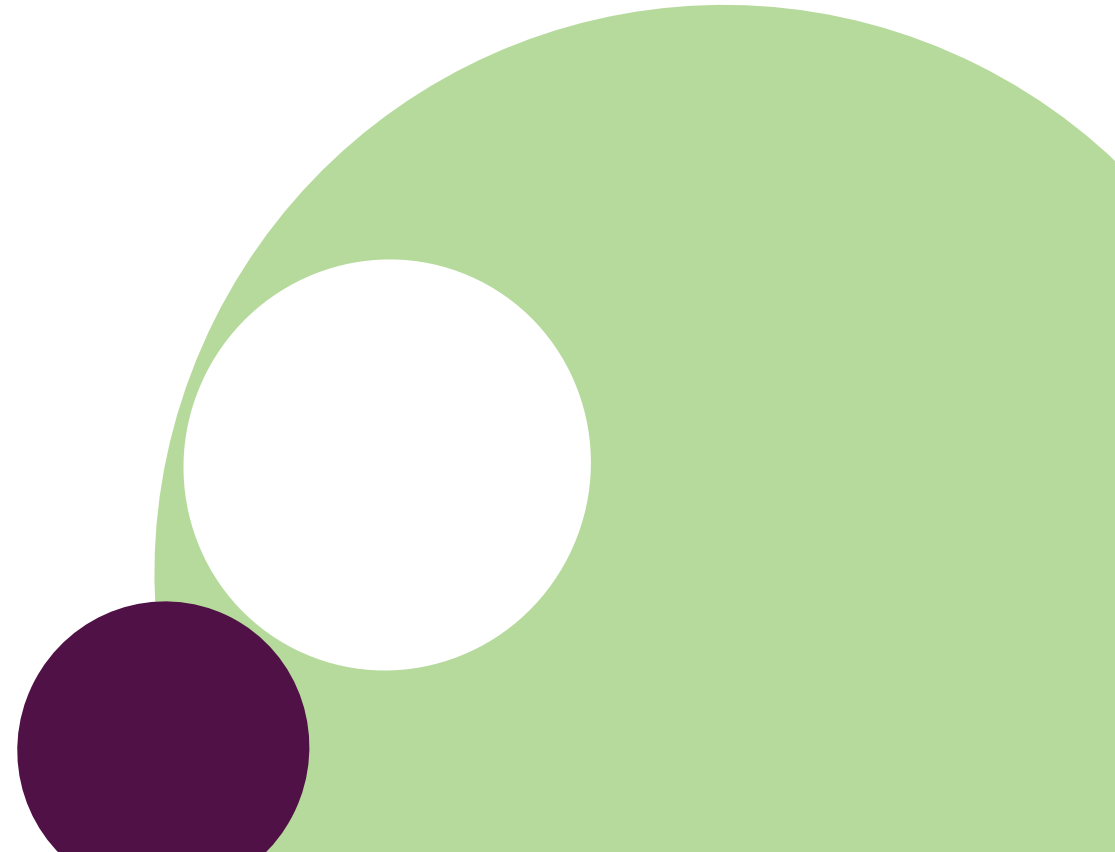
Similarly, it is also essential to introduce pension credits for care-related career breaks in occupational pension schemes. As described in the 2021 Pension Adequacy Report, reduced earnings, higher concentration in part-time work and career gaps related to women's caring responsibilities substantially contribute to the gender pension gap.

Finally, when it comes to young carers and young adult carers, it is important to ensure that their caring role does not prevent them from enjoying their rights as children or to access education, training or employment. **A key focus should therefore be in promoting a whole-family approach – i.e. a family-led strategy that provides adults and children with the tools they need to set goals together, create plans, and achieve those goals.**

10

Adopt the **CARERS' PERSPECTIVE** in all relevant policies

As a rule of thumb, the perspective of carers should be systematically considered in all policies that may affect them at international, national and regional level.



The way forward

Up until COVID-19, future proofing care essentially meant trying to provide better outcomes for care users despite constrained resources – in other words, achieving better results with less resources. However, the crisis seems to have led to a change of attitude and mindset on the part of decision-makers who cannot ignore that the care sector has been the binding glue of our societies in the last two years. In a not-too-distant past, the idea of an EU proposal on a coordination mechanism concerning long-term care would have been considered as implausible to say the least. So, the announcement of an EU Care Strategy on the topic is a major turn of events. Naturally, the Strategy is only a means to an end and policy action must be enforced at national and regional level to make a real difference in the life of Europeans.

To ensure that the EU Care Strategy delivers concrete results, it should be treated as a prominent priority at all levels and appropriate means should be mobilised.

In particular, the European Commission should ensure that:

- › The Care Strategy is mainstreamed in all relevant policy areas beyond Employment, Social Affairs and Inclusion, including Health, Gender Equality, Disability, Research, Anti-discrimination, Digitalisation, Economic Recovery, Sustainable Urban Development, Rural Areas, Migration, Demographic Ageing;

- › An ad-hoc transversal coordination mechanism should be put in place across Commission services in order to ensure that the various initiatives that are being developed and that have a bearing on care and caring are underpinned by a consistent vision;
- › A regular review of progress is organised, for example through an annual event centred on a dialogue with all stakeholders;
- › Meaningful participation of all stakeholders, including informal carers, is ensured at all stages of the design, implementation and evaluation of the Strategy.
- › Adequate EU funding is geared towards the objectives of the Strategy, including through the Recovery and Resilience Funds and Research programmes (Horizon Europe, EaSI, Erasmus+, etc.);
- › Awareness raising activities are foreseen, including among others a European Year of Care.

Moreover, the European Parliament should keep an active role in the development and implementation of the Strategy, ensuring that citizen's needs are echoed and that momentum is maintained, building on an ambitious approach.

As said, no decisive progress will be achieved without the active mobilisation of member states, who should be encouraged to develop their own strategic plan for Care, in line with the vision agreed upon at EU level. This roadmap should be defined in collaboration with all relevant stakeholders and should include objectives, funding resources and participatory annual reviews.

It goes without saying that the Eurocarers network will continue to contribute to this debate through evidence-based recommendations for the benefit of all informal carers in Europe in the coming months and years.

For more information, please contact Claire Champeix, Policy Officer at cc@eurocarers.org.

Notes

1. [European Commission Work Programme 2022, COM\(2021\) 645 final](#)
2. Integrated care models: an overview, WHO, 2016
3. Health and long-term care workforce: demographic challenges and the potential contribution of migration and digital technology, EUR 30593 EN, Publications Office of the European Union, Luxembourg, 2021, ISBN 978-92-76-30233-9, doi:10.2760/33427, JRC121
4. <https://eurocarers.org/publications/impact-of-the-covid-19-outbreak-on-informal-carers-across-europe/>
5. <https://ec.europa.eu/newsroom/just/items/625317>
6. <https://www.age-platform.eu/publications/european-quality-framework-long-term-care-services>
7. <https://www.who.int/publications/i/item/9789241550109>
8. <https://eurocarers.org/publications/enabling-carers-to-care-explained/>
9. (bathing, washing, feeding, dressing, managing incontinence...)
10. (e.g. dialyses, management of oxygen/nebulisers, monitoring of blood and insulin levels in the case of diabetes, tracheotomy patient care, blood pressure monitoring, colostomy bag management, administration of medication, diet monitoring, etc.)



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