



SUPPORTING INFORMAL CARERS

Developing social rights and seizing the opportunity to rebalance the European Union

*Eurocarers' contribution to the European Commission's Consultation
on a European Pillar of Social Rights, December 2016*

1. Introduction

Eurocarers very much welcomes the launch of a Consultation on a European Pillar of Social Rights by the European Commission (EC) on the 8th March 2016 and applauds the willingness to rebalance the European and Monetary Union's integration process through a stronger focus on the employment and social dimensions. From Eurocarers' perspective, it is indeed clear that further progress and cooperation in the social field are needed, and the EC's initiative is therefore relevant and promising.

Informal carers - though too often disregarded - provide a crucial contribution to our societies. Does this proposal succeed in taking their role and difficulties into account?

Eurocarers welcomes the recognition that "people with caregiving responsibilities", as well as parents, should benefit from "adequate leave arrangements" and "access to care services". Nevertheless, the proposal falls short as, beyond the area of work/life balance, evidence shows that support to informal carers makes a huge positive difference **in a variety of areas**, ranging from health and long-term care to gender equality, equal opportunities, employment, education, etc. Eurocarers' contribution to the consultation therefore aims to pick up on all the domains listed in the proposal by the European Commission, in order to promote a multidisciplinary approach, analyse practical examples, and **show how informal caregiving intertwines with major challenges affecting our ageing societies**. Eurocarers' contribution emphasises the need to address all of these dimensions and improve the mainstreaming of informal caregiving across relevant policy areas to develop a truly carer-friendly political ecosystem. Informal caring should not remain invisible to policy makers anymore but should be recognised and valued as a building block of our social protection, health and long-term care systems.

2. Eurocarers' contribution: main highlights

❖ **The social right to provide informal care to a relative should be formally recognised**

There are more than 100 million informal carers in the European Union (EU) today and more and more people will have to combine work and care responsibilities as the effects of demographic ageing on our societies begin to show. While caring for a relative can bring a lot of personal

satisfaction, it also has a cost. Being a carer is often associated with poverty, physical and mental health problems, isolation, work/care balance issues and financial worries. Without adequate support, these people are likely to reach a breaking point and to become unable to provide quality care anymore. Some policies and practices have been developed, mostly at local level, in order to address this reality. These include the provision of information, counselling, training, income support, respite care, special leave arrangements and – generally speaking – empowering measures targeted at informal carers.

However, these initiatives remain largely insufficient, extremely fragmented, geographically uneven and not always sustainable.

Against this backdrop, recognising a social right to provide care to a relative at European level would constitute a strong and positive signal and foster convergence among Member States on the issue of informal caregiving. The recognition of informal carers' social rights would notably:

- Contribute to raising awareness of the invaluable contribution made by informal carers and countering the discrimination they face in various situations, specifically at school or university, and at work;
- Contribute to gender equality policies that take into account the fact that women provide approximately two third of care and their role as caregivers can be seen as a cause of the gender pay and pension gaps, as well as an obstacle along their career;
- Foster a comprehensive approach towards adequate support services based on informal carers and dependent people's actual needs; and
- Contribute to the implementation of the rights of dependent people themselves, notably the United Nation Convention on the Rights of People with a Disability¹.

❖ **Supporting informal caregivers is a sound investment for employment**

Informal caregiving responsibilities during youth are an important obstacle to the completion of education and a factor of early-school dropout. Adult informal carers face important difficulties in accessing and retaining employment. If at work, caregiving responsibilities are an obstacle to access full-time quality employment, lifelong learning and upward mobility. In order to address these realities, comprehensive policies aimed at helping to reconcile work and informal caregiving are strongly needed.

First, working conditions must be adapted to the needs of informal carers, through special leave arrangements, flexible and secure work contracts (including the possibility to adapt one's working schedule on short notice when needed), income compensation for special leaves, etc. In addition, awareness should be raised within the enterprise about the added-value as well as the challenges attached to informal caregiving, in order to break the isolation often felt by carers at work, facilitate the implementation of necessary adaptations and, eventually, retain workforce with caring responsibilities.

Support to informal carers should also be implemented through adequate and accessible services, information delivery, psychological support, counselling, and accessible training. In particular, while

¹ Notably Article 19 recognising "the right of persons with disabilities to live independently and be included in the community" and article 28 recognising "the right of persons with disabilities to an adequate standard of living for themselves and their families".

training can help carer to deliver quality care while preserving their own health, it can also contribute to validate and upgrade informal carers' skills and support their integration in the labour market. Implementing policies aimed at helping to reconcile work and informal caregiving would effectively contribute to economic recovery through increased employment in the EU, as well as to the social integration of informal caregivers.

❖ **Supporting informal carers is a sound investment for the sustainability of our health and long-term care systems**

Informal care is crucial in the provision of adequate care and should be supported accordingly. Informal carers currently provide over 80% of all care and the economic value of unpaid care - as a percentage of the overall cost of formal long-term care ranges from 50 % to 90 %. Informal care is one of the cornerstones of our care systems and a key asset to address the challenges posed by demographic ageing. Informal caregiving helps to contain the costs of health and long-term care, while also supporting widespread preferences among the elderly for being cared for in their own home. However, in order for their contribution to remain sustainable, as well as to improve their quality of life and the well-being of their carees, our health and long-term care systems must evolve to better meet their needs through integrated approaches, in line with the principles defined in the WHO Framework for Action on Integrated Services Delivery.

Integrated social, health and long-term care services should:

- Build on the recognition and empowerment of informal carers;
- Deliver personalised services, coordinated around the needs of patients and their informal carers;
- Be based on rights, notably as recognised in the United Nations Convention on the Rights of People with Disability;
- Underpin the provision of adequate health and long-term care both at home, in parallel with the development of deinstitutionalisation policies, and in care institutions and hospitals;
- Integrate the role of benefits and insurances as key stabilizers of a carer's income;
- Develop adequate training targeted at professional and informal carers, focusing on the delivery of quality integrated care;
- Involve all the relevant stakeholders, including public and private health providers, local and regional authorities, etc.

❖ **Supporting informal caregiving: a transversal priority for a carer friendly society**

Evidence shows that supporting informal carers, together with ensuring they have access to the services they need represents a sound investment, with a return not only for carers themselves but also for their carees and society as a whole from a social and economic point of view. Nevertheless, issues related to caregiving frequently fall between different policy areas and stakeholders, and are consequently too often left aside of the agenda setting process.

Eurocarers therefore recommends the following:

1. **Support to carers should be mainstreamed in all relevant EU policies**, and the principle of a 'care proof-check' adopted.

2. **Policy coordination** engaged within the Europe 2020 strategy should include relevant **objectives and quantified targets**, regarding access to services and support for carers, and adaptation of health and long-term care systems.
3. **Standards and benchmarking instruments** would greatly help to build consensus and assess progress. They should build on **improved comparative research and data collection, and should be co-designed with carers**.
4. The use of **all EU funding instruments** (ESF, ERDF, ESIF) at national level should be aligned with these objectives. Support to informal carers must be included in the priorities of the **next programming period**. Corresponding budgets **should not be considered as an expense but as an investment**.
5. As part of the activities directly supported by the EU, the European Commission should:
 - Develop **awareness-raising initiatives** (a European Year of Carers for example), and encourage awareness-raising activities at all levels;
 - Encourage the **exchange of expertise and experience** through specific EU action programmes and projects;
 - Keep **supporting organisations that represent carers** at EU level and are active in transnational exchanges and awareness raising activities (for ex. through the EaSi programme).
6. Care-related issues are often overlooked as they fit at the intersection between a range of policies areas. Governance should be adapted to address them better. Notably though:
 - Ensuring **closer cooperation on informal care** between relevant Council preparatory bodies, as well as between the relevant Directorate-Generals.
 - **Involving carers** in all relevant consultations, and advisory boards.

Conclusion

There is now clear evidence that, together with the formal provision of people-centered care services, supporting informal carers through participative and integrated policies focusing on their wellbeing, employment and empowerment is key to the sustainability of our health and long-term care systems. Besides, such policies constitute a positive investment, which is beneficial to employment and social cohesion, rather than an expense.

Informal caregiving concerns everyone. If the EU wishes to ensure its citizens keep perceiving it as a forward-looking model for positive cooperation and a tool allowing to address current societal challenges and generate concrete changes in their daily life, it must protect and defend informal carers' social rights.

Eurocarers hopes that the announced White Paper will reflect these much needed priorities. In the meantime, our network will remain actively involved in the debate concerning the European Social Pillar as well as other relevant policy developments at EU level, in order to share experience and proposals on how to develop policies and programmes which support informal carers effectively.

To access the full Eurocarers' response to the consultation, please click [here](#).

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