C/2024/6018

23.10.2024

Opinion of the European Economic and Social Committee

Caregivers

(own-initiative opinion)

(C/2024/6018)

Rapporteur: **Pietro Vittorio BARBIERI**

Advisor	Carlo GIACOBINI, for the rapporteur
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1. Conclusions and recommendations

1.1. The European Economic and Social Committee (EESC):

1.2. notes that ([1]) the European Care Strategy does not contain measures that go far enough in terms of supporting the situation of informal carers, and notes that Directive (EU) 2019/1158 ([2]), in line with its legal basis, only applies to persons who are in an employment relationship; calls on the Commission to put the topic of informal carers high on the political agenda, and to establish a Platform for the exchange of best practices in order to support Member states in implementing workable solutions to remedy existing shortcomings for informal caregivers; calls on the Member States to implement the recommendations of the Council Recommendation on access to affordable high-quality long term care by taking appropriate steps to adopt policies and measures intended to support the situation of informal carers;

1.3. notes that the living conditions of informal carers are often adversely affected by a physical and mental overload, marginalisation and isolation, and thus calls for Member States' policies to encourage a wide provision of high-quality long-term community care services;

1.4. pointing out that informal family care often arises from a decision that is not voluntary, but imposed because of inadequate services and supports, calls for self-determination to be guaranteed and for people to be given the freedom to choose, by introducing the appropriate policies, safeguards, measures and services;

([1]) Opinion of the European Economic and Social Committee on The role of family members caring for people with disabilities and older persons: the explosion of the phenomenon during the pandemic (OJ C 75, 28.2.2023, p. 75).

([2]) Directive (EU) 2019/1158 of the European Parliament and of the Council of 20 June 2019 on work-life balance for parents and carers and repealing Council Directive 2010/18/EU (OJ L 188, 12.7.2019, p. 79).

1.5. considering the risk of burnout and physical and mental overload to be particularly high among informal carers, especially long-term carers, stresses the need and urgency for Member States to introduce policies that guarantee the widespread availability of respite services and solutions to support and protect informal carers (preventive medicine and respite care);

1.6. noting that there is also significant gender inequality in informal family care, calls for this inequality to be mitigated ([3]), including by strengthening and expanding the implementation of the existing provisions of Directive (EU) 2019/1158 of the European Parliament and of the Council of 20 June 2019 and of the European Care Strategy;

1.7. stressing the fact that informal family care causes the tangible and intangible impoverishment of the people concerned and their families, calls for Member States' policies to provide for measures to contain and prevent these effects, including by considering introducing appropriate economic transfers;

1.8. calls on the Member States to put a greater focus on taking awareness-raising measures aimed at encouraging and facilitating the take-up of long-term care services and supports by people in need of long-term care, their families, long-term care workers and informal carers, including at regional and local levels, as provided for in Recommendation 2022/C 476/01 ([4]);

1.9. considers it crucial for informal carers to be able to maintain their normal employment and pay, and thus calls for the work flexibility measures provided for in Directive (EU) 2019/1158 to be bolstered and expanded;

1.10. notes that often, when the caring responsibilities of an informal family carer come to an end, it is not possible for the person concerned to get a new job or return to their previous job, and thus calls for the employment policies of the Member States to introduce incentives, guarantees and solutions to ensure that these citizens can return to paid employment and put the experience they have gained to good use;

1.11. considers it of major importance, in order to monitor the impact of the rules and regulations, to have qualitative and quantitative data available describing the actual living conditions of informal carers; calls, here, for further research strategies to be adopted, in particular with the cooperation of Eurofound and with the involvement of stakeholders;

1.12. calls for family carers to be included in the International Day of Care and Support so that they are recognised in the European care system.

2. **General comments**

2.1. In a previous opinion ([5]), the EESC outlined the background to this issue and also included findings and analysis regarding informal care.

2.2. The *2021 Long-Term Care Report – Trends, challenges and opportunities in an ageing society*, published by the Social Protection Committee (SPC) and the European Commission (DG EMPL), provides an additional overall picture of this issue and contains a considerable amount of useful information describing the impact of informal care.

2.3. Specifically, the *Long-Term Care Report* sets out the adverse impacts on the personal income and pensions of people who provide informal care to older family members or family members with disabilities who require a high level of support, and the resulting impoverishment.

([3]) Opinion of the European Economic and Social Committee on 'Gender Equality Strategy' (OJ C 364, 28.10.2020, p. 77).
([4]) Council Recommendation of 8 December 2022 on access to affordable high-quality long-term care (OJ C 476, 15.12.2022, p. 1),
([5]) Opinion of the European Economic and Social Committee on The role of family members caring for people with disabilities and older persons: the explosion of the phenomenon during the pandemic (OJ C 75, 28.2.2023, p. 75).

2.4. Directive (EU) 2019/1158 on work-life balance for parents and carers extended the rights of carers by creating an entitlement to flexible leave days and flexible working arrangements for people caring for family members who require care. It sets out measures to reconcile work and family life and promotes gender equality in the workplace, encouraging a more equal distribution of family responsibilities between men and women. It also introduced additional safeguards against discrimination suffered by parents and carers in the workplace, prohibiting adverse treatment based on family circumstances or care needs.

2.5. Directive (EU) 2019/1158, formally transposed in almost all EU countries, does not deal with the situation of informal carers who are not in employment or who have given up work in order to carry out and fulfil their informal care duties and role.

2.6. The European Care Strategy ([6]) sets out key objectives to improve care, including with regard to accessibility, quality, sustainability, innovation and social inclusion. It sets out measures and actions to achieve the objectives of the strategy, which may include promoting best practices, financial support for care programmes, technological innovation in the area of care and collaboration between Member States.

2.7. The European Care Strategy calls on the Member States to 'design support measures for informal carers, e.g. counselling, psychological support, respite care and/or adequate financial support', that do not discourage labour market participation, 'together with policies to formalise informal care'. The Council Recommendation of 8 December 2022 ([7]) covers access to affordable high-quality long-term care. The Recommendation concerns 'all people in need of long-term care, and all formal and informal carers. It applies to long-term care provided across all care settings'.

2.8. The Recommendation defines 'informal care' as follows: long-term care provided by an informal carer, namely someone in the social environment of the person in need of care, including a partner, child, parent or other person, who is not hired as a professional long-term care worker.

2.9. *Recommendation 2022/C 476/01:*

2.9.1. recommends, in point 9, that Member States 'establish clear procedures to identify informal carers and support them in their caregiving activities by:

a) facilitating their cooperation with long-term care workers;

b) supporting them to access the necessary training, including on occupational health and safety, counselling, healthcare, psychological support and respite care, as well as supporting them in balancing work and care responsibilities;

c) providing them with access to social protection and/or adequate financial support, while making sure that such support measures do not deter labour market participation'.

2.9.2. recommends, in point 10(g), that Member States take measures 'to raise awareness, encourage and facilitate the take-up of the available long-term care services and support by people in need of long-term care, their families, long-term care workers and informal carers, including at regional and local levels';

2.10. *European Parliament Resolution of 5 July 2022 towards a common European action on care* ([8]):

2.10.1. in point 72 'urges the Commission to present to the Parliament and the Council a European Carers Programme and as a part of it a European Informal Carers programme with a package of actions at EU level on informal care, and, where the competences are at the national level, calls on the Member States to support this European strategy by ambitious and coordinated actions and national programmes to identify, recognise and acknowledge the different types of informal care provided in Europe, and identify different needs of different groups of carers including young carers and mobile carers to facilitate employment to be declared and ensure insurance and social protection coverage, regardless of their different residence or administrative situations and status';

([6]) COM(2022) 440 final.

([7]) Council Recommendation of 8 December 2022 on access to affordable high-quality long-term care (OJ C 476, 15.12.2022, p. 1), hereinafter referred to as 'the Recommendation'.

([8]) European Parliament resolution of 5 July 2022 towards a common European action on care (OJ C 47, 7.2.2023, p. 30).

2.10.2. in point 73 'calls on the Member States to consider the formalisation of informal care and different financial support options based on their different needs and realities, with a view of guaranteeing carers good standards of rights, financial support and social protection'.

3. **Background to the opinion, including the legislative proposal concerned**

3.1. The Commission Communication on the European Care Strategy states ([9]) that investing in the formal care sector would help ensure that informal care is a choice rather than a necessity. Caring for loved ones has a high societal and economic value. It also states that people with caring responsibilities should have a choice about the extent to which they want to combine care with paid work. They should therefore have access to services that enable them to reconcile their caring responsibilities with their professional lives and to benefit from support and assistance (prevention, screening) according to their life choices.

3.2. According to recital D of the European Parliament Resolution of 5 July 2022, '80 % of all long-term care in Europe is provided by informal carers, overwhelmingly women, deprived of fair working conditions, mostly unpaid and/or without adequate social support, which makes care an extremely gendered issue'. It adds that 'informal care provision is associated with lack of rights such as sick leave and annual leave, as well as maternity, paternity and parental leaves, reduction of employment rates, increase of poverty and social exclusion rates, reduced mental health and increased feelings of social isolation and loneliness, which negatively impacts on their physical and mental health, well-being and social inclusion', and states that 'women's contribution in unpaid care work adds an estimated USD 11 trillion to the global economy each year, which is equivalent to 9 % of global GDP'.

3.3. According to recital 11 of Recommendation 2022/C 476/01 'the estimated value of hours of long-term care provided by informal carers' is 'around 2,5 % of the GDP of the Union'. Recital 12 draws the conclusion that 'relying heavily on informal care will not be sustainable and formal care needs and pressure on public budgets are expected to increase'.

3.4. Recital 20 of the Recommendation states that 'informal care has been essential in long-term care provision, as informal carers, mostly women, traditionally carry out the bulk of caregiving, often due to a lack of accessible and affordable formal long-term care'.

3.5. On the other hand, many people also choose to provide or to receive informal care as a matter of personal preference. However, providing informal care can negatively affect carers' physical and mental health and well-being, and is a significant obstacle to employment, particularly for women. This has an immediate effect on their current income and affects their old-age income due to a reduced accrual of pension rights, which can be even more significant for carers who have additional childcare and parental responsibilities.

3.6. The European Care Strategy points out that providing care has serious consequences for informal carers, including adverse effects on their current and future income and on their mental health. The strategy reports that women provide the bulk of care and this often leads them to adapt their work patterns to care responsibilities, including by taking career breaks, working part-time, or leaving the labour market entirely and prematurely. This is particularly challenging for single parents, most of whom are women. Some people face a double burden of caring for children and other dependent family members at the same time. In pre-pandemic 2019, about one third (32,6 %) of women aged 25-49 outside the labour force indicated that care responsibilities were the main reason for not seeking employment, compared to 7,6 % of inactive men.

4. **General comments**

The European Care strategy:

4.1. sets the objective of expanding the opportunities for all stakeholders to share their experience and learn from each other, through mutual learning programmes on all dimensions of care;

4.2. calls on the Member States to create the conditions to enable care providers, including civil society organisations and social economy stakeholders, to play an active role in the design and delivery of high-quality care services and in improving working conditions in the sector, and to support regional and local authorities' efforts to invest in care services;

([9]) In point 3.2.

4.3. as was the case with Directive (EU) 2019/1158, does not explicitly take into account the situation of informal carers who are not employed in another job or who have given up work to engage in informal care activities, in terms of setting out measures to support their situation.

The EESC:

4.4. notes that there is a real gap between the European Care Strategy, its implementation and the reality on the ground, and that that is keenly felt by civil society organisations, healthcare professionals and care recipients. The EESC also notes that Directive (EU) 2019/1158 is not being implemented uniformly across the Member States;

4.5. regrets that access to rights is obstructed, particularly financial rights and the right to information about available programmes, and that access to support is complicated and often associated with excessive and complex bureaucratic red tape and a lack of information;

4.6. notes that the issue of social representation needs to be addressed if the objective is to make progress on implementing proper, sustainable solutions;

4.7. again stresses the need to develop knowledge in this area through ongoing ad hoc studies and statistics. Here, it might be useful for the EESC to work with Eurofound or even co-conduct its own future study;

4.8. encourages social dialogue at sectoral and company level so that progress can be made in terms of work organisation that enables informal carers who are also in paid employment to better reconcile their caring role with their professional life. This is not at all about the employer financing the caring role but about facilitating it through the organisation of work;

4.9. wants to place greater emphasis on self-determination when it comes to people choosing to be informal carers and, equally for the care recipient, in terms of choosing and accepting their informal carers. It should be stressed that it is essential to put the requisite conditions in place that give family members the freedom to choose whether they want to stay at home as carers;

4.10. believes that the roll-out of the European Care Strategy should be accompanied by the construction of robust, affordable and accessible social/institutional care systems. This requires structural investments in quality public services to support those in need of care and the family members that care for them on an informal basis. The EESC notes that for instance Social Employers & CEMR & EPSU's Joint Statement on EU Economic Governance Review ([10]) expressed their concerns about the EU Council mandate for the negotiations on the review of the EU's economic governance rules and stated that Member States' potential efforts to invest in social services for the benefit of their citizens' wellbeing must not be hindered by EU economic governance rules ([11]); the EESC called for further and in-depth scrutiny by the co-legislators, before the adoption of the new Regulation on of the Debt Sustainability Analysis (DSA) methodology, to avoid any unintended automatic consequences arising from new austerity policies, in particular considering the social impact of the measures to be eventually foreseen ([12]).

4.11. highlights the fact that workers who are simultaneously informal carers often cannot continue in regular, long-term employment and progress in their careers is a form of inequality, adversely affects the purchasing power of households relying on informal assistance and causes tangible and intangible impoverishment. It therefore amounts to a net loss from an economic point of view, as it means:

— skilled workers are lost to the workforce (underemployment in the care sector);

([10]) https://www.ccre.org/img/uploads/piecesjointe/filename/EU_Economic_Governance_review_EPSU_CEMR_Social_Employers_Joint_Statement.pdf.

([11]) Social Employers & CEMR & EPSU Joint Statement on EU Economic Governance Review.

([12]) Opinion of the European Economic and Social Committee on the proposal for a Regulation of the European Parliament and of the Council on the effective coordination of economic policies and multilateral budgetary surveillance and repealing Council Regulation (EC) No 1466/97, the proposal for a Council Regulation amending Regulation (EC) No 1467/97 on speeding up and clarifying the implementation of the excessive deficit procedure and the proposal for a Council Directive amending Directive 2011/85/EU on requirements for budgetary frameworks of the Member States (OJ C, C/2023/880, 8.12.2023).

— the investment made in training workers who then give up their jobs (by choice or obligation) is lost;

— a loss related to the share of paid work in the sectors of care and support for people with reduced autonomy.

4.12. stresses the need to activate forms of advocacy to push for the right to respite care for all. Over the past twenty years, formal carers have become increasingly visible players in the organisation of social systems, and the need to support them must now become a priority on the political agenda. Longer life expectancy, the move to home-based care, and more inclusive forms of support are just some of the changes affecting the millions of people in the EU who care for people on a daily basis. It is a political and a public health issue, which must guide the strategies regarding the care of the most vulnerable in a sustainable balance between public solidarity and mutual family support;

4.13. believes that a comprehensive set of supports for people is needed in the framework of European social policies, and that national social policy reforms need to be supported and encouraged.

5. **Towards policies to support informal family caregiving**

5.1. The EESC calls on the Member States to implement the Council Recommendation on access to affordable high-quality long term care by taking appropriate steps to adopt policies and measures intended to support the situation of informal carers; the EESC takes note ofthe call from European associations of family caregivers – particularly following the hearing organised by the EESC in March 2024 – to expand the scope of the European Care Strategy itself, to:

5.1.1. increase formal support by ensuring and expanding the range of services to meet the needs of informal carers through the proposed 'European Care Guarantee' ([13]), including by strengthening the implementation of existing provisions;

5.1.2. the proposed guarantee would enable lifelong access to care services, and would help to iron out the disparities across Europe and within the Member States in terms of the availability and affordability of these services;

5.1.3. increase the availability and accessibility of care services, facilitating the entry and movement of non-EU operators and workers; the EESC suggests focusing on all healthcare workers in Europe, regardless of their migration and residential status;

5.1.4. consolidate a broad range of high-quality long-term care services, through measures regarding the training and upskilling of formal and informal carers;

5.1.5. guarantee – not least with a view to combating burnout, physical and mental overload and abuse – respite and reception services and health prevention and monitoring services, including informal ones, particularly for long-term care situations;

5.1.6. guarantee widespread emergency response services to be deployed in emergency care or health situations;

5.1.7. guarantee people's right to self-determination in terms of choosing to be informal carers, removing the substantive grounds that determine their decisions in this matter;

5.1.8. avert the risks of impoverishment and tangible and intangible deprivation including through specific monetary transfers and financial support, particularly in long-term care situations and in cases of giving up or losing out on regular paid employment;

([13]) OJ C 140, 21.4.2023, p. 39 and OJ C 486, 21.12.2022, p. 37.

5.1.9. take action to maintain and compensate for the level of household and personal income with respect to other social security schemes;

5.1.10. provide for measures and support to allow informal carers who have given up their jobs to concentrate on care to return to paid employment; work towards reinstituting career development, professional reintegration and maintaining links with the world of work;

5.1.11. combat – including by strengthening and expanding the implementation of Directive (EU) 2019/1158 – situations of gender inequality among informal carers who are in employment;

5.1.12. incentivise home-base care and healthcare services to avert the risk of segregation and isolation, as well as to enable monitoring of situations where there is risk of burnout or abuse;

5.1.13. monitor at European level the issue of informal care and assess the results of the measures introduced within the European Care Strategy's research and monitoring mechanisms;

5.1.14. facilitate the cost-effective deployment of telecare, communication and home support technologies, without doing away with human support;

5.1.15. include family caregivers in the International Day of Care and Support so that they are recognised in the European care system.

Brussels, 10 July 2024.

The President
of the European Economic and Social Committee
Oliver RÖPKE