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

(own-initiative opinion)

(2023/C 75/11)

Rapporteur: **Pietro Vittorio BARBIERI**

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(for/against/abstentions)	170/0/0

1. **Conclusions and recommendations**

1.1. The EESC expresses its concern at the living conditions of people who provide long-term care for relatives with disabilities and chronic and degenerative diseases, including cognitive decay and cancer.

1.2. The EESC notes that these situations have become even more dire during the COVID-19 pandemic, making structural measures in social policies and services indispensable.

1.3. In order to optimise the social policies and better tailor the necessary support, the EESC emphasises the need to establish a common definition of the role and the situation of a family member providing long-term care for a relative with a disability or suffering from chronic or degenerative diseases — including cognitive decay and cancer — outlining specific characteristics and scaling the interventions, as well as valuing the role of those involved, including within community services.

1.4. The EESC notes the need to further define the phenomenon through sociological studies and analyses, and through statistics that focus on the impact of long-term caregiving on the caregiving relative, regardless of whether or not they are also otherwise employed.

1.5. The EESC believes that the approach to managing this issue of family members providing care should be based on joint action by public policies, employers through social dialogue and, finally, family caregivers themselves and the organisations that represent them, ensuring that they are involved from shaping public policy all the way through to its implementation.

1.6. The EESC stresses the importance of ensuring health protection services, including preventive healthcare and regular specialist medical check-ups, and of promoting specific training on how to look after their own health, for citizens who provide long-term care for their relatives.

1.7. The EESC calls for specific surveys to be carried out in national pension schemes, aimed at gathering information with a view to scaling and adapting the right to alternative forms of remuneration for those who are forced to give up employment to provide long-term care for a family member with a chronic or degenerative disease, or who has a disability.

1.8. The EESC, noting the ongoing gender disparity among family caregivers, and in line with opinion on the *Gender equality strategy* ([1]), calls for action to mitigate this gender inequality, including by strengthening the implementation of recommendations already set out in Directive (EU) 2019/1158 of the European Parliament and of the Council ([2]).

1.9. The EESC, noting the as yet limited awareness of the living conditions of those concerned, calls for a European day to be established for people who provide long-term care to family members, aimed at raising awareness of the issue and encouraging appropriate support policies and measures.

1.10. The EESC highlights the importance of providing housing support and home services with a particular focus on health and nursing needs, as well as psychological support for the caregiver and the family unit, or for the person with a disability themselves.

1.11. The EESC stresses the importance of encouraging and ensuring emergency services for unexpected events, which make it impossible to provide treatment in the long term or temporarily, and relief services, that limit the effects of excessive and prolonged overloading. There should also be concessions and facilitated procedures that reduce red tape for carers.

1.12. The EESC considers the provision of services and support that enable people with disabilities to take independence pathways outside the family unit of origin to be crucial. This includes the provision of services and support through pathways to personal autonomy, alternative housing solutions, and independent living pathways for people with disabilities. Such policies inevitably also have a positive impact on the burden of care shouldered by family members, who are otherwise obliged to provide long-term care.

1.13. The EESC calls for consideration to be given by Member States to adopting measures, including through financial aid, that address the risk of impoverishment of those who — despite specific policies, services and support aimed at combating this phenomenon — are nonetheless forced to give up paid employment, or reduce their working hours, in order to provide long-term care for their relatives.

1.14. The EESC calls for the ample provision of quality long-term assistance services to be encouraged in Member State policies.

1.15. The EESC calls for employers to be encouraged and supported who promote flexible working arrangements and fringe benefits beyond those already provided for under state rules for employees that provide ongoing care for relatives.

2. **Description of the phenomenon**

2.1. Eurostat's 2018 statistics on Reconciliation of work and family life ([3]) showed that over 300 million EU residents belonged to the 18-64 age group, and that around a third of these had care responsibilities. This translates to around 100 million people who cared for children aged younger than 15 years, and/or incapacitated relatives (ill, older and/or disabled) aged 15 years or more. In contrast, around 200 million people in the EU had no care responsibilities at all. Of those who did, the majority (74 %) cared for children aged younger than 15 years who lived in the same household. Of the remaining 26 %, 3 % cared for children living outside the household, 7 % for multiple children living both inside and outside the household, 4 % for both children and incapacitated relatives, and the final 12 % for incapacitated relatives only.

([1]) OJ C 364, 28.10.2020, p. 77

([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).

([3]) 'Reconciliation of work and family life', Eurostat 2018.

2.2. In 2018, one in three EU residents aged 18-64 years had care responsibilities (34,4 %, compared to the 65,6 % who had no care responsibilities at all). The breakdown of the group with care responsibilities was as follows: 28,9 % cared for children younger than 15 years of age only, 4,1 % cared for incapacitated relatives aged 15 years or more, and less than 2 % for both young children and incapacitated relatives.

2.3. The majority of those who provided care for incapacitated relatives were women: 63 %, compared to 37 % of men. These caregivers mostly belonged to the older age groups: 48,5 % were aged 55-64, and 35 % were aged 45-54. Only 5,5 % belonged to the 18-44 age group.

2.4. Across all current (27) and former (1) Member States (EU-28), there was a 3,3 percentage-point gap between men (2,5 %) and women (5,9 %) who confirmed having reduced or interrupted their working time for more than one month during their current or previous employment due to care responsibilities for ill, older and/or disabled relatives. The largest gap was found in Bulgaria (6,8 p.p.) and the smallest in Cyprus (1,1 p.p.), with women more often than men making changes to their work life (Eurostat, 2018).

2.5. In 2018, 29,4 % of employees in the EU-28 said that it was generally possible for them to work flexible (adapted) hours and to use whole days of leave for care. Differences were observed across all EU Member States. Slovenia had the highest rate of employees with the possibility for both flexible hours and time off for care (60,4 %), followed by Finland (57,1 %) and Denmark (55,1 %). The lowest rates were recorded in Hungary (7,5 %), Poland (7,3 %) and Cyprus (3,8 %). On the other hand, 1 in 4 employees (25,2 %) said they did not have the possibility to work flexible hours or to take whole days off for care. As with those who did, the trend varied across Member States, with ranges from 6,9 % in Latvia and 7,7 % in Slovenia, to 58,6 % in Poland and 58,7 % in Cyprus (Eurostat, 2018).

2.6. Effects on health: in 2009 Elizabeth Blackburn, Carol Greider and Jack Szostak won the Nobel Prize in Medicine for the discovery that demonstrated the biological impact of stress common in long-term caregivers. Long-term care shortened the telomeres of mothers of children with special needs by between 9 and 17 years. The impact of this prolonged stress is largely supported by international scientific literature.

2.7. During the hearing of 4 July 2022, the European Commission revealed that between 33 and 39 billion hours per year are spent on informal care, equivalent in value to between 2,4 and 2,7 % of the EU's GDP. The MFF — the amount of EU investment in innovative projects for the future — totals less than half this amount, at around 1,02 % of EU GDP.

2.8. The personal experiences of family caregivers, gathered by disability NGOs, show that opportunities for social interactions and for maintaining cultural and sporting interests are severely constrained and restricted due to the often unpredictable personal care activities that fall to them and a lack of alternatives to the care they provide, which is very often compounded by deprivation of personal time and space for relief.

2.9. There is a gender disparity when it comes to long-term care activities for relatives with disabilities, and chronic and degenerative diseases, which pushes the additional workload onto women, as evidenced in statistical literature and in the personal experiences of those concerned. The greatest impacts include carers giving up their jobs, limited career progress, being forced to scale back to part-time work and, more broadly, material and other forms of impoverishment.

2.10. In the EU, 25 % of women and 3 % of men said they could not take up paid employment or that they were forced to work part time due to care duties they had for family members, children, older people or those with illnesses ([4]).

2.11. Those who give up employment are often not covered by social security contributions for old-age pensions in later years, and thus are likely to end up in the welfare or destitution support systems.

2.12. The scaling-back and reduction of personal and family services, albeit in different ways across EU countries, is causing even more of a burden for citizens who provide long-term care for relatives with disabilities and chronic and degenerative disorders, including cancer.

2.13. As these carers are not carrying out work in a framework of an employment relationship, they do not benefit from health protection measures and prevention measures against ill health that have been stabilised and consolidated for employed workers.

2.14. Looking at the personal experiences of family caregivers, it appears that continuous and long-term care activities (among others) are an often obligatory or forced choice borne from the inadequacy of care services and a desire not to institutionalise the dependent relative; even where service standards are good, there is still quite a significant residual burden of care.

2.15. The family unit of origin's dependence on care due to a lack of alternatives, help and support often leaves those with disabilities unable to lead autonomous and independent lives.

2.16. Eurofound's Living, working and COVID-19 study ([5]) noted a significant increase in both formal and informal home care responsibilities and a fall in the use of residential care during the pandemic.

2.17. In EU countries, social protection spending on institutionalisation in potentially segregated residential facilities tends to be largely and strategically greater compared to spending on policies for supporting autonomous and independent living, despite the principles and guidelines of the EU Strategy for the Rights of Persons with Disabilities 2021-2030, in which the European Commission called on Member States to implement good practices of deinstitutionalisation in the area of mental health and in respect of all persons with disabilities, including children, to strengthen the transition from institutional care to services providing support in the community.

2.18. Care overload affects a wide array of people whose individual circumstances shape the intensity, duration and type of care provided, in addition to the potential progression of the same, and consequently the overload. These include people with mental disabilities, severe intellectual disabilities, those affected by senile dementia and those who suffer from chronic or degenerative diseases, including cancer. In many cases, even strictly health-related care is left to the charge of the caregiver.

2.19. Despite the considerable differences, certain stereotypes surrounding family care still persist. For example, the stereotype that reduces family care situations to inevitable fate or to a mere emotional and conscious choice made by the family caregivers themselves. Imposing personal care on the relatives of the person with a disability, in certain specific situations, hinders the dependant's ability to live autonomously and independently, compromising and limiting their choices and opportunities to follow their own path in life.

2.20. Despite the considerable differences linked to the varying quality of support services, emergency management (carer illness, specific acute situations, housing emergencies, conflict and uncontrolled stress, etc.) is a particularly important factor during exceptional events and in terms of the related stress and anxiety.

([4]) OJ C 194, 12.5.2022, p. 19, point 3.8.
([5]) https://www.eurofound.europa.eu/publications/report/2020/living-working-and-covid-19

2.21. In situations of increased pressure and with a lack of alternative solutions to direct family care, the possibility of losing the family caregiver (to loss of personal autonomy, degenerative disease, old age or death) causes profound and justified anxiety. This anxiety heightens where there is a total lack of viable alternative care. Exclusively relying on a family member to shoulder the burden of care leads to the isolation of the family unit, especially in very intensive cases, with predictable and sometimes even pathological effects.

2.22. In EU law, there is no uniform recognition of the role of those who provide care for relatives with chronic or degenerative diseases, or with a disability, including of its value in relations with services, but also of the risks and the needs involved in their care activities.

2.23. Cases of increased exclusion, risk and disadvantage appear to be linked to the quality and quantity of family, personal, disability and independent living services, as well as home services (particularly healthcare and rehabilitation); however no surveys have been able to identify and outline with certainty all aspects of this possible link, nor provide potential good practices.

2.24. Directive (EU) 2019/1158 on work-life balance for parents and carers laid out a series of interventions in the form of family care to offset gender inequalities, as well as further interventions for a better balance between care and working time; beyond the analysis of the real impact in the Member States, the Directive does not cover family carers who are not otherwise employed, who have given up work or who are retired.

2.25. Support for citizens who provide long-term care for relatives with a disability or who suffer from chronic or degenerative diseases is often provided by non-profit organisations founded by the family members themselves, as revealed in the hearing of the thematic study group on disability rights of 16 September 2021.

2.26. In the EU-27, around 6,3 million people work in the long-term care sector — that is 3,2 % of the entire EU workforce (based on LFS data, 2019). There are large differences between Member States, with the very low rates recorded in certain countries (1,8 % or lower in Bulgaria, Croatia, Cyprus, Estonia, Greece, Hungary, Italy, Lithuania, Poland and Romania) most likely reflecting a dependence on informal (family) care in these countries, and also a reliance on home caregivers employed by families, which falls outside these statistics.

2.27. One Eurofound study (2020) noted that the wages in long-term care and other social services were 21 % below the average, and called for collective bargaining in the sector to be promoted to address this problem ([6]).

3. **Building a policy to assist caregivers**

3.1. There is a need to establish a common definition of the role and the situation of a family member providing long-term care for a relative with a disability or suffering from chronic or degenerative diseases, including cognitive decay and cancer, outlining specific characteristics and scaling the support measures — a definition that helps recognise the status, policies and support services in EU countries.

3.2. A comprehensive review of welfare policies shows there is both a need and an opportunity to value and ensure the involvement and participation of citizens (both caregivers and dependants) in jointly programming the services that concern them and, earlier still, in strategic policymaking.

3.3. In order to define the phenomenon, it is imperative that a study be carried out on the situations and living conditions of citizens who provide long-term care for relatives with disabilities and chronic and degenerative diseases, including cognitive decay and cancer.

([6]) Eurofound (2020), *Long-term care workforce: Employment and working conditions.*

3.4. For the purpose of providing accurate information for policy-making in this area, Eurostat should update the *Reconciliation of work and family life* survey from 2018 and further investigate the impacts of long-term caregiving on the caregiving relative, regardless of whether or not they are otherwise employed.

3.5. Citizens who provide long-term care for relatives should be guaranteed health protection — including prevention measures against accidents they have in their caring duties, as well as against diseases and ill health resulting from their care duties — that offers appropriate protection as similar as possible to that guaranteed for employees and the self-employed.

3.6. It would be desirable to carry out economic, legal and impact analyses aimed at determining shared, fair and sustainable criteria for recognising the labour-intensive working conditions of long-term caregiving for relatives in the case of citizens who also juggle regular employment at the same time.

3.7. Economic, legal and impact analyses should also be undertaken with a view to pinpointing economic support measures for those who give up employment to care for a family member who is older or has a chronic or degenerative disease, or who has a disability.

3.8. In line with the opinion on the *Gender equality strategy* ([7]), action must be taken to mitigate gender inequality in the area of long-term caregiving for relatives, including by strengthening the implementation of the recommendations already set out in Directive (EU) 2019/1158.

3.9. The success and efficiency of policies and services for family members who provide long-term care are closely linked to the policies and support provided to individuals with a disability who wish to or who can live independently, including outside the family unit of origin where they are tied to the latter due to a dependence on care.

3.10. Knowledge and awareness of the phenomenon still appears to be patchy and limited to a few observers and social actors. This limited awareness needs to be rectified, including through specific initiatives, in order to strengthen and encourage appropriate support policies and measures. The EESC therefore calls for a European day to be established for people who provide long-term care to family members.

3.11. The EESC urges the European Union to work closely with the Member States to improve living conditions for both long-term caregivers of dependent relatives and for the family unit as a whole, as well as to prevent care from being an imposed activity. Specific measures to reach these goals should include:

— recognising and valuing the role of those involved, including recognition within community services;

— ensuring housing services and support in order to prevent isolation, marginalisation and physical and mental overload;

— strengthening home services with a special focus on health and nursing needs;

— providing psychological support services for family caregivers and the family unit;

— providing for concessions and facilitated procedures for carrying out administrative activities;

— ensuring emergency services for unexpected events or where it is not possible to provide care;

— ensure relief services that limit the effects of excessive and prolonged physical and mental overloading of family members;

— addressing, including through financial aid, the risk of impoverishment of those who give up paid employment or reduce their working hours, and of the family unit as a whole;

— encouraging the ample provision of quality long-term assistance services in Member State policies;

([7]) OJ C 364, 28.10.2020, p. 77.

— promoting, where possible, pathways to personal autonomy, alternative housing solutions, and independent living pathways for people with disabilities;

— implementing support measures for family members who provide care based on joint action by public policies (recognising and strengthening the role of the family caregiver; reliable and available services; carer health; promoting resistance solutions; social protection and compensation schemes for those who provide care, etc.), employers through social dialogue and, finally, the family caregivers themselves and the organisations that represent them, ensuring that they are involved from policy shaping all the way through to its implementation.

Brussels, 26 October 2022.

The President
of the European Economic and Social Committee
Christa SCHWENG