

European Parliament  
Informal Carers Interest Group

**Addressing care poverty:  
how inequalities prevent older people to access the support they need**

Virtual meeting of the European Parliament Informal Carers Interest Group  
28<sup>th</sup> November, 12.30-14.00 CET

REPORT

**Sirpa Pietikäinen MEP** opened the meeting and made the following points:

- *As today's meeting would probably be the Group's last in this Parliamentary term, it would have an eye on the past as well as on the future: an eye on the past as the topic - care poverty as a multi-faceted theme - has not been explicitly addressed in this Interest Group until now; however, it has been an inherent part of its advocacy efforts carried out during the last three terms of this Parliament, with the adoption of the EU Care Strategy as the 'jewel in the crown'; an eye on the future as this theme should be taken forward as an explicit priority for EU action in the field of informal care in the next European Parliamentary and Commission term of office.*
- *This concept is important as it brings together the findings of three important disciplines: feminist social policy research, gerontological research and research into poverty and social inequalities.*
- *In addition, it addresses both the socio-economic dimension of accessing long term care as well as the socio-economic outcomes for carers as it relates to situations where older people need care and support but do not receive adequate help - when individual care needs are more extensive than the help and assistance available from formal and informal sources.*
- *It addresses how financial and other barriers impact on access to care and how these boost the prevalence of informal care provision in Europe.*
- *Therefore, it seems like a perfect 'umbrella' for the future work of this Interest group.*
- *It has been said many times in these meetings: as much as 80% of all long-term care in Europe is provided by family, friends and neighbours.*
- *Access to care is a determining aspect, both for those cared for as well as for informal carers, who otherwise will need to carry the lion's share at their own expense - in many cases in physical, mental as well as financial terms.*
- *So, measures should be taken to address and prevent care poverty, and this concept should find its way in the implementation as well as the monitoring and outcome assessment of the EU Care Strategy.*

Keynotes

Sirpa Pietikäinen MEP then gave the floor to Professor Teppo Kröger (University of Jyväskylä, Finland), who introduced the concept of care poverty and its implications for policy development, making the following points:

- Until now, the discussion on social care has not sufficiently focused on the primary (outcome) question, i.e., *do people who need help receive adequate support?*
- The main emphasis has been on the concept of unmet (long-term care) need(s); however, that concept does not cover the social problem related to this lack of adequate care nor its urgency; there is also no reference to inequality, deprivation, disadvantage and social exclusion - and human rights.
- Care poverty relates to a situation where, as a result of both individual and structural issues, people in need of care do not receive sufficient assistance from informal or formal sources, and thus have care needs that remain uncovered.
- This concept aims to provide a new starting point for discussion on social care, connecting studies on unmet needs to policy discussions on care systems, poverty and social inequality.
- Care poverty is seen as a lack of informal and formal care resources. Poverty and care poverty are often connected but are to be understood as separate issues.
- Besides low income, care poverty is connected to living alone, poor health and a high number of I/ADL limitations.
- Care poverty impacts on quality of life, physical and mental health, cognitive functioning, human dignity, mortality, use of health care and residential care services. It can be understood as a failure of the welfare state as well as deprivation of a basic human need - as a human right violation
- There are various domains of care poverty, related to personal, practical and socio-emotional care needs.
- There is little research on the consequences of care poverty for family carers to date; fortunately, knowledge is increasing. What has been shown (e.g., EUROFAMCARE, 2005) is that the well-being and health of carers and their older relatives are clearly connected, that care poverty leads to suffering not only of the older person but also of the family carer and that care poverty jeopardises the continuation of informal care arrangements. In other words, the provision of supplementary formal care would support the care arrangements and reduce the risk of care poverty.
- In terms of EU policy and care poverty, the European Pillar of Social Rights (2017) clearly states that ‘Everyone has the right to affordable long-term care services of good quality, in particular homecare and community-based services’. The EU Work-Life Balance Directive (2019) introduced the right to a 5-day annual carers’ leave. The European Care Strategy (2022) requests Member States .to increase access to high-quality and affordable care services as well as improve working conditions and work-life balance for carers. In other words, EU policies are well in line with the goal of reducing care poverty.

However, there are policy issues that could be emphasised more strongly, such as

- Develop collaboration between formal and informal care
- Put more focus on the outcomes, especially among the high-risk groups
- Define care poverty as a key criterion in the evaluation of national care systems and as a benchmark in their development
- Underline that access to adequate care is a basic human need as well as a human right

**Marisa Matias MEP** then gave the floor to **Dana Bachmann (European Commission, DG EMPL)**. She recalled some key facts with regards to lack of access to long-term care as well as the data showing that long-term care costs can be dramatically high, even when public support is available. In order to

address the different challenges that impact long-term care systems, the 2022 Council Recommendation aims to ensure long-term care that is affordable, available and of high quality. It also includes invitations for actions related to addressing workforce and skills related challenges and support for informal carers. This Recommendation is currently being implemented by Member States; its agenda is ambitious. There is still a long way to go but a sizeable number of steps to help Member States in their implementation efforts have already been taken or are underway. In terms of monitoring and governance, in almost all countries national long-term care coordinators have been appointed. Two mutual learning events brought the coordinators together to discuss quality and social protection for long-term care. An indicator-based monitoring framework is being developed together with the Indicators Sub-group of the Social protection Committee. Member States have to report to the Commission on implementation measures by mid-2024. The Commission will also submit to the Council a report on implementation in 2027.

Addressing the European Care Strategy - of which the Council Recommendation is part- Mrs Bachmann explained that this consists of 4 pillars, which contain a number of practical actions:

1. *Long term care services*: the Commission focuses on policy dialogue and mutual learning between the national long term care coordinators and within the Social Protection Committee, the Employment Committee/ EMCO as well as with international bodies such as the WHO and OECD. More specifically, a strategic partnership with WHO focuses on the development of a long-term care self-assessment tool and the developing of support material for informal carers. The self-assessment tool is being piloted in Lithuania and Ireland (in 2024) and it will be further refined to be made available in 2024. The Commission is continuing its long-term cooperation with the OECD to measure effectiveness of social protection of long-term care; a report will be published next year. Positive developments in long-term care are underway in many Member States, as shared by national coordinators.
2. *Workforce*: this pillar addresses skills, social dialogue, working conditions, occupational health and safety related to formal care provision as well as support for informal carers. Earlier this year, the Commission adopted a Decision setting up a European social dialogue committee for social services. There is also an on-going study on admission conditions and pathways for third- country nationals working in the LTC sector in the EU, as well as a thematic study on the application of EU labour law in the long-term care sector, and a review of the application of occupational safety and health issues in the health and long-term care sector (by EU-OSHA). Cedefop also published a policy brief on skills in the care sector.
3. *Technical assistance*: use is being made of EU funding programmes relating to innovation, digitalisation and social and economic cohesion (e.g., Horizon Europe, Digital Europe, (ESF+, ERDF and others). Under a flagship of the Technical Support Instrument on Integrated care 4 projects are starting, involving 4 Member States: EL, ES, IE, IT; and in addition, under the 2021-2027 programming period of the ESF+ it is estimated that approximately €6,7 billion are programmed for projects supporting health and long-term care sectors and services in 22 Member States. A number of 7 social innovation projects in long-term care financed under the EASI programme funds are completed or about to be completed providing interesting results with potential for scaling up ((new care models based on person-centred and integrated approach, strengthening care provision in rural areas, etc.). Furthermore, under the Resilience and Reform Programmes €7,3 billion are earmarked for LTC for 18 Member States.
4. *Improving data*: under this pillar, an ESTAT led Task Force on long term care statistics is working to improve the data availability for Long-term care, and policy is being monitored via existing processes

such as the European Semester and Social Open Method of Coordination. The Commission works together with the Indicators subgroup of the social protection committee to develop a monitoring framework for the implementation of the Council recommendation on long-term care. Discussions with regards to availability and affordability of long-term care already took place, and in the next months the focus will be on quality, workforce and informal carers. This work should be finalised in June 2024.

## Panel

**Marisa Matias MEP** then introduced the panel, which addressed the following questions:

- What, from the point of view of your organisation, are the most salient socio-economic factors hindering access to care for older people and how does this impact informal carers?
- How could this be changed?
- What type of action would you recommend for the EU and national levels to address socio-economic inequalities as a barrier to access to care?
- What can your organisation contribute to this?

**Fernando Chironda (European Anti-Poverty Network - EAPN)**, stated that

- LTC systems are highly complex as there are so many social services related to it.
- It is often associated with care for older people but is connected to all age groups.
- The COVID-19 pandemic, with its heavy impact on health and LTC systems, clearly demonstrated the structural lack of investment in the sector, the difficult working condition, the need for and lack of social innovation and issues related to migrant workers.
- All these issues relate to and have an impact on poverty, social inclusion and fundamental right - and the concept of care poverty brings together all these main challenges.
- The pandemic clearly showed that access to affordable and high quality LTC services is by no means a given for all people, and the impact is strongly felt of those who are already vulnerable, such as carers and older people.
- The need for LTC is likely to increase in the coming years and this demographic change undermines and underlines the need for a policy shift, addressing structural inequalities and marginalisation. IN order to bridge the care gap, investment in health and social infrastructure will not be sufficient; the root causes of inequality need to be tackled. Income and social protection are determinants of, full coverage and accessibility of health and long-term care services, as currently, access to these services is correlated with income status of the beneficiaries. Sustainable adequate healthcare systems are required to provide equal access.
- In the EU, the bulk of care is provided by informal care providers - usually women - and free of charge. The impact on these carers - usually women - is not considered. This calls the way our welfare state, our social protection systems and funding for health care systems are being arranged.
- A comprehensive rights-based approach, considering investment, work quality and human rights is required if LTC systems are to become fair and equitable. The concept of care poverty can function, as a guide.

Relating the concept of care poverty to situation and experiences in Ireland, **Clare Duffy (Family Carers Ireland)** said that:

- A 2019 study by the ESRI which explored unmet need in relation to homecare across 11 European countries, ranked Ireland as the second highest country in terms of homecare-related unmet need. Only 25 % of respondents had access to homecare. Unlike other countries where affordability was the issue, in Ireland homecare services simply are not available to meet demand.
- The research showed a clear correlation between unmet homecare needs and poverty, with those experiencing unmet need for homecare 2.5 times more likely to also experience material deprivation.
- Care poverty does not only apply to older people; in Ireland, adults with a disability are 2,5 times more likely to have unmet care needs than older people.
- Care poverty in Ireland is driven primarily by rapidly growing demand for care services against a backdrop of a lack of informal carers, inadequate funding for formal care services and a chronic shortage of staff within the care sector.
- One aspect, different from other Member States, relates to the adoption in 2009 of a law giving older people a statutory right to nursing home care. Under the Nursing Home Support Scheme Act, (Fair Deal) an older person, assessed as in need of nursing home care has a right to nursing home care. However, they have no equal right to be cared for at home. This anomaly has forced many older people into nursing homes because they have no option to be cared for at home, which is most often their preference. Therefore, a further dimension of care poverty could be considered i.e. when people cannot access care in their preferred setting.
- The Irish experience shows the importance of ensuring that legislation and/or social policies do not incentivise one form of care over another.
- It is also important to consider the consequences of care poverty which are frequently borne by family carers - on their financial security, on their work-life balance, on the high levels of out-of-pocket expenses they incur. In Ireland, a new Long Term Carer Contributions Scheme will come into effect on 1 January 2024, ending decades of pension disadvantage experienced by long-term family carers, the majority women.
- This will give family carers caring for more than 20 years access to the State Pension Contributory by treating their years of caregiving in the same way as paid employment.

**Philippe Seidel (AGE-Platform Europe)** underlined that the concept of cp is useful as a framework for the issues faced in LTC provision. He further stated that

- For many older people, leading independent lives is not a reality. The absence of care for persons in need of it is mainly due to financial issues. Research has pointed out that about half of older people do not receive the care that they need. In most Member States, even with public support for long-term care, the cost of care puts people below the at-risk of poverty line.
- Public policies should address care poverty as this leads to the deterioration of health and social inclusion throughout life, impacting on the risk of care need.
- This is true for people in need of care as well as for informal carers, as the latter need to step in when there is no public support for long-term care services. Unable to combine care provision with work obligations, many carers have to work less or leave employment completely (affecting their income as well as their social protection rights), and risk social isolation and exclusion - in other words, carers are the ones that pay for the absence of formal care services in several ways.
- In addition to these financial issues, there are other areas to consider, such as human rights, social inclusion and well-being; all of these go hand in hand.



- It is therefore crucial to consider that the absence or inadequacy of policies has important short- and long-term social costs.
- There are huge variations between EU Member States with respect to their long-term care spending levels and available resources. The available resources are loosely correlated with the extent to which social protection systems cover long-term care services and prevent poverty risk.
- On a positive note; there are some examples of Member States where the public system covers people financially. While not perfect, these systems do make clear that it is possible to change for the better and access the issue from a social protection perspective.
- As far as the Informal Carers Interest Group is concerned, it is important to make the financial side of informal care visible and include social protection in the equation. Income support, right to leave from work, support services and accrual of pension rights should on one hand prevent poverty for carers, while on the other hand they make the invisible cost of lack of care services visible to public budgets.
- Importantly, access to professional services has to be expanded so that informal carers truly have a choice to care.

**Luke Ming Flanagan MEP** invited MEPs present to take the floor. **Frances Fitzgerald MEP** underlined the importance of the Informal Carers Interest Group and its advocacy work, which needs to return after next year's elections. She also said that:

- The EU Care Strategy presents a great opportunity, and its implementation needs to be carefully monitored. In that respect it is good to see the many initiatives the Commission has taken so far, like the Pact for Skills and inclusion of the topic in the social dialogue as these are very important arenas to discuss and progress the care issue.
- The concept of care poverty is key to inform policy makers, a, given demographic ageing, access to care will be a defining issue across the EU over next decades.
- Data gathering, data sharing and networking are also very important as they will put the spotlight on best practice and prevent countries from reinventing the wheel.
- Formal care provision should be looked at in all its aspects, such as staff shortages, working conditions, migrant workers and training.
- As far as informal carers are concerned, it should be born in mind that caring is tough and demanding work, which mainly falls on the shoulders of women - with little possibilities to rely on formal services.
- Long-term care should therefore be looked at from a gender as well as from an equality perspective.
- There should be choice for people to get the care they prefer where they prefer it, avoiding people to remain in hospitals and nursing homes when they should not be.
- Next year's EU elections will provide the opportunity to insert the key points relevant to long-term care into the parties' election manifestos, so that the topic can find a solid place at the top of the political agenda - and remain there.

**Maria Matias MEP** fully agreed with the points raised by Frances Fitzgerald and - as the meeting was running late - only added that, if the root causes of societal inequality are not addressed appropriately, care poverty will remain a problem. Structural solutions are required.

**Luke Ming Flanagan MEP** stated that having more women in the European Parliament might help to firmly put the topic of LTC on the EU policy agenda as most carers are women; they are the carers and take most of the brunt and consequences of this work. Their experiences should be heard and acted upon.

One of the points made in the meeting referred to the fact that adults with a disability have 2,5 X more problems to access care services. This is an issue that should be looked at.

### Audience debate

**Carers Scotland** informed the audience of a study that is being carried out on carers over the age of 65, in order to gather information on the impact of caring on their lives in terms of finances, health and social life. The organisation would welcome contacts with organisations or individuals carrying out similar research.

**Frank Goodwin (former President of Eurocarers)** made a plea for recognition of the home as the preferred place to receive care. He also underlined the importance of asking those cared for their priorities and preferences, in order to ensure the best individual quality of life.

### Conclusions

**Luke Ming Flanagan MEP** concluded by praising the work of the Interest Group, emphasising its importance and the need for it to be active in the next Parliament. The Group provides a platform for advocacy based on real expert opinion and life experience and will help keep the urgency of addressing LTC alive.

He welcomed the notion of care poverty as a 'guideline' towards future work of the Group, adding that, if informal carers are not cared for, they will pay the price - mentally and physically.