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European Parliament  
Informal Carers Interest Group

*'Towards an ambitious EU initiative on long-term care'*

Virtual meeting of the Informal Carers Interest Group  
23 February, 14.00-16.00

**Meeting objectives:**

- Highlight the increasing policy interest on long-term care and carers, more specifically the consultation on the implementation of the European Pillar of Social Rights, its outcome and next steps
- Be informed of the EPP initiative in the European Parliament on a European Care Strategy
- Exchange views on the priorities for EU action in relation to long-term care/carers
- Explore possibilities for EU action to increase concrete policy attention for long-term care/carers across the board, e.g., by means of a dedicated strategy/initiative.

**AGENDA**

14.00-14.10 *Welcome and aims of the meeting*

*Update on developments re the Informal Carers Interest Group*

- Sirpa Pietikäinen MEP
- Luke Ming Flanagan MEP
- Marisa Matias MEP

14.10 – 14.25 *Calling for a European Care Strategy*

- Dennis Radtke MEP
- Frances Fitzgerald MEP

14.25-14.50 *Consultation on the European Pillar of Social Rights: findings and implementation*

- Dana Bachmann, Head of Unit 'Modernisation of Social Protection Systems', DG Social Affairs, Employment and Inclusion
- Rui Fiolhais, President, Institute of Social Security, Portugal

14.50-15.05 *Implementing the European Pillar of Social Rights; how to enhance carers' rights?*

- Stecy Yghemonos/Claire Champeix, Eurocarers

15.05-15.30 *Panel response: towards an ambitious initiative on long-term care*

- Jiri Horecky, European Ageing Network
- Borja Arrue, AGE-Platform Europe
- Paola Panzeri, EPSU
- Luk Zelderloo, EASPD

15.30 -15.55 Audience debate

15.55-16.00 Conclusions and close

- Sirpa Pietikäinen MEP
- Luke Ming Flanagan MEP
- Marisa Mattias MEP

## REPORT

**Sirpa Pietikäinen MEP** welcomed participants and underlined the importance of the meeting's topic. As the Social Pillar is now about to take a further step towards its implementation, the time is right to reflect on the possibility of developing a dedicated strategy on long-term care. In addition, there is growing interest in the European Parliament to explore and develop such a strategy, which should be implemented at EU as well as at national levels. However, while it is important to talk about care and caring across the board, Sirpa Pietikäinen MEP underlined the need for specific attention for the role and support needs of informal carers; any EU care strategy should include a special strand or programme on this issue.

**Luke Ming Flanagan MEP** provided a brief introduction of the Informal Carers Interest Group, which aims to critically *monitor and analyse EU policy development for its impact on carers and to propose and advocate concrete action in order to improve the day-to-day situation for Europe's many carers, working in close partnership with relevant stakeholders*. He informed the meeting that, last summer, an effort was made to increase the number of MEPs supporting the Interest Group; it now consists of 26 MEPs from 10 countries. He stated that now is the time to address the issues of informal carers as the COVID-19 pandemic has put the spotlight on their needs.

**Luke Ming Flanagan MEP** then gave the floor to **Dennis Radtke MEP**, who provided the background to the PPE's initiative to put in place a comprehensive European Care Strategy. There are a number of critical issues to address in relation to long-term care provision and a European Care Strategy can help deliver change and progress. The political momentum is now and a concrete proposal for such a Strategy will be finalised in the short term. It is important to note that policy and action in the field of care provision care remains the competence of the Member States. The Strategy would not change that; it would complement national actions, while respecting subsidiarity. It would be a matter of agreeing minimum standards, both for those providing as well as those receiving care. Who could possibly be opposed?

Mr Radtke MEP expressed his intention to involve and include stakeholders – such as those present today - in the development and implementation of a future Strategy. The window of opportunity is open now; we should not let it slip by.

**Frances Fitzgerald MEP** then presented the proposed content of the Strategy. She underlined the need to push this issue forward in the European Parliament, to take charge and involve the other EU institutions and relevant stakeholders. As with health issues, care issues transcend national

boundaries. The COVID-19 crisis has made very clear that we have to work together – no country can tackle health challenges like cancer, diabetes and MH on their own. New models of interaction between the EU and Member States are required:

Rather than talking about national competence the focus should be on complementarity as there is scope to explore what the EU level can do to complement the national level.

The idea of a European Care Strategy is shared by many; there may be different names for various initiatives but the goals are the same. The idea is to ensure the maximum that can be done at EU level. A fresh look at the decade ahead is required. The focus of today is on making an ambitious effort on long-term care; but each of the areas of the care continuum (childcare, eldercare...) will need implementation plans. And there are initiatives we can build on.

The European Care Strategy would address the following aspects:

**Data collection** – in order to develop a Strategy, it is crucial to have a clear picture of the current situation. Who is being cared for and how, what are the circumstances of those cared for, is the care provided paid or unpaid...In order to generate this data, mechanisms for robust data generation are necessary.

**Gender aspects** are important in relation to care provision and work/life balance. The implementation of the Work/life Balance Directive is important in this respect.

**Working conditions:** this relates to paying decent wages and securing social welfare and pension rights.

A proper care infrastructure needs to be developed; Europe is losing out trillions of euros as the potential of many citizens remains untapped. There could be many more jobs in area of care provision; it is a matter of choice, motivation and understanding.

**Funding:** never before has Europe made so much money available to its Member States. The Recovery and Resilience Facility specifies how the money should be spent; investment in the care systems should become part of the national action plans.

**Setting targets;** the Barcelona targets for early childhood education need to be revised; this could be an opportunity to include other quality care measures, e.g., related to long-term care and care for disabled persons.

Frances Fitzgerald MEP concluded by stating that subsidiarity should not stop us from getting the best of what Europe could do for care.

Luke Ming Flanagan MEP then gave the floor to Dana Bachmann (Head of Unit 'Modernisation of Social Protection Systems, DG Social Affairs, Employment and Inclusion, European Commission), who stated that the Commission will adopt the Action Plan to implement the European Pillar of Social Rights in the first week of March.

A public consultation on the Pillar was held last year in order to feed into the preparations for this Plan. Apart from the Pillar's specific principle on the right to long term care (Article 18) there are many other principles with a bearing on care and caring, e.g., work life balance, equal opportunities, old age income, education, training and lifelong learning and others. Over 1000 contributions were received from a wide variety of stakeholders, some of which specifically focus on long term care, including the role of informal carers. These highlight the importance of the EU addressing the challenges of demographic ageing, labour market changes, shortages of available and affordability long term care and lack of options in care provisions. Also, they address the need to expand community and home care services and wind down traditional residential care; they underline gender equality issues, and the need to improve respite care, work/life balance and training possibilities. Social protection is also referred to as there is a need to provide adequate credits for career breaks related to care provision. And of course, they refer to the challenging working conditions in formal care provision, related to: heavy schedules, heavy physical tasks, psychological pressure, inadequate wages and career development prospects.

In general, respondents ask for an overarching approach taking all elements of care provision into account.

In terms of next steps, the Action Plan will set the Commission's vision on how to respond to the strong need and urgency to take action in the field of long-term care. Meanwhile, the Commission has also launched a consultation on its Green Paper on Ageing, covering among many other dimensions of ageing, also the issue of access to quality affordable long-term care; these two initiatives are closely linked. In addressing long term care, it is also important to build on existing acquis, such as the Work/Life Balance Directive.

Responding to Frances Fitzgerald's outline of a future European Care Strategy, Mrs Bachmann stated that there are ongoing initiatives in relation to the building blocks proposed: On data availability, the Commission has commissioned a study on informal carers, which is – inter alia - looking at hidden costs to society in terms of carers withdrawing from the labour market, acknowledgement for the contribution of carers and taking stock of the impact of caring responsibilities on mental and physical well-being and income. The Commission is working together with the Social Protection Committee (SPC) to prepare a report on long term care, exploring challenges and opportunities across the EU and taking stock also of the immediate impact of the COVID-19 crisis; this will be finalised in June. In relation to targets, Mrs Bachmann referred to the ongoing work of the SPC's Indicators Subgroup, which aims to develop reliable indicators that allow comparison between Member States. She further stressed that the Pillar Action Plan will also address the issue of indicators for the different principles of the Pillar. As regards skills and professional development the EU Skills Agenda has a strong focus on upskilling and reskilling of the workforce, including measures to address attractiveness to priority sector and sectors focusing shortages. Such actions could benefit also long-term care sector. Last but not least, EU funding under the new MFF and the Recovery and Resilience Facility could be mobilised to support reforms and investments in Long Term Care.

**Luke Ming Flanagan MEP** then gave the floor to **Rui Fiolhais (President, Institute for Social Security, Portugal)**. He stated that care provision as a theme is highly appropriate, in order to promote active ageing, to recognise the potential of older people and to ensure the provision of quality care.

Portugal is one of the 'oldest' countries; therefore, the country is taking an active interest in the topic. There are many reasons to promote policies that ensure long-term care provision, aligned with the principles in the Social Pillar. In addition, there is the ongoing consultation on the Green Paper on Ageing; both these initiatives are of the utmost importance for the Portuguese EU Presidency.

Portugal invests in keeping people in their natural environment, even if they get highly dependent. For several years, carers have been claiming recognition of their role in society. This has had effect: the Portuguese government has approved an 'Informal Carers Statute' which stipulates a set of rights and support measures; in other words, the state aims to create the necessary conditions to enable carers to provide good care. It entitles primary caregiver to cash benefits, to periods of rest, to social and psychological support and to tax benefits. The Carers Statute is a pilot project – it is not yet implemented across the board. It currently covers 30 municipalities.

Despite that fact that the pilot was launched in the middle of the ongoing pandemic, most of the measures are underway. To facilitate access to the scheme, an information support line was launched and 18 informal carers offices have been set up in social security district centres. So far, 460 carers have been taken up by the scheme and many more have applied. Another innovative element relates to the fact that health and social services are jointly involved. The Statute facilitates personalised intervention plans for informal carers as well as training and education. It helps to promote 'ageing in place', ensuring the necessary conditions to take care of dependent persons as well as minimising the impact of dependency of those cared for.

It values both those who provide care as well as those who receive care. Solidarity and dignity are key words in this respect.

Taking over the chair **Marisa Matias MEP** gave the floor to **Stecy Yghemonos (Director, Eurocarers)** and **Claire Champeix (Policy Officer, Eurocarers)**.

**Stecy Yghemonos** welcomed the idea of a European Care Strategy; the timing for such an initiative is perfect. Eurocarers has been pushing for such an initiative on care and caring since 2013; all of the key challenges – growing care demand, declining supply, good quality and sustainable health and care services, over-reliance on carers as well as the impact of caring on carers themselves are issues for all Member States. Therefore, it only makes sense to have a coordination process at EU level, underpinned by a Strategy.

Eurocarers is in the process of collecting data on the impact of the pandemic on carers. The first results show that the corona crisis has nothing but intensified the challenges faced by carers across

the EU: there are more carers, providing more care and more intense care. Carers also feel more isolated.

A coordinated holistic European initiative to address all dimensions of care and caring is required. This is why Eurocarers produced a new Strategy on carers 3 years ago. This outlines the 10 steps that should be taken to develop a carer-friendly society (<https://eurocarers.org/strategy/>). While the Strategy mainly focuses on care it also addresses taxes, pensions, employment and other areas that have a bearing on carers. The question of enabling choice is essential: becoming a carer should remain a choice for everybody.

Eurocarers also keeps an eye on national/regional policy developments with an impact on carers; and there are lots of promising trends. It seems that an increasing number of policy makers is waking up to the idea of supporting carers. However, it is complicated to strike a balance between access to good quality professional care and reliance on informal care. Stecy Yghemonos shared a detailed overview of the state of play at Member State level (LINK) and provided some good practice examples, such as new legislation in Germany addressing work/life balance, the Carers Statute in Portugal and a new carers strategy in Sweden. While support measures in place may differ, it looks like countries are pursuing similar goals. This is what we need at EU level: Member States working towards the same objectives - on both formal and informal long-term care - coordinated and fostered at EU level.

All the pieces of the puzzle seem to be on the table for an overarching and ambitious EU level initiative on care and caring: The Green Paper on Ageing, the Work/Life Balance Directive, the upcoming SPC report, last year's Ageing Report, the Gender Equality Strategy, the Beating Cancer Plan, the UN Convention on Human Rights for People with Disabilities, and EU action on the digital transformation of health and care. All of these recognise and call for more support for informal carers; the basic elements are already in place but need to be connected.

**Claire Champeix** stated that the process of defining the Pillar's Action Plan created high expectations amongst carers. In this respect, the Work/Life Balance aspect is crucial. The WLB Directive adopted in 2019 could be seen as a break through, since it was the first time that carers were recognised and addressed in a legislative instrument. However, when taking a more critical look it has become apparent that many countries already complied – so the 'new measures' for carers were not as new as they looked. Entitlements are too often provided at a minimal level. A narrow-focused notion of informal care (i.e., based on type condition, severity etc.) is being used, with strict eligibility criteria applying. In many cases carers are reliant on the approval or discretion of employers. In other words, while the Directive was a very welcome initiative, the discussion on proper work/life balance measures should be considered an unfinished journey.

Claire Champeix underlined that Work/life Balance is just one of the many areas where the Pillar can make a difference for carers; in its submission to the consultation on the Pillar, Eurocarers underlined that it can also address the need to approach young carers as a group at risk; to extend carers rights to training and lifelong learning, ensure adequate income for carers, make the case for pension credits

for carer as well as support activities for an ambitious EU initiative on long-term care. Given the number of policy areas concerned and the complexity of these, a well-balanced policy mix is required.

The Eurocarers submission provides a detailed overview of the issues at stake and the positive initiatives already taken for each of these areas (at local, regional, national and EU level); and Claire Champeix urged MEPs to use this as a checklist during the upcoming discussions on the Pillar and its Action Plan.

There are many other areas where the EU is having an impact on carers (e.g., such as transportability of rights, the coordination of social security). Therefore, a coordinated approach is needed, making use of existing activities and policy programmes, such as the Semester Process and EU financing mechanisms.

**Marisa Matias MEP** then invited the panel to speak, addressing what they would see as crucial steps towards the development of an EU strategy on long-term care as well as their particular priorities.

**Jiri Horecky (President, European Ageing Network)** stated that one of main goals of his organisation is to advocate for access to and affordability of long-term care; the organisation's vision (<https://www.ean.care/en/articles/long-term-care-2030>) reflects this, along with a set of 'policy pointers'. EAN focuses on three main pillars of activity, i.e.

- Informal care: the biggest pillar yet there is a lack of support for informal carers
- Community based care: this is the most important pillar of formal care; yet, in some countries this is not sufficiently developed
- Residential care: this is the smallest pillar, especially for older people with dementia and/or where care cannot be provided by other means

The future challenges that are often mentioned when talking about long-term care are already being faced, i.e., limited human resources, understaffing, qualifications issues and the competences of caregivers. Other challenges relate to ensuring the appropriate usage of new technologies and preparation for active ageing. Many strategies are declarations already exist in relation to active ageing; however, few of these have resulted in real actions and funding.

A redefinition of social policies at all levels is required; it must be clear who pays for what and who is competent and responsible (state, regions, municipalities, care receivers, family members). Moreover, efforts must be sustained.

National governments are responsible for the design of long-term care services and systems; however, those that work 'on the ground' in long-term care can and should play a role in initiating change and progress – we owe that to formal and informal carers as well as to those in need of care. The existing EU mechanisms and programmes – such as the Semester and Structural Funds – need to be put to use, to enhance working conditions for staff, to raise attractiveness of the sector and initiating strategic initiatives that will guarantee sustainable long-term care policies for the future.



**Borja Arrue (Policy & Project Officer, AGE Platform Europe)** stated that long-term care is a priority theme for his organisation and welcomed the push towards EU level action, making use of the current momentum. The long-term care challenges have been there for a long-time – they are not new. Many relevant EU initiatives, as listed by Stecy Yghemonos, are already on the table; these need to be brought together to set a new level of ambition for policies and services. It is not just about facilitating access to care. It is also about services and policies that can help materialise ambitious policy goals in terms of human rights of those in need of care. It is about social participation and equality.

AGE Platform Europe asks for common access and quality indicators; not only in terms of numbers and statistics but also through qualitative approaches, capturing the experiences of people in need of care. When addressing sustainability, the cost of long-term care as opposed to the cost of not having long-term care (in terms of lower employment rates among women, poverty and social exclusion, increased acute healthcare costs, etc.) also needs to be part of the equation.

A Care Strategy could be helpful. AGE, in its submission to the consultation on the Pillar of Social Rights, asks for legislative action. This may not be possible in all areas connected with long-term care - but there may be possibilities in some, such as market regulation. Whatever form it takes, a sustained EU commitment and monitoring is needed to implement the existing and upcoming EU tools on long-term care. This should include integrating long-term care in the European Semester and the Recovery and Resilience Plans.

AGE urges the European Parliament to push the Commission and the Council to be more ambitious in the field of long-term care. The organisation is currently working on an initiative with ESPU and EDF, to ensure that there will be an investigation on what went wrong during the COVID-19 crisis in care. Some 90 MEP are already supporting this. AGE also commits to build the capacity of its members to support the implementation of the Action Plan of the Pillar at local, regional and national levels. In addition, combining the Pillar's Art17 (addressing disability) with Art18 on LTC would make sense; the silos between ageing and disability should be broken down so that learning from each other's experience and advances, and addressing the needs and realities of older people with disabilities, becomes possible.

**Paola Panzeri (Policy Staff, EPSU)** explained that her organisation represents 8 million workers. Health, social services and gender equality are important themes.

EPSU covers providers of public services but also the non-profit sector and companies, and advocates the rights of care workers. For instance, EPSU is working hard to ensure the transposition of the Work/Life Balance Directive into national legislation. This Directive is not the final solution; it was an important step forward but it only goes part of the way to creating proper working conditions.

The ultimate aim would be to have available, accessible, affordable, high quality services to enable people to cope. Investment in services and in staff for those services is required as a matter of urgency.



Trade unions are the natural allies for families, service users and informal carers as they are working hand in hand to ensure support services that have high quality, wherever they are provided. High quality services can be provided if staff is well prepared and trained – staff that has enough time to care. Fair wages should be guaranteed. The pandemic has exposed some of these issues – they were there before but now they are more visible than ever.

Recruitment and retention are another issue. Social dialogue is important at all levels, with social partners working together for social justice. Public employment services need to be involved.

Paola Panzeri also underlined the need for validation of the skills of carers; re-entry into the labour market is an important issue, with people being enabled to choose the direction in which they want to go – back to their former job or doing something different.

**Luk Zelderloo (Director, EASPD)** outlined 6 points which should be part of an ambitious and overarching EU Care Strategy.

First, the *focus should be on those supported*. Long-term care should be person-centred, both for carers as well as for the receivers of care. Policies often focus on statistics, the institutions – on the receivers 'caring machinery'. However, it should be on the people - most care is provided by partners, families and parents rather than by professionals or institutions.

Second, care should be provided in the *natural environment* of those who need care whenever possible – it is essential to respect the choice and preference of the person cared for.

Third, the COVID-19 pandemic made clear that *social care is not seen as essential*. This is a grave mistake. Structural investments are needed in this sector, making up for the under-investment that has gone on for over a decade. We have to invest in staff and in informal carers, not just in public services. Not-for-profit providers play a major role. The second lesson coming out of the pandemic is the *huge potential of digitalisation*. However, in order for this to work, the digital divide needs to be bridged, ensuring that all can benefit.

Fourth, *co-production* should be the norm for services provision and system development, e.g., all relevant stakeholders co-creating the systems. The EU should invest in development of co-production mechanism and approaches as research shows that co-created services are more effective, less expensive and more sustainable than top-down system development.

Fifth, *public procurement practice should be reviewed*. Generally, these systems are rigid, do not follow changing needs and can have a damaging effect on working conditions. Other ways to support services and systems should be explored, e.g., personalised budgets.

Sixth, *flexible solutions* need to be promoted, facilitating 'hybrid' care models, developed by professional care staff working with carers and their (empowered) cared for. There is no place anymore for total institutions taking over the life of individuals.

If we want a social Europe, resilient and ready for the next pandemic, a good part of the Recovery and Resilience Facility should be spent on developing a higher quality of support services - and that includes investment in informal carers.

### Discussion

The following issues were raised:

- The Portuguese informal Carers Statute is a welcome initiative but its implementation needs to be stepped up as only 1% of the available budget has been used so far.
- Carers should be recognised as a priority group for vaccination.
- More and better data are required in relation to carers – much is unknown about who they are and how many. EUFAMI informed the meeting of a recent LSE study on the value of informal care in mental health care. The study will be presented in a webinar organised on March 9 webinar.
- In order to get better data, questions regarding carers could be added to the national census in all Member States.
- It would be useful to talk more about home care than about community care as carers get lost when the focus is on the community. Home care would require formal recognition, like nursing home care, with the accompanying appropriate levels of acknowledgement and support services. As it stands, carers providing care at home to people with high dependency level often find themselves in a position of exploitation and isolation.
- Many people who are caring do not self-identify as carers, in particular in mental health and cancer care.
- Lessons need to be learnt from the first wave of the pandemic about what went wrong in nursing homes in order to better plan and organise our care in the future. Could the lesson be that we may have over-used institutional care and the better develop community care needs to be developed?
- Recognition of the skills of informal carers is needed.

### Conclusions

**Luke Ming Flanagan MEP** underlined the importance of the Informal Carers Interest Group as most care is indeed provided by informal carers, at home. This is where most people want to be cared for and therefore, systems need to cater for that and enable carers to care.

**Marisa Matias MEP** stated that the meeting generated a lot of very important information; it will be required to assess it all in order to decide how to best move ahead. It is clear that there is a momentum for action at EU and national levels and that there are a number of existing 'hooks' that will need to be incorporated in our work ahead, such as the Social Pillar, the European Semester Process and the Social Scoreboard.

She also underlined the importance of the fact that many carers do not identify themselves as carers. A proper map of carers is needed to ensure that carers indeed make use of their entitlements and support.

**Sirpa Pietikäinen MEP** thanked co-chairs, colleagues' speakers and participants for the interesting meeting, which has underscored the fact that formal and informal care are not enemies – they complement each other and they both need to be improved. While looking at the different care models for the future, special account needs to be taken of the special needs of informal carers.

She called on participants to continue the cooperation and push forward the idea of a European Care Strategy, with a separate strand on the role and needs of informal carers and invited Eurocarers to explore this possibility.