



## European Parliament Informal Carers Interest Group



# *EU Work/life balance initiative and the European Pillar of Social Rights – time for a comprehensive EU Carers' Strategy*

**21 November 2018  
Report**

**Julie Ward MEP** opened the meeting, and reminded those present of the mission of the Informal Carers Interest Group i.e. 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.*

She underlined the importance of carers and the need to secure more political attention to their needs and situation, as carers are critical in the provision of care across the EU. They should be seen as the backbone of care provision, and their issues relate to a range of policy domains, including social protection, gender equality and youth policy.

Julie Ward MEP welcomed the topic of the meeting, i.e. to link the current discussions surrounding the draft Work/Life Balance Directive and the European Pillar of Social Rights to the specific needs and rights of carers. These policy developments have provided a concrete impetus for a renewed EU-level Carers Strategy.

She recalled that Eurocarers and the Informal Carers Interest Group developed and launched a draft Carers Strategy some 5 years ago. While this did attract attention and was endorsed by a number of key EU-level stakeholders, overall political support for the initiative was lacking at that time. With the adoption of the Social Pillar and the related ongoing debates on work/life balance, it is felt that both the time and political situation is now right to further explore the feasibility of such a much-needed Strategy. Not only does the Pillar directly and specifically refer to the right to health and long-term care, many other rights listed also have a bearing on the lives and quality of life of carers and those cared for. In other words, the Pillar seems to provide the perfect background and impetus for an even more and ambitious and politically realistic Call to Action. The Pillar provides the right political momentum which needs to be capitalised upon and Eurocarers has done well for seizing this moment.

Julie Ward then gave the floor to the first speaker, **Ana Carla Pereira (European Commission, DG EMPL)**, who informed participants of some of the main elements relating to the current Commission discussions in the area of long-term care. First of all, while it is a useful step forward to have a European Pillar of Social Rights on paper, this should now be turned into reality. While Principle 18 of the Pillar explicitly states that *'everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services'*, it will take time, efforts and resources to turn this principle into a reality.



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With respect to long term care, the Commission has identified 4 main challenges:

- In relation to access and equity, the Commission's main message relates to ensuring that there is systemic and professional care on offer for those that need it. As this is by no means the case across the EU, the main burden of care falls onto informal carers. Research (Eurostat, 2016) has pointed out that 15% of older people – the growing societal group most in need of care – are at risk of poverty and have difficulties to meet their needs. This obviously has an impact on access to care and services. Other research, carried out by Eurofound (2016), has shown that 30% of the total population have substantial to moderate problems to pay for care and support services. The trend in some countries towards privatisation of services is also pushing up costs.
- In terms of sustainability, projections show that countries with a stronger tradition in providing a public services offer of long-term care spend more money in this area. Until 2070, the costs for long term care will go up – in some countries the figures will almost double. These costs projections only tell one part of the story; informal care and its burden on are not included in these figures. With the growing number of older people in need of care, countries will be increasingly challenged to sustain the care offers that exist. In this context, Ana Carla Pereira referred to a 'little tsunami' that we need to be prepared for. Over the last 15 years the policy focus has been on pensions; long term care was almost viewed as its 'poor little brother'. However, given the growing need for care, similar attention should be paid to long term care. When that stage is reached, the policy focus should not only be on sustainability; access and quality are also important. All these challenges should be addressed in parallel.
- With respect to quality, there are challenges relating to the definition of what quality could entail, beyond ensuring personal dignity and minimizing the need for long term care. Moreover, quality standards vary across the EU; and quality is difficult to measure.
- And finally, regarding employment, work/life balance aspects come into play. We need to make sure that women are part of the labour market and that they are enabled to combine their various roles (care and work) in a comfortable and appropriate manner. It is a well-known fact that women have lower incomes and pensions, and care responsibilities play a large part in this difference.

The proposed Work/Life Balance directive is for the first time taking account of care responsibilities, and includes a proposal for 5 days annual Carers Leave. The Commission is of course aware of the fact that 5 days is very little. The proposal should be seen as an initial signal of the need for more recognition and more attention. It is a signal of commitment in a difficult political reality; those 5 days are contested by a number of countries. There are other aspects in the area of employment which impact on carers, such as precarious working conditions and short-term contracts. Also, the working conditions for formal carers need to be improved and the care professions should be recognised and valued. Issues relating to informal carers becoming formal carers are also relevant – how can skills developed as an informal carer be validated?

The complexity and diversity of long-term care provision across the EU also needs to be borne in mind as it makes the discussion very difficult. The Commission is not yet capable of systematising a robust analysis of the situation across the EU. More data is needed to clarify the issues; a recent study, commissioned to European Social Policy Network clarifies some of the issues and analyses the systems in each of the member states. One of the big shortcomings is the lack of comparable data; this is an impairment for policy dialogue.

In conclusion, Ana Carla referred to an upcoming Social Innovation Call, inviting actors looking into the issues of long-term care to come forward with projects and ideas that could be scaled up at national level.



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The next speaker, **David Casa MEP**, informed the audience of the state of play regarding the Parliament report on the Work/life Balance Directive, of which is Rapporteur. He agreed with previous speakers that the Social Pillar is a step in the right direction; it puts social policy where it belongs – i.e. at the very top of the EU agenda – aiming to ensure that the EU is the best place to live, invest and work, promoting equality between men and women, modernising the EU social policy framework and take account of labour market needs.

The Work/Life Balance Directive is a welcome attempt on the side of the Commission to implement a part of the Social Pillar.

Mr. Casa MEP then underlined the importance of informal care as it relieves member states of the care burden; on the other hand, it deprives the state of taxes, as many carers are not managing to combine work and care – and need to reduce working hours or drop out of the labour market altogether. There is a clear need for action in this domain, and aiming to create a better work/life balance and better work opportunities is a first step in the right direction.

The Work/Life Balance Directive proposal is ambitious. As a Rapporteur, David Casa underlined that he has a difficult job to achieve a balance between economic priorities and actions directly benefiting citizens. There is a need to find a common ground and reach this double objective.

Mr. Casa MEP then reminded the audience of the key points of the proposal which addresses paternity leave, parental leave and carers leave as well as the right to flexible working arrangements. With respect to carers, the proposal stipulates a specific Carers Leave of 5 days.

The European Parliament's EMPL Committee has adopted Mr. Casa's report, providing him with a clear mandate to negotiate; various Trilogues have indeed taken place already. The process is steadily moving in the right direction, with a possible Interinstitutional Agreement in place before the May European elections.

Mr. Casa MEP underlined that the Parliament's demands are reasonable; however, what is being proposed may not be possible to implement. However, MEPs do not wish to lower their ambitions as EU citizens expect the Parliament to act on their behalf, both in terms of leave duration as well as in terms of remuneration. But it is already becoming very clear that a significant number of Member States are reluctant when it comes to discussing and agreeing remuneration, and this particularly holds true in the area of the Carers Leave. Some

Member States have good systems in place; however, the focus mostly is on the person needing care rather than on the person providing it. There is a reluctance to change systems that work. Nevertheless, the time is right to discuss a comprehensive Carers Strategy, covering all the aspects and areas.

In conclusion, David Casa MEP emphasised the work that will be required to implement the Social Pillar. We have to be fair about this and not mislead citizens. He expressed his commitment to ensure that the issues that can be addressed will indeed be addressed, to ensure that the objectives of the Work/life Balance proposal will become a reality. For him, the Carers Leave is a red line and agreement with the Council must be found.

The next speaker was **Stecy Yghemonos (Eurocarers)**, who introduced Eurocarers' a proposal for a new EU Carers Strategy, triggered by the new political reality offered by the Social Pillar. As background to the Strategy he underlined the growing incidence of age-related conditions due to demographic ageing, leading



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to an increasing demand for care. According to research, informal carers provide over 80% of all care in Europe. The economic value of unpaid informal care in the EU - as a percentage of the overall cost of formal Long-Term Care provision – is estimated to range from 50 to 90 %. Carers clearly will be essential to meet the challenges posed by ageing societies. However, free choice and personal autonomy should remain at the core of any initiative focusing on them.

The Strategy comprises 10 main steps identified by the Eurocarers network in order to implement a carer-friendly policy environment. It seeks to recognise, support and empower informal carers across Europe in a comprehensive and coherent manner; in addition, it is designed to help policy makers (as well as other stakeholders who have a bearing on the lives of carers) acting at EU, national and regional level to consolidate existing approaches and to inspire new initiatives in favour of carers' rights. The 10 steps are closely interconnected and are in line with a vision of care which:

- Adopts individuals', carers', families' and communities' perspectives as participants in, and beneficiaries of, trusted care systems organised around their needs and preferences;
- Respects and supports people's right to choose freely whether they want to be a carer, and to what extent they want to be involved in caring;
- Recognises and values carers as equal partners in care;
- Supports and empowers carers to manage their caring responsibilities with confidence and in good health and to have a life of their own outside of caring; and
- Seeks to prevent situation where carers are disadvantaged, or discriminated against, by virtue of being a carer.

Stecy Yghemonos then briefly introduced the Strategy's 10 Steps, i.e.

**Step 1 - Define and Acknowledge Carers:** focus on the need for an agreed definition of carers which can drive the implementation of systematic and proactive approaches to consolidate and flesh out carers' existing legal rights and set out principles for carer support.

**Step 2 - Identify Carers:** focus on raising awareness about informal care and to collect data about carers (e.g. national census, surveys) and on putting in place measures to inform care professionals about informal care and the need to support carers.

**Step 3 - Assess the needs of Carers:** focus on development, uptake and quality of carers assessments tools to personalise carers' support plans and the need to identify and involve carers' organisations in the design, implementation and evaluation of these tools.

**Step 4 - Support multisectoral care partnerships for integrated and community-based care services:** focus on establishment of partnerships to ensure that care services respond to the needs of the community effectively and holistically.

**Step 5 - Facilitate carers' access to information and advice about care, caring and care-life balance** focus on development of one-stop shops for carers to access information about care, caring and the support measures, including ICT tools.

**Step 6 - Pay attention to carers' health and prevent negative health outcomes:** focus on informing healthcare professionals about the health risks of informal care, on health promotion, counselling and training of carers to prevent negative health outcomes and on access to emotional support.

**Step 7 - Give Carers a break:** focus on the need for respite measures (e.g. financial support for breaks, accessible respite services), implemented by the local level.

**Step 8 – Provide Carers with access to training and recognise their skills:** focus on strengthening carers' skills to improve the quality of their care and to maximise the opportunities to maintain an active professional life; also, on certification and validation of carer competences to value their skills and facilitate their (re-)entry and attachment to the labour market.



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**Step 9 - Prevent Carers' poverty and allow them to maintain an active professional/educational life;** focus on the need to invest in high quality, affordable and accessible formal long-term care services, on financial support to carers, on carer-friendly employment and on the need to identify and address the needs of young carers.

**Step 10 - Adopt the Carers' perspective in all relevant policies**

### Panel response

As the first panelist, **Marian Harkin MEP** welcomed Ana Carla Pereira's frank statement regarding the need to put flesh on the bones of the Social Pillar. The Commission has done much work on pensions and it is hoped that there will be similar political attention for long term care. The consequences of demographic change are well known by now; Member States are well aware of the challenges. Long-term care provision is one of those and that political discussion needs to be launched in earnest.

The Social Pillar is a wonderful document - but it now needs to be brought to life. The Work/Life Balance Directive is one of the actions that aims to do so. Not everything in the proposal is relevant for carers but the Carers Leave is of real value. Also, a recent European Parliament report on transparent and predictable working conditions is very important for carers. However, as already flagged by David Casa MEP, the battle in Council is fierce as many countries are not in favour of the Carers Leave as proposed. She underlined that it is not only up to the Parliament to fight this battle, even if we have a strong Rapporteur and even if the Carers Leave is the Parliament's red line. More importantly, organisations present have a responsibility to tackle their MEPs and MPs, their relevant ministers and policy makers and national level and advocate for change.

As far as the Strategy proposed by Eurocarers is concerned, this contains many excellent thoughts and ideas. One of the notions could be strengthened is the need to address the relationship between carers and health professionals. This is not always easy as many carers are left standing on the periphery. While the needs of the cared for person are of course very important, carers and their rights and needs also must also be brought into the process. This is becoming more and more obvious as hospital stays are getting increasingly shorter; the home care situation therefore needs to cater for more complex care needs (for which they often are not trained), causing an increasing burden.

The second panellist, **Margaret Walker (EUFAMI)** briefly introduced her organisation, which aims to represent all family members of persons affected by severe mental ill health at European level so that their rights and interests are recognised and protected. EUFAMI's main focus is on schizophrenia, bipolar disorder and major depressive disorders. Research has shown that most informal carers in the area of mental health are older and provide care for 15 years or more.

EUFAMI has followed the debates surrounding the Work/Life Balance Directive and Social Pillar with great interest; both initiatives are highly relevant for carers. The challenge now is to make the best use possible of these initiatives and analyse what they can bring us and how we can move them forward.

One of EUFAMI's main priorities relates to the need to put appropriate and accessible services in place, as caring should be a choice – not an obligation. In addition, the financial security of older carers needs to be ensured. Caring involves costs, especially when caring for persons affected by severe mental health conditions as in many cases there are further complications such as addiction. Families therefore may have to pay debts or have to bail out the person they care for. Apart from these direct costs, there are pension gaps, with women being disproportionately affected: in many cases they decrease paid work or leave their jobs altogether in order to be able to provide care. A holistic approach to social protection, pensions and long-term care is required; mental health should be on the same par as physical health.



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EUFAMI hopes that the Carers' Leave will be retained in the proposal as it is a useful starting point; this can be achieved in the short term and will support longer-term goals. In order to get to those longer-term goals,

work should be done by organisations around the table to support statistics and data provision, for instance on the numbers of carers and the economic aspects of caring (e.g. huge government savings thanks to the vital work of carers).

EUFAMI welcomes the idea of a comprehensive Carers Strategy and will work with Eurocarers to support its dissemination and implementation. In conclusion, Margaret Walker warmly thanked the MEPs for their ongoing support.

The third panellist, **Penny Clarke (EPSU)** stated that EPSU supports a universal, rights-based approach giving equal weight to the quality of jobs/working and pay conditions as to the quality of the service provision. Financing, regulation and control needs to be incorporated into the design of adequate policies. Formal and informal care are complementary to each other. The EU has the necessary legal framework to support quality formal and informal care for all (Article. 14 of the Treaty, the Protocol on Social Services of General Interest, European Pillar of Social Rights principles...). A dedicated European Parliament Intergroup on the implementation of the European Pillar of Social Rights could be a useful future platform.

The EU also supports social dialogue, which is vital in ensuring quality of care and employment. Quality of work, decent pay and working conditions, and training for all workers is important.

However, the right to care (i.e. to be able to care for others as well as be cared for) needs to be implemented in practice. In some Member States the situation is much better than in others, largely due to better welfare policies, greater public investment, more equality and a stronger social dialogue. The EU should support all Member States to move towards solid welfare models. In relation to long-term care, the recommendations from the recent joint report from the Commission and Member States have not been properly followed-up: much could be done with the recommendation stating that there are "*equity and efficiency reasons*" for Member States to integrate long term care needs into their social protection systems.

Gender equality and WLB policies play a role. Working time and work organisation, care leaves, and care services should be addressed together. The ETUC *Time to Care* report provides a good overview. EPSU, together with ETUI, published a relevant report entitled "She works hard for the money - tackling low pay in sectors dominated by women."

Penny Clarke also emphasized the need for the EU's and member states' economic and fiscal policies to support sustainable public financing of care and other public service services. Economic policies need to give more weight to well-being and sustainable development; marketisation and commercialisation of public services does not improve the objective of securing quality of care for all.

The final panellist, **Sirpa Pietikäinen MEP** (European Alzheimer's Alliance) referred to a report adopted in the European Parliament last week, entitled 'Care services for improved gender equality'. This is the first European Parliament report demanding a specific European carers' Programme.

Providing informal care is not always easy and brings along many challenges and choices.



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As informal as well as formal carers are usually women, care provision can be viewed as a gender issue. These carers are underpaid, underserved and under supported and this topic needs to be moved higher on the political agenda as it is linked to discrimination.

Sirpa Pietikäinen MEP warmly welcomed Eurocarers' proposed Carers' Strategy and underlined that there is an actual possibility to push it through; the European Parliament would be supportive and the Work/Life Balance proposal provides a concrete policy 'entry point'. The Finnish Presidency could also play a role as this coincides with the installation of a new Commission and a new work 5-year programme for the EU. The Finnish Presidency could push for recognition of carers issues and the need for action, following the model of the French Presidency several years ago; this committed itself to ensure comprehensive EU-level action on Alzheimer's Disease. This is now in place and the national programmes which have been established as a result are particularly positive, as many decisions on services and resources are a national competency rather than an EU one.

However, like Marian Harkin MEP, Sirpa Pietikäinen MEP underlined the importance of advocacy and influencing at the national level.

The next Parliament will also need to be prompted and stimulated to work on this; it might be useful to ask the various factions' Spitzenkandidat' as well as all the candidate MEPs questions on his/her views on carers and their potential support for EU-level action.

It would also be important to bear in mind the needs of the different groups of carers, e.g. young carers and those that care for persons affected by mental ill health.

### Close

**Sari Tervonen (Eurocarers)** thanked the MEPs for their continued support and for hosting this important meeting. Informal care is a political issue. We need to think about our values and how societal systems can take account of these values. It is very clear that we need to work hard at every level – local, regional, national and European – if we are to effectuate change. Next year's election provides a useful opportunity to do that.

**Julie Ward MEP** closed the meeting, underlining the importance of ensuring support for carers and her willingness to cooperate with those that are active in this area.