



## Meeting of the European Parliament Interest Group on Carers

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Brussels, 20 October 2015

### Meeting report

**Marian Harkin MEP** opened the meeting with a special welcome to the visiting Irish carers group. She briefly introduced the Interest Group as a forum for debate and policy action taking initiatives that can lead to/influence EU policy initiatives. Marian Harkin also reminded participants of the objectives of the meeting, i.e. inform participants of the European Semester Process and its current focus on health and long term care and discuss how this Process could have a stronger focus on carers.

She stated that long term care is increasingly becoming an important issue on the Member States' health and social policy agendas. While the EU cannot legislate in this area, it can facilitate discussion and exchange of good practice and experience and the area of long term care seems to lend itself well for this type of informal cooperation. The Semester, with its country-specific policy recommendations, is potentially a strong tool to help member States reform health and long term care systems, and is therefore highly relevant for carers.

The first speaker, **Christoph Schwierz (European Commission, DG ECFIN)** provided an overview of the background of the European Semester and the work done in the field of health and long term care. He explained that the European Semester is a cycle of economic and fiscal policy coordination within the EU. It is part of the European Union's economic governance framework. Its focus is on the 6-month period from the beginning of each year, hence its name - the 'Semester'.

During the European Semester the Member States align their budgetary and economic policies with the objectives agreed at EU level. Member States come forward with their economic plans, which are then analysed by the Commission (and a number of experts); on the basis of this analysis, the Commission issues country-specific recommendations for action. The Semester basically addresses all policy fields, and therefore, it is a complex process involving many of the Commission's Directorates-General. The Semester also addresses the fiscal sustainability challenges in relation to pensions, health care and long term care policies, as expenditure in these areas are growing and is projected to grow – mostly in the area of long term care. The European Semester was 'streamlined' recently, which means that there is room for more feedback on the Commission analysis of the country reports.

Underlining the recognised political relevance of addressing health and long term care systems in the European Semester, Christoph Schwierz recalled the May 2012 Council conclusions on the sustainability of public finances in light of ageing populations.

Country-specific recommendations in the field of health and long term care are developed on the basis of the Commission assessment of the Member States' proposed reform plans, supported by expert advice, peer reviews of health system performance and in-depth sessions with external experts. Discussions are held with the Member States in various committees, such as the Social Protection Committee. It also needs to be borne in mind that European Semester offices exist in all Member States; these can be contacted by interested stakeholders in order to make sure Member States address the right priorities in their proposals to the Commission.

In 2014, 16 countries received a country-specific recommendation in the field of pension, 16 in health care and 6 in long-term care. Carers do specifically feature in some of the country reports (5). Better data on carers and informal care are needed as these are currently not being collected in a standardised way.

In terms of implementation of the recommendations, progress was highest in long-term care, closely followed by health care. Examples of recommendations were provided for 5 countries, showing the variation between Member States in terms of system as well as progress in these fields.

In conclusion, Christoph Schwierz stated that the European Semester is a powerful tool to address Member States' main policy challenges. It gives the Commission the possibility to advise Member States on many areas which are usually within national competence - including health and long term care.

Adding to Christoph Schwierz's presentation **Marian Harkin MEP** listed the 6 country-specific recommendations for Ireland, which included one on the need to increase cost effectiveness of the health care systems and the need to cut pharmaceutical spending.

She then gave the floor to the second speaker, **Stecy Yghemonos (Director Eurocarers)**, who briefly introduced Eurocarers as the organisation promoting recognition of the role and added value of carers at EU level and ensuring that informal carers are part of the EU and national political agenda.

Eurocarers has a strong interest in the Semester, as the demand for care is increasing, putting pressure on health and long term care systems. Action needs to be taken as - with fewer people contributing to social protection systems while demand is growing - systems will not be sustainable. In many cases, this action merely consists of budget cuts and short term approaches.

Innovative approaches are required and in this context Stecy Yghemonos outlined three possible future health systems scenarios:

- *Health incorporated systems*, with governments liberalising the markets and corporations providing new products and services, and innovation being driven by patients and carers
- *New social contract systems*, with governments being the driving force for efficient health systems and with explicit targets for healthy lifestyles
- *Systems driven by empowered individuals*, leading to increasing demand in ICT solutions and diagnostic equipment, sharing health data and a booming market for healthy living.

The best scenario probably lies somewhere in the middle, with a focus on patient centred community based care services as well as on ensuring equity and access for all.

The European Semester process offers a number of entry points for carers and their issues, and one of these is the fact that the Commission urges Member States to consult with stakeholders. This means that carers' organisations can have an impact on the priority setting of their countries. Unfortunately, the consultation does not happen in practice yet - information on how to feed into the process is difficult to obtain. On the positive side, however, Eurocarers has a strong link with the Commission's Directorate General for Employment and Social Policies (through its EaSI partnership) and this ensures the possibility of direct dialogue about the challenges related to health and long term care services. The organisation could therefore be helpful to help carers associations to find the Semester's entry points and shape the messaging in order to ensure appropriate attention for carers as part of health and long term care systems.

### **Panel discussion**

The first speaker was **Philippe Seidel (AGE Platform Europe)**, who briefly introduced his organisation as a European platform of older people working on all policies that concern them. As regards the European Semester, AGE Platform Europe has followed this process from the start and tries to influence the agenda setting as well as mobilise its members to act with their national Semester contact points and governments. The organisation also produces position statements on the content of the country-specific recommendations.

The background of the Semester lies within the Europe 2020 strategy. One of the objectives of the latter is to increase employment to 75 %, which means a focus on older workers and women. In many cases, informal care is provided done by older women (55+), who are not in paid employment (in some countries only one in three women between 55 and 65 is working). This is a huge loss to the labour market and society as a whole. There is a need to invest in formal care provision and facilities to support carers as well as needs to change working time regulations to ensure carers can work in order to contribute to the labour market and maintain their social protection rights later in life.

Philippe Seidel underlined that older women and informal carers need support. Age discrimination in the labour market needs to be addressed; there needs to be flexibility in working time and recognition of the contribution of carers. There should be services to support carers and possibilities for respite care. AGE Platform Europe is advocating for a Carers Leave Directive, which would stipulate that carers maintain their social security rights when they need to take a career break in order to care for a loved one.

As regards the Semester, in some countries the country-specific recommendations address the need for facilities relating to dependency, in most others on cost effectiveness. In many cases, cost-effectiveness measures consists of cuts in expenditure, which run counter the objective to increase employment. The overall impact of the Semester on carers seems therefore to be negative.

The second speaker, **Luk Zelderloo (European Association of Service Providers to People with Disabilities)** briefly introduced his organisation, which represents some 11.000 organisations across Europe.

The workforce in the area of disability is under pressure; the demand for services is increasing, waiting lists are longer waiting lists and family structures are changing. Women constitute 85 percent of this workforce, and despite high unemployment rates, there shortages of staff are common. The low salaries in this sector are a negative factor in attracting people.

The Semester's country-specific recommendations do have an impact on the care provision sector, so EASPD has produced reports and positions statements, looking closely at the individual country reports. Building capacity at national level is also a priority, as stakeholders can work to fine-tune national policies. Luk Zelderloo underlined that the Semester process is not so complicated and quite easy to understand; however, it is complicated to ensure that civil society has an impact on the outcome.

Many of the county-specific recommendations have an impact on families and long term care. But they can be misleading: 'optimise public spending' usually means 'reducing costs' – and in the care provision sector, this cost-cutting relates to staff costs and reductions in services. It is also important to analyse the potential impact of recommendations that are not specifically targeting the social domain. For instance, recommendations on the need to open the market for social service provisions means in reality that working conditions will go downhill, people will leave and services will deteriorate. Moreover, when recommendations call for closure of care institutions and the development of society alternatives, the result in many cases is that the institutions are indeed closed but there are no alternatives. In other words, the recommendations can have unbalanced effects.

Luk Zelderloo concluded by emphasizing the importance of the European Semester as it has the potential to promote innovation and reform in long term care and social services. For instance, it can help to ensure a better coordination between formal and family care. If we want to ensure this happening we have to build capacity at national level. The Commission is open for input so we have make use of that opportunity.

The final speaker was **Paul de Raeve (European Federation of Nurses)** who spoke of the 3 million nurses providing high quality care across the EU. In order to have a highly qualified workforce, education and training are required. According to Paul de Raeve, the health workforce is a mess in the EU context, despite the Commission's Joint Action in this field. Yet, with an ageing society and increasing care demand, formal and informal care provision is key. Hospitals and community care providers should cooperate and strive towards integrated care. EHealth and ICT applications also hold great potential to improve care and support formal and informal care providers. EFN has developed 5 guidelines for eHealth, which will be launched in the European Parliament and promoted at Member State level as well.

As far as the Semester is concerned, social care workers, nurses and carers should address the national Semester contact points to make their voices heard and their issues known.

## **Discussion**

Before opening the discussion Marian Harkin MEP gave the floor to **Luke Ming Flanagan MEP** and **John Dunne** (President of Eurocarers). Luk Ming Flanagan emphasised that Member States get value for money out of carers, and that carers provide a great service to the state. Carers and nurses cannot go on strike – they are assumed to have a special calling, which is sometimes used as a tool against them.

**John Dunne (President of Eurocarers, CEO of the Carers Association Ireland)** underlined the importance of the Semester, not least because it can be used as a way to make national government officials listen. This is a roundabout way of acting but it can help introduce change. He reminded the visiting Irish carers that, as far as carers and their issues are concerned, many of these issues are not

within the acting power of the Commission; national governments remain firmly in charge. He also referred to the Irish Carers Strategy which is a slow burning process which is producing results. Lastly, he announced that his organisation will be merged with Caring for Carers in to one organisation, i.e. Family Carers Ireland

In the discussion the following issues were raised:

- The importance of recognition and acknowledgement of the invaluable work and contribution of carers was underlined many times.
- Most carers and their organisations are surviving on charity work – without those charities carers would be lost. The only support carers get are from families, while carers contribute so much. In many cases carers are not qualified for the caring tasks they are expected to perform.
- Carers themselves have (mental) health needs and these need to be taken into account as well.
- When carers fall ill themselves, there is no alternative care or respite care available. Unfortunately, the European level cannot address this issue – it is within national competence.
- Carers are considered unemployed – but they cannot combine care and work responsibilities because of the way workplaces are structured.
- The Irish carers allowance is not easy to obtain and is very low. The system of obtaining them does not seem fair. The way it works needs to be changed.
- When disabled children turn 18, there seem to be no services available anymore. Children vs adult services are two different worlds – it seems like the government has forgotten that the person still has a disability. Another age barrier can be identified: persons over 65 with disability moving into long term care face similar problems. These age break lines and the lack of continuity of support systems need to be addressed.
- There seems to be little awareness of what the EU does and the semester seems an interesting entry point to influence and fine-tune policies. Action needs to be taken to keep pushing to increase awareness of what carers do and the contribution that they make.
- Prevention is a key concept in the area of both healthcare as well as long term care. If conditions can be prevented, carers might have to spend less time with those cared for. While the Semester seems to be about cost cutting and sustainability, it should have a stronger role in helping to put preventative measures in place. The negative impact of austerity on health care has been enormous, both for systems as well as for patients. Should the semester not actually prevent this from happening?
- Questions were asked as to why long term care seems to get less attention than health care. This should be rectified and stakeholders should make their voices heard.
- More information and clarity on clinical pathways would be useful, and prevention should become part and parcel of clinical pathways. Lots of information on the clinical pathways for certain conditions is already available and needs to be brought together.
- The examples of day-to-day barriers and issues faced by carers make clear that the current health and long term care systems are not ready for challenges ahead. The main challenge for the future is bringing support to the people rather than the reverse.
- Input in policy development from the grassroots level is crucial; policy makers should increase their capacity to listen in order to understand what is required. The European Commission is willing to listen and encourages input and we need to ensure that we organise ourselves and provide the right messages.
- Innovative, long term solutions are required but politicians want to see results in terms of cost-efficiency during their term of office. Cutting budgets is therefore the usual result.

- Many important EU level actions and policies were not mentioned, such as action on rare disorders and the related centres of expertise, the Cross border Directive, action on chronic disease. However, it was remarked that the EU organisations present are certainly working in all these areas as well.

Christine Marking, 22 October 2015