

Dear readers,

*Here we are with the fourth and last issue of 2014 of EuCaNews, the Newsletter of EUROCARERS (or EuCa), the European Association Working for Carers! The first section has been renamed “News from the Executive & the Secretariat” to take into account the contributions now coming from the recently established central office in Brussels, as witnessed by the presentations by our Director reporting the contents of two recent events on long-term-care. Christine Marking’s usual update on recent EU policy developments is complemented by a report on “Investing in Health” which provides a good overview of the approach taken by Member States regarding future health care in Europe. The “Carers in Action” section presents a contribution calling for a better definition and more precise use of the term “carer”, which is often improperly used to mean “family carer”. The section dedicated to research is opened by a summary of the main findings of the ELMI project, which last summer conducted qualitative research on elderly family carers of patients with dementia in Romania, aimed at collecting information on the availability of support services for them in this country. In the same section, you will find also a call for partners for a project on “Human Resource Strategies for Working Carers”, seeking to analyse the strategies adopted by companies to deal with their employees who are informal carers, as its coordinators would like to extend this study beyond the Belgian borders. Finally, the “In brief” section presents some short snippets of information about various issues, including a call for papers for the 6<sup>th</sup> International Carers Conference on 3-6 September 2015, which this year will be preceded by EUROCARERS’ Annual General Meeting (AGM).*

*Please keep in mind that **your feedback, comments and ideas for the Newsletter are important** to help us to improve it. So please do not hesitate to send us any contribution relating to your own organisation, experiences or relevant events, which you would like to disseminate to a larger audience interested in caregiving issues in Europe. Please try to keep your contributions as concise as possible (i.e. 1.500 words maximum).*

*A peaceful Christmas and a bright 2015 from*

**Giovanni Lamura**  
(INRCA, Italy  
e-mail: [g.lamura@inrca.it](mailto:g.lamura@inrca.it))

&

**Hilary Arksey**  
(freelance consultant;  
e-mail: [hilary.arksey@virgin.net](mailto:hilary.arksey@virgin.net))

## CONTENTS

	Page
<b>NEWS FROM THE EXECUTIVE COMMITTEE &amp; THE SECRETARIAT</b>	<b>3</b>
<b>Eurocarers co-organises workshop on adequate social protection for long-term care with European Commission and AGE Platform, by Stecy Yghemonos</b>	<b>3</b>
<b>Eurocarers takes part in Peer review seminar on long-term care – Dilemmas concerning sustainable financing, by Stecy Yghemonos</b>	<b>4</b>
<b>EU POLICY DEVELOPMENTS</b>	<b>5</b>
<b>Updates on recent EU policy developments, by Christine Marking</b>	<b>5</b>
<b>Investing in Health: The 'Missing Dimension' of the Europe 2020 Strategy for Smart, Sustainable and Inclusive Growth, by Stecy Yghemonos</b>	<b>6</b>
<b>CARERS IN ACTION</b>	<b>12</b>
<b>Family carers: definition and recognition, by Brigid Barron</b>	<b>12</b>
<b>RESEARCH ON THE MOVE</b>	<b>14</b>
<b>Elderly family carers in Romania, by Licia Boccaletti</b>	<b>14</b>
<b>A human resource strategy for an informal carer friendly working climate: call for partners</b>	<b>15</b>
<b>IN BRIEF</b>	<b>16</b>
<b>About EUROCARERS</b>	<b>17</b>

## NEWS FROM THE EXECUTIVE COMMITTEE & THE SECRETARIAT

*In this section of the Newsletter, we report the core issues discussed during the meetings (face-to-face or via teleconference) that take place periodically between the members of the EUROCARERS Executive Committee, as well as recent events and activities involving Eurocarers' Secretariat.*

### **Eurocarers co-organises workshop on adequate social protection for long-term care with European Commission and AGE Platform**

**By Stecy Yghemonos (Director of Eurocarers)**

On 20 November 2014, Eurocarers co-organised and took an active role in the workshop “Social protection for long-term care”, as part of the fourth annual convention of the EU Platform against poverty and social exclusion in Brussels. The poverty platform is a coordination tool moderated by the European Commission which brings together key actors of the fight against social inequalities (including Eurocarers). It aims to support Member States in the development and implementation of equitable and sustainable policies in the field of Social inclusion, Pensions, Health and Long-term Care (including the role of informal carers). Sebastian Fischer, Chief Executive of Voice of Carers Across Lothian (Scotland) and former Eurocarers board member, took part in the panel discussion on behalf of our organisation. Stecy Yghemonos was the rapporteur of the workshop to the EC report on the event. The annual Convention attracted more than 600 participants from the 28 Member States, including ministerial delegations.

As highlighted in the [Report on Adequate social protection for long-term care needs in an ageing society](#) produced by the Social Protection Committee and the Commission services, dependency on long-term care is a significant health-related economic and social risk for individuals and their families. Social care needs are not covered as comprehensively in social protection systems as the health care of people with long-term care needs. The primary responsibility for obtaining the required social care therefore often shifts to the dependent persons and their relatives. A lack of social protection (through benefits in cash or the provision of services) against the risk of dependency thus exposes many Europeans to an increased risk of poverty and social exclusion, and their number is likely to grow as Europe's population ages.



The workshop concluded that users and carers should have the opportunity to influence the content and the way health and social care services are provided to them. In addition, the process towards a holistic approach to long-term care should recognise the huge unpaid contribution of informal carers to users, the economy and society as a whole. Among other things, carers should be entitled to allowances, public health and pension insurances, training, advice

and respite care breaks. Structures should also be developed to make sure the interests of informal carers are promoted and defended in LTC systems.

For more information about this event, please visit the [EC website](#) or contact [Stecy Yghemonos](#).

### **Eurocarers takes part in Peer review seminar on long-term care – Dilemmas concerning sustainable financing**

#### **By Stecy Yghemonos (Director of Eurocarers)**

Within the preparations of the long-term care reform in Slovenia, the fiscal sustainability of the system in the context of demographic pressures is a crucial issue. Currently, there is indeed no uniform system of long-term care in the country. Different forms of services and benefits are provided within the health care, social and parental protection, pension and disability systems and the system of care for the disabled, and are regulated by different acts in these areas.

In order to exchange with other Member States and benefit from their experience and expertise, the Slovenian ministry of Labour, Family, Social Affairs and Equal Opportunities organised a peer review seminar on the 18-19 November in Ljubljana. Representatives from 12 Member States took part in the seminar. Eurocarers was also invited to contribute to the debate as a relevant stakeholder in the field and its executive Director, Stecy Yghemonos, presented the network's position based on members' contributions.

The Peer Review seminar provided a good overview of the Member States' Social Protection and Social Inclusion policies and of their impact on dependent persons and their relatives. It also demonstrated that although long-term care is an area in which diversity amongst member states is greatest, four main challenges consistently face national long-term care systems, i.e. a growing demand, declining supply of potential (professional and informal) carers, the quality as well as the financing challenges. The event provided a great opportunity to encourage member states to seek to realise a 'Carer Positive' community that enables carers to achieve a stable work-life balance and access health and income supports appropriate to the care they are providing. The points made on the added value of carers were very well received by the participants and Slovenia intends to include specific measures to support them in its new approach to long-term care.

For more information about this event, please contact [Stecy Yghemonos](#).

# EU POLICY DEVELOPMENTS

## Updates on recent EU policy developments

By Christine Marking (adviser to the Executive Board)

### New Commission takes office

The new European Commission took office on 1 November 2014. Most relevant new officials are:

- **Vytenis Andriukaitis**, Commissioner for Health and Food Safety;
- **Arunas Vinciunas**, Head of the Commissioner's Cabinet;
- **Paula Duarte Gaspar**, Cabinet Member, responsible for Programme management and diseases;
- **Annika Nowak**, Cabinet Member, responsible for medicinal products;
- **Marianne Thyssen**, Commissioner for Employment, Social Policies, Skills and Labour Mobility (i.e. she is in charge of the Social Open Method of Coordination, which addresses quality, accessibility and sustainability of health systems);
- **Stefaan Hermans**, Head of the Commissioner's Cabinet;
- **Vasiliki Kokkori**, Cabinet Member, responsible for social protection (including health and long term care related issues);
- **Carlos Moedas**, Commissioner for Research, Science and Innovation;
- **Antonio Vicente**, Head of the Commissioner's Cabinet;
- **Evelyne Lecocq**, Cabinet Member, responsible for health.

Eurocarers has sent "welcome letters" to the above three Commissioners, congratulating them on their appointment, calling for support on Eurocarers' issues and initiatives and asking for a future meeting. Commissioner Andriukaitis, responsible for Health and Food Safety, has already responded positively to our meeting request.

For more information: [http://ec.europa.eu/commission/2014-2019\\_en](http://ec.europa.eu/commission/2014-2019_en)

### Council conclusions on patient safety refer to carers

Ministers responsible for health met on 25 and 26 November 2014 and a relevant set of Council conclusions were adopted, under the heading "*Patient safety and quality of care, including the prevention and control of healthcare associated infections and antimicrobial resistance*". They focus on the current trend of shifting care from hospitals to outpatient care, including primary care and home care, and the need for continuous education and training of health professionals and carers. Furthermore, the conclusions recognize patient empowerment and involvement as an essential part of good quality and safety of care and the importance of health system performance assessment.

Member States are invited to consider the implementation of guidelines, recommendations and good practices on patient safety and to promote the education and training of healthcare staff on patient safety and to encourage health professional organisations to build an 'inter-professional patient safety culture' which allows integrated and high-quality processes of care. Member States should also encourage the participation and empowerment of patients, families and their informal caregivers, as well as patient organisations, through evidence-based and unbiased provision of information and education, and promote patients' participation in decision-making in the healthcare process in order to contribute to the prevention of adverse events.

*To download the report, please refer to following link:*

[http://www.consilium.europa.eu/uedocs/cms\\_data/docs/pressdata/en/lisa/145976.pdf](http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lisa/145976.pdf)

### **Next meeting of the European Parliament Interest Group on Carers**

The next meeting of the European Parliament Interest Group on Carers is planned for 4 February 2015, and will be hosted by Jean Lambert MEP. Its topic will deal with carers and social exclusion. More information on this meeting will follow in the next issue.

*For more information on the contents of this section, please contact Christine Marking via Eurocarers' Secretariat: [info@eurocarers.org](mailto:info@eurocarers.org)*

### **Investing in Health: The 'Missing Dimension' of the Europe 2020 Strategy for Smart, Sustainable and Inclusive Growth**

**By Stecy Yghemonos (Director of Eurocarers)**

On 1 December, Health Ministers had an exchange of views on the basis of a note prepared by the Italian Presidency on Investing in Health: The 'Missing Dimension' of the Europe 2020 Strategy. This debate provides a good overview of the approach taken by each of the member states regarding future health systems and the role of the European Commission in defining these. Obviously, this debate forms an important part of the political environment in which Eurocarers works. It is therefore essential to understand the different sensibilities on these topics. This document provides a summary of each member state's position on the subject.

The representative of the Italian Presidency of the EU (which ends on the 31 December 2014) opened the debate by saying that the Presidency had made the Europe 2020 strategy one of its guiding principles to aim for sustainable and smart growth. The EU is currently proceeding with a mid-term review of the strategy based on a Commission consultation (to which Eurocarers responded in November 2014). In spite of the improvements in healthcare policy, the impact of this has been confined to a side-line role in the Europe 2020 strategy and it is important to look at the role health can play in the strategy. The need to contain expenditure cannot be ignored, but health should be seen as a social investment that translates into an

economic investment. Consequently, those ministers responsible for public finance should be more involved with the work of Health Ministers.

Commissioner Andriukaitis said that there are clear links between health and the Europe 2020 agenda. The Commission expects to make proposals in 2015 on this issue. The health sector accounts for 8 percent of the EU workforce and 10 percent of the GDP. It is also growing and good health in an ageing population is essential to ensure fuller working lives. Concerning innovative health-related investments, he noted that this varies widely from country to country with some performing very well. Last but not least, health issues can be a cause of poverty and vice-versa.

The representative of **Germany** said that health can contribute to economic growth, but it should not be looked at only in this respect. Health is a question of citizens' well-being. The diversity of national health systems should be protected as this is a national competence. It is up to the Member States to develop national assessment instruments to enable the Member States to be able to compare their own systems to see where weaknesses lie. This could enable common indicators to be developed in the future. She then argued against any process designed to harmonise health systems in the EU.

The representative of **Hungary** agreed on the important role of the health sector in the Europe 2020 strategy. Due to a jump in needs in the health area, the efficiency of health systems is essential and improving the indicators would help in this respect. The exchange of best practices would be helpful. The limited number of key EU 2020 health objectives should be maintained, but the development of new indicators and sub-targets in the field is not appropriate and would therefore not be supported. He stressed the need for the Commission to not go beyond its competences in this respect.

The representative of **Poland** said that health can contribute to the creation of jobs, innovation and help the elderly stay in work. Health expenditure is therefore an investment. Poland would like to see a declaration on the role of health in the 2020 strategy.

The representative of the **Netherlands** welcomed the principle of care cooperation in the EU, but healthcare should not be in the 2020 strategy in a prominent way as the strategy can only work if it is focused on a small number of targeted instruments. He then stressed that healthcare is a national competence. This means that the Member States are responsible for the choices they need to make in organising the delivery of healthcare. If the healthcare performance assessment HSPA<sup>1</sup> is included in the European Semester<sup>2</sup>, this will impact the freedom of the Member States to organise healthcare delivery. Public health can help the economy and better coordination is required between the different ministries within a Member State.

---

<sup>1</sup> Health System Performance Assessment (HSPA) allows decision-makers to measure the performance of health systems as a whole and to report results regularly to the public and relevant stakeholders, but has been developed in relatively few European countries.

<sup>2</sup> All Member States have committed to achieving the Europe 2020 targets and have translated them into national targets. But only if the individual efforts of all countries are coordinated and focused, can they result in the desired impact on growth. Therefore, the EU has set up a yearly cycle of economic policy coordination called the European Semester. Each year, the Commission undertakes a detailed analysis of EU Member States' plans of budgetary, macroeconomic and structural reforms and provides them with recommendations for the following 12-18 months.

The representative of **Austria** said that if too much is changed in this area, it will undermine the entire process of the strategy. Health is closely linked to the improvement of the social condition. Healthy people perform better economically, but health cannot only be looked at in this respect. As regards to budgeting, he said that there are no studies showing the link between budget and outcome. How the money is used is what is important. Certain indicators at the EU level could be useful but when assessing performance, EU level work is currently insufficient, and he argued against new systems.

The representative of **Lithuania** agreed on the importance of healthcare for the economy. Health in itself is an asset and public health forms part of the national capital. Only healthy residents can contribute fully to competitiveness. The ageing society will need more healthcare and as such the sustainability of healthcare systems depends on their ability to adapt to an ageing society. The Semester can play a role in the exchange of best practices.

The representative of **Belgium** said that the quality of healthcare has a humanitarian side and an economic one. This cannot just be seen in terms of cost. However, there does need to be efficient expenditure as well as cooperation at the EU level to share good practices. The share out of European competence should however respect the national competence. She called for the EU to build on the work of the WHO such as that on non-communicable diseases. Better healthcare design is possible and there should be more cooperation with the Social Protection Committee.

The representative of **Ireland** said that opportunities for dialogue and engagement need to be strengthened. Ireland is moving away from block-grant budgets toward activity based funding. This is about purchasing value and not just reducing budgets. Investing in prevention and an outcomes based approach are key aspects of the Irish approach. A healthy population is fundamental for the economy. He noted that certain indicators can help the exchange of best practice and this should be facilitated when the Member States want.

The representative of the **UK** noted that the pressures of an ageing society are clear to see. As part of this approach, the UK has introduced an outcomes framework, which measures success and not just the number of interventions. The UK is trying to encourage innovation and to preserve the long-term sustainability of the healthcare system. The UK supports the ambition of the Presidency in the mid-term review, but it does not agree that health should be a focus of the strategy. There should not be indicators on health. The EU has a role to play in healthcare with legislation on pharmaceuticals and helping with the exchange of best practices. However the Member States must retain their competence to organise and deliver their health systems.

The representative of **Slovenia** said that health expenditure should be seen as an investment for the future. She called for more attention to be paid to the question of not negatively impacting the health of citizens in the search for economic growth. She also called for more to be done to reduce the divergences between the Member States. Anything that helps bring about greater healthcare quality at the EU level should be welcomed. However, national specificities must be respected. There can be no one size fits all approach. The efficiency of national healthcare systems should be measured at the national level. Before a universal model is introduced, a lot of additional thought would be required.

The representative of **Sweden** said that the mid-term review is very helpful. A strong dynamic strategy for sustainable growth remains fundamental. The EU must not reduce its ambition. The Swedish government believes in the need to offer high quality healthcare to the whole population. This is an ambitious objective that will need a lot of work. Everything that the government does impacts health and economic growth and a link between good health and a long life needs to be established. Health outcomes should also be looked at. He then stressed the need to respect the specificity of the national healthcare systems. Sweden has its own assessment system that allows them to assess any weak spots.

The representative of the **Czech Republic** agreed on the need to look at the strategy. The improved efficiency of political measures could be achieved by closer linking of the goals. He asked that the Commission allows more time for the national recommendations to enable them to better cooperate with social partners. More time needs to be devoted to healthcare systems in the Member States and it should be better taken into account in the 2020 strategy. He thus supported the ideas of the Presidency in this respect. Long-term sustainability of healthcare systems is fundamental and the EU could help through the exchange of best practices. He then said that silo budgeting is not optimal for healthcare planning, but it is up to the Member States to decide how to organise themselves. He called for further work on the development of existing indicators as opposed to the creation of new ones.

The representative of **Croatia** said that better implementation of the existing objectives is more important than the development of new ones. As for public health, any investment will contribute to the success of the strategy. Only healthy workers can be fully efficient. The role of the health sector as a driver of economic growth is not yet fully recognised. Innovation and R&D help drive growth and SME development.

The representative of **Romania** said that in the context of economic growth and employment, the recent investment plan of the Commission must be welcomed and used for the health sector. He then said that the implementation mechanisms should be improved. The relationship between a resource and results based approach needs to be better understood. Health expenditure is an investment. The Health System Performance Assessment<sup>1</sup> in the Semester<sup>2</sup> could be better used. He then highlighted that national differences should be better taken into account.

The representative of **Spain** argued that in previous health councils, it has already been stressed that the health sector contributes to growth and should thus be better included in the EU 2020 strategy. She said that Spain is investing in innovation. She agreed on the need for closer cooperation between the Health Group and Social Welfare Group within the Council.

The representative of **Finland** agreed that a healthy population is a prerequisite for a healthy economy and vice-versa. Reducing health gaps is also beneficial economically. However, health has its own societal value. She called for cross-sectoral cooperation on the basis of health in all policies. The EU should be pushing on this. She also called for the increased inclusion of health experts in debates on health policy including in the creation of indicators in the 2020 strategy. She then said that the inclusion of health in the Semester<sup>2</sup> must be on a general level in order to respect national differences. An innovative approach is essential for sustainable healthcare systems.

The representative of **Portugal** said that health requires a special emphasis in the 2020 strategy. A healthier population contributes to greater economic efficiency and social equity. The management of healthcare system should be outcomes based, although the resources being used should be born in mind. The systematic use of health indicators is a positive thing as long as national competences are respected. The Semester<sup>2</sup> should make better use of the Health System Performance Assessment<sup>1</sup>.

The representative of **Estonia** said that the Health System Performance Assessment (HSPA)<sup>1</sup> is a useful tool to show measurable results. It could also be used to improve efficiency of healthcare systems. However, there should not be an obligation to apply the HSPA at the EU level. This is a national competence.

The representative of **Cyprus** noted that health is a high cost spending sector and the lack of comparable data means that it is difficult to judge the impact of investment. Better management and allocation of available resources in the short-term (silo financing) should not be seen as a panacea as a long-term solution based on an outcomes based approach is required. The ongoing economic crisis may be a block on the shift towards an outcomes based approach. He called for the Commission to look at how the HSPA<sup>1</sup> could be used to bring this about. In addition, he argued that health could be better included in the Semester<sup>2</sup> process.

The representative of **Greece** noted that the crisis has put budgets under pressure and placed health systems under threat. Greece needs to increase the efficiency of its spending on healthcare. Silo budgeting allows Greece to achieve this. The approach of promoting better health through investment would create budgetary savings. However long-term planning requires budgetary resources and these are not always available. Health spending should be highlighted in the European Semester<sup>2</sup>.

The representative of **Denmark** agreed on the economic importance of the healthcare sector. Denmark would like to exchange best practices. However, Denmark believes that the existing 2020 strategy objectives are sufficient. The Semester<sup>2</sup> already embraces health and long-term sustainability. There should be comparisons across borders to share best practices, but EU cooperation should take into account the progress already made in the Member States. The representative mentioned that work should also be carried out with the WHO and OECD to build on the data that they have created.

The representative of **Bulgaria** said that the five headline targets of the strategy remain valid and should not be changed. There are doubts about including more health items in the strategy and the Semester<sup>2</sup>. The Semester concerns economic and not health policy. The present form of the Semester is correct. She then asked if there is a sufficient legal basis for the priorities of national health plans to be decided at the EU level.

The representative of **Luxembourg** said that health systems have a positive role to play in terms of economic growth and social cohesion. The visibility of health in the Semester<sup>2</sup> should increase, but the assessment of healthcare systems should not be carried out only on a macro-economic basis. It would be desirable to see the new assessment process (HSPA)<sup>1</sup> achieve results, but it should not call into question the competence of the Member States. Drawing up health indicators should be done alongside the work of the social protection

committee. The specificities of health systems should be better taken into account in the Semester. National authorities must be given the resources to address challenges.

The representative of [Malta](#) said that the economy must underpin the health sector. To reach European Semester<sup>2</sup> goals, an outcomes based approach must be adopted. The use of European funds to monitor systems and healthcare reforms is important. He noted that silo budgeting goes against integrated healthcare. The HSPA<sup>1</sup> should be the main mechanism used in the assessment of health systems and should tie together input and outcomes. However, each Member States should be left to decide the structure of its own HSPA.

The representative of [Slovakia](#) said that sustainable healthcare systems should be a shared priority. Planning should rise above short-term thinking. Investing in healthcare should not be seen as a cost.

The representative of [Latvia](#) noted that a clear and goal orientated 2020 strategy is essential. Investment in health systems is a pre-condition for prosperity. A greater reflection of the health sector is required in the strategy and Semester<sup>2</sup>. As regards to the annual growth survey, he called for the involvement of the welfare protection committee. The next health Council will look at cooperation between the high level working party and the social protection committee. How to enhance the health sector in the Semester will also be debated.

The representative of the [Italian](#) Presidency noted that there was a lot of passion around. She said that the Council believes in the importance of health in achieving the 2020 goals. Compartmentalised budgeting should be avoided as the focus should be on outcomes. The HSPA<sup>1</sup> methodologies should be used to help compare different healthcare systems.

Commissioner Andriukaitis noted that health plays an important contribution to the economy. He agreed that subsidiarity should be respected. The Semester<sup>2</sup>, which was launched last week, included elements on ensuring the sustainability of healthcare systems. The EU needs a healthy and productive workforce. He welcomed the ambition to remove silos in healthcare systems and for the adoption of an outcomes based approach. He noted that e-health solutions could also be beneficial. He then said that good practices could be used within the country specific recommendations.

# CARERS IN ACTION

## Family carers: definition and recognition

By Brigid Barron (Caring for Carers Ireland, Innovation & Programme Manager)

### Introduction

The titles of Carer and Family Carer are frequently confused. Carer is a general term used to describe caring by all including professional, paid care workers, home helps, volunteers and family carers. Amongst all of this, the unique and distinct role of the Family Carer is blurred and obscured, which makes it increasingly difficult for Family Carers' voice to be heard and for their needs to be recognised. Family Carers who choose to care should be empowered to do so without detriment to their inclusion in society and to their health and wellbeing.

The family continues to be the strongest and most reliable source of care for older people, people with disabilities and those who are chronically ill. The majority of people in need of care continue to be cared for at home rather than in institutions. Families show a high degree of adaptability to the needs of dependants.

### Proposed Definition: Carer

The title "Carer" has a broad meaning, but generally refers to paid professional carers, home helps, home care workers, volunteers and all paid care workers engaged under a contract of service. This includes voluntary care work for a charity or community organisation and those who provide care as a requirement of a course for their education and training.

### Proposed Definition: Family Carer

A Family Carer is someone who is providing an ongoing significant level of unpaid care to a family member or friend who is in need of that care in the home due to illness or disability or frailty. Family Carers provide a unique and dedicated service to their families and communities. They have the right to be recognised and respected for the important contribution to society. Family Carers generally have an emotional relationship and legal responsibility for the person for whom they are caring. They undertake responsibility for the management of the person's care, welfare and social needs over time, and in many cases for years. It is critical that the needs of Family Carers are articulated to those with responsibility for the development of policies that directly or indirectly impact on their lives and for those for whom they care.

People who are providing a significant amount of care often do not recognise themselves as Family Carers and need to be encouraged to do so, in order to empower them to access services and supports to meet their own needs and those for whom they care. Recognition of the role and contribution of the Family Carer is critically important. Grouping paid and unpaid carers under the term carer obscures and obstructs access to services and supports

for the Family Carer. The continued use of the term Carer further isolates and excludes Family Carers from receiving much needed support from their families, communities and the State. Policy makers and decision makers need to recognise the role of Family Carers which is undertaken in the home unseen and unheard – often seen as women’s work. Therefore it is important that in identifying the Family Carer and their unique role that this will help in bringing improved clarity to this role and how it differs from that of the paid care worker.

In Ireland, Family Carers have the right to be recognised for the central role which they play in community care and in creating a community of caring (Carers’ Charter Caring for Carers Ireland 1991). Whether caring for a child or a parent with a disability or illness or an elderly family member, carers, through their selfless hard work, knowledge and compassion, enhance the quality of life of thousands on a daily basis. We want to send a strong message to carers that we recognise and value their immense contributions to the well-being of the people that they care for.

A key objective of Government policy for older people, children and adults with an illness or a disability is to support them to live in dignity and independence in their own homes and communities for as long as possible. Family Carers are vital to the achievement of this objective and are considered a backbone of care provision in Ireland. For some, however, a lack of recognition and respect of their work can lead to a sense of disconnection from society and from opportunities that people take for granted. Carers have an expert knowledge of the person and of the condition of the person for whom they are caring. However, many can feel that this expertise is undervalued and often ignored when decisions relating to the care recipient are being made. Carers should be considered as key partners in the caring process and should be consulted with when decisions are being made about the care recipient’s needs.

Recognising the contributions of Family Carers is essential to fostering a climate in which they feel valued and supported to continue in their caring roles. Caring for Carers Ireland call on all health and social care agencies, including the media, to adopt the title Family Carer when referring to Family Carers in the future.

For more information on this topic please contact Brigid Barron: [bbarron@caringforcarers.org](mailto:bbarron@caringforcarers.org).

# RESEARCH ON THE MOVE

## Elderly family carers in Romania

By Licia Boccaletti (AnzianieNonSolo, Italy, member of the Executive)

In summer 2014, the ELMI project partnership ([www.elmiproject.eu](http://www.elmiproject.eu)) conducted qualitative research on elderly family carers in Romania. The research involved qualitative interviews with ten 10 elderly family carers organizations. The overall aim was to collect data on carers and structured questionnaires to analyse the availability of support services for family carers with a focus on carers of patients with dementia.

### *Elderly family carers profile*

The majority of carers supported by the organizations interviewed are female (87%), they care for their parents, grandparents, wives and husbands, sisters and brothers who are suffering from the following diseases: strokes; dementia (Alzheimer); disability; mental illness; cancer. The average age of the carers is 49; the average years of their caring activity is around 5 years (minimum 3, maximum 10). They carry out activities regarding: lifting, nutrition (food preparation, feeding etc.), personal hygiene (e.g. bathing, dressing and undressing), relation/psychological support, taking care of the house (cleaning, ironing etc.), support in administrative procedures, organization of care (management of professional/domestic care workers, ...), providing medications, rehabilitation, walking outside, do shopping, monitoring the health status.

### *Public and private services*

The services provided by public institutions are a monthly financial support, addressed to severely disabled people, and home care services. The services available provided by private institution are respite care, skill validation system (paid services), information and counselling, homecare services, support groups and religious support (free services).

### *Qualifications*

Once the caring activity ends, if carers decide to become professional in the care sector, in Romania they can take the following qualifications: *Ingrijitor batrani la domiciliu* (Home caregiver), or *Infirmiera* (health care assistant). In Romania as reported by the interviews carried out, there aren't at the moment training opportunities addressed to informal carers.

### *Future job perspective for informal carers*

All the interviewees consider the transition from carers status to professional care worker as a good option, because carers can have the skills they have acquired through their personal experience recognized in the labour market and get a salary from it. Moreover, some carers

can become dependent from their caring activity and in this way, once the beloved one dies, they can avoid a double trauma: the loss of their relative and of their daily activity. All the interviewed people point out also the fact that carers are emotionally and physically stressed and they are at risk of burnout. They are convinced that formal training can support them to prevent and deal with this severe syndrome.

### *The ELMI project*

“ELMI” is a LLP-Leonardo Da Vinci project. Its main goal is to support elderly family carers through an innovative web-based training course which will have the double aim of a) helping them acquire skills useful in their current caring role; and b) enhancing their competences in view of acquiring a professional caring role once the informal caring comes to an end. This tool has been elaborated in Italy by “Anziani e non solo” and it will be transferred to the other project organizations in Romania.

For more information please contact Licia Boccaletti: [progetti@anzianienonsolo.it](mailto:progetti@anzianienonsolo.it).

### **A human resource strategy for an informal carer friendly working climate: call for partners**

**By the Knowledge Point Informal Care (Howest University College of West Flanders, Belgium)**

As described in the previous issue of Eurocarers Newsletter (n. 13 issued in October 2014), until March 2015 the research group ‘*Kennispunt Mantelzorg*’ from the *Howest University of Applied Sciences (Bruges, Belgium)* is working on a **European Social Fund project** that aims to develop a Human Resource strategy for companies who have informal carers amongst their employees. These informal carers combine the care in their own social environment with a paid job. Our goal is to produce a guide with tools for companies that wish to develop a company-specific and ‘informal care-friendly’ human resource strategy.

Because the current research project meets important societal needs in our aging society, we would like to extend this project beyond the Belgian borders. We are therefore looking for international partners with interests and/or expertise in this research area, who are willing to explore the opportunities for cooperation. Supporting a good working-care balance across Europe is essential, if we want to face future challenges.

In case you would like to receive more information in this regard, please contact: [kennispuntmantelzorg@howest.be](mailto:kennispuntmantelzorg@howest.be).

## IN BRIEF

**Call for papers to be presented at the 6<sup>th</sup> International Carers Conference on 3-6 September 2015:** Papers are now sought for the 6<sup>th</sup> International Carers Conference taking place in Gothenberg on 3-6 September 2015. The themes for this conference refer to four core areas: *health, social care and well-being* (how do modern societies and economies manage care in the face of demographic change and more mobile populations?); *combining work and care* (how can we support people to manage their working and caring lives, contributing to business, economic and social sustainability?); *paying for care* (how can we share the costs of care between the individual, family, community and the state? and ensure there is a vibrant market for care?); *technology-enabled care and support* (how can new technologies support the delivery of care, transform the lives of individuals and families and drive economic growth?). **Deadline for submissions is Friday 27 February 2015.** For more information, please refer to: <http://www.neilstewartassociates.com/sh323>.

**The Winter edition of Care Alliance Ireland Exchange Newsletter is available:** the Winter 2014 edition of "*Care Alliance Ireland Exchange*", the newsletter edited by this Irish carers association, is now available to download. Issues covered in this edition include a report on the Relationship between Family Carers and Home Care Workers; the recruitment of a New Policy and Research Officer; the profile of New Directors of Care Alliance; an Update on National Carers Strategy Monitoring group; and the launch of the "Palliative Hub". The Newsletter also includes all regular pieces on National News, Members News, Caring in Numbers, Research and Practice Publications and International News from the Caring sector in Ireland, as well as a new section on Governance matters. To download the newsletter please [click here](#).

**New Project on "What is 'Good Care' from a Care Worker's Perspective?":** The Chamber of Labour for Vienna has commissioned the European Centre for Social Welfare Policy and Research (one of our members) to undertake an explorative study about how the various categories of professional care workers perceive quality of care. Qualitative interviews and focus groups will be carried out to elaborate an inventory of key issues to define structures, processes and results in the context of professionals' current working conditions in long-term care. The empirical results of this study (expected by Summer 2015) will underpin the ongoing debates about reforms in vocational education and practice with tangible recommendations for improvement. For more information please contact [Kai Leichsenring](#).

**Recent launch of a new piece of research on the relationship between Family Carers and Home Care workers:** our member organisation Care Alliance Ireland has recently launched a significant piece of research entitled "A Literature Review on the Relationship between Family Carers and Home Care Support Workers". This report brings together all the key research on the topic in a concise, considered and comprehensive manner. As one of the speakers (Gerry McCaffrey) at the launching event put it, "*this piece of work is a major contribution to Family Carer research and in particular on an aspect which is often overlooked: the triadic and often interdependent relationship between a paid home care worker, a client in need of support and the wider family*". The report is published in two formats (one as a full report, the other as a "Key Findings" document) and is available to download from the Care Alliance website: [www.carealliance.ie](http://www.carealliance.ie).

## About EUROCARERS

*EUROCARERS was officially established in Luxembourg in December 2006. Its origin lies in two European networks: Carmen, a network on integrated care and Eurofamcare, a research network on carers of older persons. In the Carmen project researchers, practitioners and policy makers, among them representatives of the carers' movement, found each other and came to the conclusion that it was time for carers to be heard at European level. The Eurofamcare network - consisting of researchers who mapped the situation of carers of older persons and the policy measures developed for this category in the EU and who did quantitative research on the support of carers of older persons in six countries - also diagnosed a strong need for carers to make themselves heard in Europe.*

*Representatives of the two networks and other interested persons met in Maastricht in 2004 on the initiative of NIZW, the Dutch Institute of Care and Welfare (later reorganised into the two organisations Vilans and Movisie), to discuss the feasibility of establishing a European organisation and decided to go ahead with this task. Christine Marking had written a preparatory paper which helped those who met in Maastricht in formulating decisions about some crucial issues. An interim board was established consisting of: Brigid Barron, President; Patrick Michielsseune, Treasurer; Marja Pijl, Secretary; and the following other members: Judy Triantafillou, Isobel Anderson, Hanneli Döhner, Caroline Glendinning and Henk Nies. Several working groups were formed. Geraldine Visser and Nicoline Tamsma made a report of the meeting. Several meetings took place in the following months and some activities were already developed before EUROCARERS was formally registered in Luxembourg at the end of 2006. In 2014, alongside the historical establishment of a Secretariat in Brussels, the process of registration in Belgium has been put forward. As a result, Eurocarers is an international not-for profit organization registered in Belgium (registration n. BE0563648885).*

*Since its creation, the association has increased, and now includes over 60 organisations and several individual associates from all European Member States. Members of the current (2014-15) Executive Committee are: John Dunne (President), Hanneli Döhner (Vice President Carers Associations), Elizabeth Hanson (Vice President Research), Marijke Steenbergen (Treasurer), Licia Boccaletti, Helle Lepik and Marja Tuomi. In addition, the Executive is supported by four advisers, Christine Marking, Frank Goodwin, Giovanni Lamura and Katherine Wilson. For more information on the members of the Executive Committee: [http://www.eurocarers.org/about\\_executive.php](http://www.eurocarers.org/about_executive.php).*

*For more information on the aims and guiding principles of EUROCARERS please go to the link: <http://www.eurocarers.org/about.php>.*

### **EUROCARERS key contacts:**

#### **Eurocarers Secretariat**

**Address :** 3, Rue Abbé Cuypers, 1040 Brussels, Belgium

**Phone:** +32 (0) 27412405

**Email:** [info@eurocarers.org](mailto:info@eurocarers.org)

**Website:** [www.eurocarers.org](http://www.eurocarers.org)

**Date of going to press: 16 December 2014**