

Dear readers,

Here we are with the ninth issue – the third in 2013 – of EuCaNews, the Newsletter of EUROCARERS (or EuCa), the European Association Working for Carers! In this issue you will find a slightly revamped look for the Newsletter, with new and reformulated headings. After the usual introductory summary on the latest Executive Committee’s decisions, the most recent developments at EU level are described in a dedicated section (i.e. no longer part of the Executive section), which this time is fully focused on the carers strategy that Eurocarers is currently launching at EU level (also thanks to Christine Marking’s efforts, despite problems with her hand, for which we wish her a speedy recovery!). The section collecting contributions from our members (now renamed “Carers in action”) contains news from the Finnish Central Carers Association (which will host next year’s Annual General Meeting on 5 June 2014), on the campaign against carers’ poverty started in Scotland and now involving more countries, and updates from our Estonian friends. From the next issue onwards, we would also like to try to include in our Newsletter a “portrait of a carer” from somewhere in Europe (or of someone who has been researching or promoting carers’ interests), and on page 14 we call for nominations in this regard. In the final section (renamed “Research on the move”), besides the usual updates on different projects, you will also find information about a recent UK report arguing for the need for more support to help carers reconcile work and care.

*As usual, **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 event, 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).*

Happy reading and take care from,

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&

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Contents	Page
NEWS FROM THE EXECUTIVE COMMITTEE	3
Topics discussed at the last Executive Board's teleconference	3
EU POLICY DEVELOPMENT	6
Proposal of an EU-level strategy in support of informal care provision, by Christine Marking	6
CARERS IN ACTION	8
News from the Central Association of Carers in Finland, by Marja Tuomi and Malla Heino	8
Campaigning for carers' rights, against carer poverty!, by Sebastian Fischer	10
The Second National Informal Care Forum and other activities in Estonia, by Helle Lepik and Ivar Paimre	12
Wanted: the view of individual carers for next issues of the Newsletter!	14
RESEARCH ON THE MOVE	15
Update on the INNOVAGE project, by Francesco Barbabella	15
Second Partner Meeting of the ICARE4EU project, by Marja Pijl	16
The KEYFORA project, by Brigid Barron	17
Support working carers to help business & boost the economy, by Carers UK	18
In brief	20
About EUROCARERS	21

NEWS FROM THE EXECUTIVE COMMITTEE

In this section of the Newsletter, we report the core issues discussed during the teleconferences that take place periodically between the members of the EUROCARERS Executive Board.

Topics discussed at the Executive Board's teleconference on 9 September 2013

The following issues were discussed during the last Executive Board's teleconference on **Monday, 9th September 2013:**

1. EU matters:

- a. EU Parliament Interest Group on Carers, meeting on 15 October 2015 to launch the EU Carers Strategy proposal: Christine has drafted a second version of the strategy which incorporates all comments received so far, including those informally made from some EU representatives who, while not opposed to the idea, are fairly critical about the text as it stands, since they will be the ones who eventually will have the task of developing and implementing the strategy. Christine will prepare a draft note to accompany the strategy proposal, to help members put it into context and underline its importance. The European Parliament Interest Group on Carers will meet on 15 October in Brussels to discuss the proposal. The meeting should lead to an initiative from the MEPs to prepare an Own Initiative report on the strategy as well as some Parliamentary Questions. Christine emphasizes that the real work will be the actual campaign to get political support for the development and implementation of the strategy. This is going to be very intensive and the contribution of the Executive Board and EuCa members will be crucial in the next steps to be taken vis-à-vis the members, the Commission, the European Parliament as well as the Council (i.e. national governments). It might be useful to try to get next year's Italian Presidency on board, for instance by holding our autumn meeting in Italy.

2. Financial issues:

- a. Accounts update: Frank and Giovanni insist on the importance to keep on track of AIDA and INNOVAGE budgets. Giovanni warns that if there are any changes it is important to communicate to the coordinator in order to check if it is feasible. If there are additional costs, we have to be sure we can be refunded. In general, the accounts, outside of projects, are going well.
- b. EUROCARERS' country of registration: We need to consider this point, as it is important in doing audited accounts. We need to think about moving EuCa Registration office from Luxembourg to another country, as it would be easier to be registered in the same country where we have the bank accounts. It is debatable whether we should open an office in Brussels, and whether we should also transfer to Brussels both bank account and the registration. Marijke offered to investigate the advantages and disadvantages to this step, by consulting with an NGO which is already established in Brussels. A decision could be taken at the next meeting or by December 2013.
- c. Treasurer Role: Frank said that he will contact Marijke shortly to develop this.

3. Membership:

- a. Report on membership strategy: By mid October, Hanneli will send an overview – currently under development by her and Henk Bakkerode - to the Executive.
- b. Report on Estonia meeting on carers: Frank reported that all went well and very positive at this meeting, which he attended on 24 August. About 100 people participated and good relationships were established.

- c. Year Plan: Frank explained that the intention is to map tasks, and make sure tasks have been completed. If there is any issue that the Executive thinks should be there, please let him know. The plan will be extended to the next AGM 2014, as suggested by Hanneli.

4. **Executive Board:**

- a. Progress bid: the proposal (which would allow Eurocarers to count on regular funding from the EU for the next four years) was submitted on time on 6 September. Towards the end of November, we hope to have some news concerning the outcome of the selection process.
- b. Link EuCa to Podio: This is a web-based tool for exchanging documents, like a cloud, and you can log-in from any computer. It is currently been used by INNOVAGE. It might be very useful. Frank will take an in-depth look at it and report back to the Executive with suggestions on how to proceed.
- c. International Short Break Association (ISBA) Conference in Germany on 9-11 September 2014: Hanneli, explained that this association is very interested in cooperation with EuCa. She is involved in planning and EuCa should consider attending this relevant event. Call for papers will be announced in the next weeks (for more information: <http://www.isba.me/indexEng.htm>).

5. **Research: Overview**: an updated version has not been sent since there were no major changes during the summer months. Here some news concerning specific projects:

- INNOVAGE: the preparation of the pilots in Germany, Sweden and Italy is about to start, in order to test the web platform of services to support carers. For the dissemination phase – to take place in late 2014 - it will be necessary to find appropriate partners in some countries where current members are not very active.
- AIDA: a European Seminar is confirmed in Brussels on 15 October 2013.
- SMART CARE (by Marja Pijl): There was a Consortium meeting in Brussels on the 4 and 5 of September. Marja received an invitation but mentioned that we were invited to the User Advisory Board but had never agreed to be actively involved in other activities, so she assumed that we were not expected to participate in the Brussels meeting. AGE, which coordinates the AB, was going to attend so will inform us and involve us when necessary. While Marja was on vacation, it was decided to set up an editorial committee which was supposed to produce articles about the users as represented by the organisations on the UAB. Marja wrote the article but so far has received no comments from the other members of the committee.
- ICARE4EU PROJECT (by Marja Pijl): On 9 September, the second meeting of this consortium took place in Utrecht. It appears to be running smoothly; it is very well organized and so far it is running on time. Tomorrow we will discuss how the experts in all EU countries will be approached and the contents of the questionnaire that will be used. There is also a dissemination plan to be discussed. It is proposed to use modern social media, including Facebook and Twitter.
- MORE YEARS BETTER LIVES: Hanneli joined the last meeting in Berlin (in continuation of Robert Anderson) and explained that this project is still discussing the workplan and the global framework, commenting that the topic of carers is not very central. We have to decide if we really want to join the meeting or just read and eventually comment their papers. Next meetings are on 25 November (Giovanni will try to attend) and 14 January. Giovanni also asked whether EuCa should join and, if so, who should represent EuCa.
- Invitation to collaborate in EU project “FAMILIES AND SOCIETIES”. This is a big project across EU. It is a very high level consortium. It is not focussed very much on

ageing. Giovanni asked if someone is interested in it, and Marja Tuomi expressed her interest but she needs more information that she will try to collect.

6. A.O. B.:

- a. Website: a brochure is planned to be uploaded in the “library” section. It was commented that the structure of the website is very old and should be updated. Under the Executive listing, we should add the affiliation organisation. Giovanni proposed appointing a part time position for the task of updating website work.
- b. AAL Forum in Sweden at the end of September: There is a session on informal carers. Hanneli will chair a session on ICT and family care and Areti Efthymiou is invited to have a presentation on INNOVAGE.
- c. Costs of teleconferences: EuCa should cover those costs for members who have to pay out of their own pocket. People will have to submit a proper bill, with their claim for expenses. We can review how this is working at the next AGM.

Next teleconference: 20 November 2013.

EU POLICY DEVELOPMENTS

Proposal of an EU-level strategy in support of informal care provision **By Christine Marking**

Meeting in Brussels on 15 October 2013, the European Parliament Interest Group on Carers has called on the European Commission to develop and implement an EU-level strategy to support informal carers as a matter of urgency. The Group has developed a proposal for such a strategy, entitled 'Enabling Carers to Care', in close cooperation with Eurocarers.

The background to the initiative is the fact that carers are an inherent as well as an indispensable part of the provision, organisation and sustainability of health and social care systems. They will become even more important in view of the changing health and care needs, due to the ageing of society and the increasing prevalence of frailty and chronic disease. Yet, despite the obvious importance of carers - both to care provision as well as to the economy and society as a whole - their interests are rarely considered in policies that impact on them in a consistent manner.

Fig. 1: Participants attending the meeting of the European Parliament Interest Group on Carers convened to launch the proposal of a EU carers strategy (left to right: two advisers to MEPs; Heinz K. Becker, MEP; Marian Harkin, MEP; Frank Goodwin, President EuCa; Fritz von Nordheim, European Commission DG Employment and Social Affairs; Madeleine Starr, Carers UK)



Marian Harkin MEP, co-chair and co-founder of the Interest Group, urged the Commission to take action now, stating that “across the EU informal carers provide 80% of the care to dependent people of all ages and this is provided free of charge. Without this invaluable resource health and social security systems would simply be unsustainable”.

The proposed strategy is a direct response to a variety of current policy challenges relating to the provision and sustainability of long term care in Europe. It outlines why support for carers is needed, makes the case for the added value of EU-level action, proposes areas where action is most urgently required and sets out tools and ways to address these issues.

“Many carers provide care 24 hours a day 7 days a week. It is crucial that they are given appropriate support and respite to enable them to keep on caring and to maintain their own health” co-chair Sirpa Pietikainen MEP stated.

Giovanni Lamura, Vice-President of Eurocarers added: “If carers are expected to keep providing care – and they are – their needs and requirements should be an inherent part of health and social policy development, and their contribution properly considered as part of the economic equation”.

The draft strategy is available at www.eurocarers.org (section “News” of the home page).

CARERS IN ACTION

News from the Central Association of Carers in Finland (www.omaishoitajat.fi)

By Marja Tuomi and Malla Heino

There are some 300,000 family carers in Finland (population 5.4 million). At present, 40,000 family carers receive support for family care from their respective municipalities leaving most carers outside the formal support system. Finnish carers strive for better recognition; they have been working together actively in a national carer organisation for over 20 years. The first national organisation, Association of Care Giving Relatives and Friends, was established in 1991 to advocate and lobby for family carers and the cared-for persons. In 2012, the Association was renamed the Central Association of Carers in Finland. Currently, there are 18 members on the staff, mainly in the Helsinki office.

Profile

The Central Association of Carers in Finland is an advocacy and support NGO for carers and care receivers. We are here for carers and they are our foremost priority. In order to accomplish this we must operate on a very diverse and challenging field. Currently, the economic recession has added extra demands on the work. In a nutshell, here's who we are and what we do:

- National advocacy and support organization for carers and care receivers, irrespective of age, gender or illness
- NGO, non profit: www.omaishoitajat.fi
- 70 local carer associations covering most Finnish municipalities
- 10,000 individual members (2013) affiliated via local associations
- 18 staff members
- Funded mainly by Finland's Slot Machine Association
- Member of Eurocarers since 2007; CEO Marja Tuomi member of the Board (2013)
- Active cooperation with patient, pensioner and senior organizations, congregations, rehabilitation institutions as well as political decision makers at national and local levels
- Legislative initiatives, statements, participation in national planning & decision-making on informal care, monitoring realization and quality of support activities for carers
- Quaterly magazine "Lähellä", handbook and booklets
- Informal care helpline from Monday to Thursday
- Guidance and advice as well as legal help for carers
- Organizing holidays for informal carers annually in collaboration with social tourism associations and rehabilitation courses in collaboration with Social Insurance Institution and rehabilitation institutes
- Training for carers and others interested in caring, such as people employed by municipalities, congregations and third sector organizations.

A comprehensive 16-hours training programme for carers - Ovet (Doors)

One of our association's "success stories", along with the constant advocacy work, in the past years has been the development and implementation of a training programme for carers. The programme has been designed to meet the various needs of carers, e.g. acquiring skills



essential in care work (e.g. patient moving and handling training, nutrition, challenging behavior etc). Not only instrumental skills are sought after in the programme but also essential is reflection on the role of a carer. Special emphasis is placed on the value of voluntary decision: carers should have a say in whether they want to become carers in the first place and how long to continue. Carers who have just commenced in their caring role are seen as a priority.

The Central Association of Carers has so far trained some 130 volunteers and staff of its own local associations as well as interested people from other NGOs, municipalities and congregations to organize and run the training groups locally. Carers who have taken part in the training programme have reported having experienced beneficial impacts on their well-being as well functional capacities. The carers report that, after the training, they take more time-off for themselves, feel more empowered, share their thoughts and feelings more openly, know more about the available support services and have courage to seek professional help. The training is cost-effective: much of the work is done on a voluntary basis with local associations' volunteers, but equally important is the good cooperation networks between the associations, municipalities and congregations. Material comprising a book and a booklet, as well as an extensive slide package, are provided for the training.

Legal milestones and activities in family care

Until 1970s family members were obliged to care for one another in Finland. During that decade the responsibility for care provision was gradually shifted to municipalities: in 1970 children's obligation to care for their parents and grandparents was lifted and seven years later also the obligation for mutual spousal care was removed from the law. Obviously, people never ceased caring and gradually support for their care provision was developed. There was increasing social discourse on caring issues from 1980s onwards and the first statute on informal care came into effect 1982. Some ten years later, an amendment was made to the Act on Social Care and the Statute on Support of Family Care was introduced.

The first comprehensive legislation for family care (Act on Informal Care Support) was introduced in 2006 giving the carers right for 2 days-off per month (now 3 days). Municipalities are responsible for the provision of support within the limits of their budgets. Informal care support includes support services and care allowance for the carer (minimum €374.51 per month in 2013) and services for the care receiver. Statutory accident insurance as well as pension scheme are included in the support. In 2011, an Amendment to Employment Contracts Act 2011 came into effect giving carers right to request leave for caring purposes.

A working group comprising a wide variety of stakeholders including policy makers, labour market organizations, researchers and NGO-representatives is preparing the first National Development Programme for the support of family cares. The final report is expected to be completed by the end of 2013.

Successful complaints to the European Committee of Social Rights

The Central Association of Carers in Finland made two complaints versus Finland to the European Committee of Social Rights in Strasbourg in 2011. Both complaints were

successful, as the Committee stated that the right of elderly persons to social protection is not effectively applied throughout the country (violation of article 23 of the Charter).

The first complaint primarily concerned the unequal treatment in different parts of the country of informal carers looking after elderly persons but also alleged that the lack of funding in some parts of the country from the start or the middle of the year leads to an unequal treatment in the delivery of services to elderly persons. The actual implementation of the national legislation varies widely in the different municipalities in Finland and informal carers are not treated on an equal basis when it comes to allocating allowances for this kind of support. The following chapters are direct quotations from the decisions of the Committee: “Based on their strategic choices and priorities, municipalities have to comply with Article 23 of the Charter. In view of the evidence brought by the complainant association, not contested by the Government, and taking into account the report of the visit to Finland of the Commissioner for Human Rights of the Council of Europe, it is considered that the extend of discretion of municipalities combined with the lack of any clear obligation of providing an allowance to informal carers or any alternative service for the elderly led to unsatisfactory overall situation in certain municipalities. The lack of uniformity in the services provided for elderly persons throughout Finland resulting from the lack of uniformity in the funding of such services by municipalities does not as such violate Article 23 of the Charter. However, the fact that the legislation allows practices leading to a part of the elderly population being denied access to informal care allowances or other alternative support constitutes a violation of this Article”.

The second complaint was about the reorganisation of long-term care, whereby former institutional care facilities (elderly homes and long-term health care wards) are being replaced by service housing, which has a significantly different pricing system. As a result, persons in need of service housing and service housing with 24-hour assistance are charged higher fees than persons in institutional care because:

- there are no upper limits on fees for service housing (also with 24-hour assistance);
- services, medicines and housing are charged as separate packages;
- the Committee concluded that insufficient regulation of fees for service housing and service housing with 24-hour assistance combined with the fact that the demand for these services exceeds supply, does not meet the requirements of Article 23 of the Charter insofar as these: 1) Create legal uncertainties to elderly persons in need of care due to diverse and complex fee policies. While municipalities may adjust the fees, there are no effective safeguards to assure that effective access to services is guaranteed to every elderly person in need of services required by their condition; 2) Constitute an obstacle to the right to “the provision of information about services and facilities available for elderly persons and their opportunities to make use of them as guaranteed by Article 23b of the Charter.”

You can find the decisions of the European Committee of Social Rights to the two complaints via these links:

http://www.coe.int/t/dghl/monitoring/socialcharter/Complaints/CC70SummaryMerits_en.pdf
http://www.coe.int/t/dghl/monitoring/socialcharter/Complaints/CC71Merits_en.pdf

EuroCarers AGM 2014 in Helsinki: We will be hosting Eurocarer’s next Annual General Meeting in Helsinki on 5 June 2014 followed by a conference on the following day. We are very happy to welcome you to Finland!

Campaigning for carers' rights, against carer poverty! **By Sebastian Fischer, Coalition of Carers in Scotland**

Scotland's second Carers Parliament took place in Edinburgh on 1 October 2013, attended by 160 carers from all constituencies in Scotland, including rural and island communities, to discuss 'carers rights' with politicians.

Caroline Dunphy, Johanne Powell, Susanne Hallermann, Sabine Feldt, Silvia Wölki and **Peter Petermann** – six campaigning carers from Ireland, Austria and Germany – attended the Carers Parliament with **Clare Duffy** (Policy Officer, Carers Association Ireland) and **Frank Goodwin** (Eurocarers President).

One highlight of the debate was the visit of **Scotland's First Minister Alex Salmond**. After a four-year campaign "From Recognition to Rights" by Scotland's carers, the first Minister announced an immediate consultation on further rights for carers and young carers, with [new carer legislation](#) being introduced in Parliament early in 2014. **Frank Goodwin** was invited to a subsequent one-hour meeting with the First Minister and was able to put the campaign for carers' rights into a European wide context.

Scotland's First Minister Alex Salmond at the second Scottish Carers Parliament on 1 October 2013 (credits: photo©marcmarnie).



On 2 October, representatives from Austria, Germany, Ireland and Scotland shared their grassroots campaign work against carer poverty. They agreed to join forces around some actions for the future and will:

1. use the annual **International Day to Eradicate Poverty on 17 October** to draw attention to the poverty risk of caring in their countries and across Europe.
2. produce for 2013 a template letter for carer organisations in different countries to amend for their own purpose. They will send this letter to their prime minister, government or political party leaders, and make use of the letter with press and media, as their resources allow
3. request Eurocarers to take up the issue of carer poverty and act as an umbrella for a growing focus of campaigning initiatives by carer groups across Europe
4. request Eurocarers to raise the issue of carer poverty at the Carers Interest Group in Brussels on 16 October and in any future policy and carer strategy development.
5. Seek more opportunities for international grassroots learning exchanges as they provide much stimulation, motivation and international solidarity.

Carers representatives from four European countries enjoying dinner together in a break of Scotland's Carers Parliament on 2 October 2013 (left to right: Silvia Wölki, Johanne Powell, Caroline Dunphy, Clare Duffy, Frank Goodwin, Sabine Feldt, Susanne Hallermann)



The Second National Informal Care Forum and other activities in Estonia By Helle Lepik and Ivar Paimre (Chairpersons of NGO Estonian Carers)

The Second National Informal Care Forum

In the light of European Year of Citizens 2013, we – NGO Estonian Carers – organized the “Second National Informal Care Forum”. It was held on 24 August 2013 at Viljandi, Estonia. (nb: The First Forum took place in October 2011). The Forum gave an overview of the

situation of informal carers across the EU. The main focus was on recognising the work of informal carers in society, combining work and family life, protecting their social rights and health, understanding the necessity of additional social services. The most important aspect relates to what the future holds for informal carers, and what kind of developments they can count on.

The Forum had some prominent guests and speakers – Minister of Social Affairs of Estonia, Mr Taavi Rõivas; Chairperson of Social Affairs Committee of the Parliament, Mr Margus Tsahkna; Social Affairs Committee and Estonian Parliament member, Mrs Helmen Kütt; Head of Viljandi City Council, Mr Tarmo Loodus; and by video shared his thoughts, Estonian MEP Mr Ivari Padar. In addition, we were privileged to host two international guests – Mr Yrjö Mattila, representative of Informal Care network of Finland and Mr Frank Goodwin, President of Eurocarers.

The Forum was successful and presented new ideas to the more than 100 people attending. The main topics discussed during the Forum included:

1. The Minister of Social Affairs gave an overview of the near future of informal carers in terms of budgetary possibilities, taking into account the new ESF funding period. The focus is on sustainability of social services and support and how to take it to the new level via social welfare measures to support employment and reduce home care dependency.
2. Social services and support for informal carers by municipalities. In Estonia, local municipalities have responsibility for organising and offering social services and support. A comparison of municipalities showed that the level of capability is very different, taking into account the location and the size of municipality. As the municipalities have the right to decide what kind of services they offer, the outcome depends on budgetary possibilities and knowledge of social affairs. Ideally, the level of services and capability of municipalities could and should be equal, or at least harmonized to some degree, across the country.
3. Daily themes of Finnish informal care. Mr Yrjö Mattila gave an overview of developments of Finnish informal care. This provided an opportunity to compare the state of informal care in Estonia and Finland. Furthermore, it shed light on understanding differences on the cultural basis, especially when in Estonia some regions are mainly populated by people with Russian background.
4. Eurocarers as European Association Working for Carers. Mr Frank Goodwin described the work of Eurocarers and developments regarding carers across the EU. Bringing his experience and sharing his views gave the audience some new ideas regarding Estonian informal care: valuing the voluntary work of carers, that in essence has a price, carers are an essential part of social care, and the sustainability of services depends on them.
5. Nature helps to support the coping of disabled persons and their family members. Mr Priit Adler, Chairman of NGO Ökokratt, described the role of nature as soothing and a potential therapeutic environment for disabled persons and their family members. How it helps to find peace and solace and widens our senses. Mr Priit Adler is also the creator of the first sensory garden in Estonia. Sensory gardens are founded on the five senses of human beings - seeing, hearing, smelling, touching and tasting.

In conclusion, the Forum was a success. Given the interesting topics and supportive audience, it is safe to say that there are exciting times ahead for us in Estonia. Although

there is much to be done in social affairs, there is hope for new developments and growth in this regard.

Other activities in Estonia

In September, NGO Estonian Carers published an **article in the journal *Social Work***. This is an Estonian professional journal published since 1997, contributing to professional growth and the broadening of horizons of people working in the social care field. The journal is published by the National Institute for Health Development and the Ministry of Social Affairs. In our article, we introduced our membership of Eurocarers and co-operation for future developments. New and wider networks give better opportunities to help informal carers by providing the best practices and useful information from all over Europe. Through the Forum, EuCa is now more widely known in Estonia and hopefully the awareness and willingness to participate in any form in EuCa's activities will increase.

On 18 September, the opening of the **first sensory garden** in Estonia took place. With NGO Ökokratt and other partners, our organization had the honour to be the first ones there. Hosting a social welfare home and coping school for disabled children was our privilege. This event received national recognition and was the start of new partnership to organize continued events to aid and help disabled children and their family members. (News clip in Estonian: <http://uudised.err.ee/index.php?06287543>)

For the remainder of 2013, our organisation is busy with **male informal carers**. Starting from September, our new project 'Male informal carers under the microscope' focuses on male informal carers, including examining special circumstances regarding male carers. Commonly, carers are female, but this initiative gives us the opportunity to see another side of caring. Also, this new project should help us to understand the coping mechanisms in place - or needed - for male carers and give us new ideas about how to support carers as families rather than just individuals.

In addition, our representative will take part in the '**Connecting Baltic Citizenship seminar**' being held in Stockholm, Sweden at the end of October. This seminar aims to create stronger networking connections between participating organisations as well as to provide knowledge about the 'Europe for Citizens' programme and other relevant tools. Our aim is to find new partners and ideas about how best to strengthen and develop the future of NGO Estonian Carers.

Wanted: the view of individual carers for next issues of the Newsletter!

One of our most active volunteers, Henk Bakkerode, suggested that, in order to give a more personal touch to our Newsletter, we should host in every issue a **portrait of a carer** from somewhere in Europe (or of someone who has been researching or contributing much to advocate the interests of carers), giving them the floor to explain what they are doing, how and why. To this end, we kindly ask our readers to **send us nominations**, including a short profile and possibly a photo of the nominated carer/researcher. Please remember the **submission deadline: 15 November 2013**. Thank you!

RESEARCH ON THE MOVE

Update on the INNOVAGE project

By Francesco Barbabella (INRCA, Italy)

EUROCARERS and INRCA are participating in the INNOVAGE project (www.innovage.group.shef.ac.uk/), a wide EU-funded project which aims at investigating the impact of social innovations on the quality of life and well-being of older people in Europe. In particular, the project will develop and test four major social innovations in different long-term care contexts. One of these social innovations will be properly coordinated and developed by INRCA and EUROCARERS: this intervention aims at developing a multilingual web platform addressing informal carers' needs, which will be implemented in 27 EU Member States. The final goal is to make available – at both European and national level – a set of web services supporting informal carers in different areas, such as: information; training on care provision; physical and psychological health; social participation; reconciliation of unpaid care and paid work; support and respite care. Additional national contents addressing employers of working carers and care professionals' needs, will be developed and implemented in certain EU countries.

On 25 September, a Stakeholder Forum was jointly organised in Sweden by the University of Sheffield (coordinator of the INNOVAGE project) and Lund University. The one-day meeting – held at the Scandic Star Hotel in Lund – was an opportunity for presenting the work plans related to the four social innovations to an external audience, comprising around 70 people (researchers, representatives of user organisations, policy makers and other stakeholders) interested in social innovations and active ageing issues. In particular, the Forum was structured so that all four social innovations could make a proper presentation of activities, as well as receive feedback from participants in dedicated discussion groups.

The presentation of the web platform for informal carers was made by Francesco Barbabella (INRCA) on behalf of the whole research team; the discussion group was then chaired by Frank Goodwin (EUROCARERS). Participants were asked to comment and give feedback on the basis of three key questions:

- *Is the platform design based on plausible and adequate conceptual principles?* Participants underlined the need to consider, especially in the implementation and dissemination phases, the dual role of carers (i.e. providing care and, at the same time, requiring assistance) and in particular the role of working carers (how is it possible to create care-supportive working environments?);
- *Do you see any significant gaps in the selected set of web-based support services? Which ones are the most relevant in your opinion?* Once again, the importance of promoting good practices of web-based services for carers through the platform was noted, as well as trying to enhance the platform subsequent to completion of the project through the development of dedicated apps for mobile devices and the connection with health data and telemedicine systems at local or national level. Some inputs were gathered concerning the possibility of further expanding the services for addressing needs of those migrant care workers privately-employed by households;

- *What problems and issues might arise in implementing such a platform in all EU countries and in ensuring its sustainability in the long-term?* Different types of issues were mentioned in this respect, including the possible lack of collaboration of formal institutions (e.g. municipalities, health services) and the need for a robust sustainability plan after the project lifetime (one suggestion was to seek further funding now!). Concerning the dissemination phase, the main input was to develop a strategy that included a mix of traditional and innovative media, in order to involve as many users and stakeholders as possible.

Generally speaking, the audience recognised the efforts made to date by the team, and evaluated the project goal and methodology positively.

Second Partner Meeting of the ICARE4EU project

By Marja Pijl

Early in September, the second Partner Meeting of ICARE4EU took place in Utrecht (NL). This EU financed project aims to collect data on integrated care for people who cope with multi-morbidity. It has been agreed that multi-morbidity will be defined in ICARE4EU as a combination of at least two or more medically diagnosed long-lasting health or health and psychiatric problems. The projects whose data will be collected will be evaluated and the best practices will be selected for further study.

The meeting was well-prepared. We received progress reports on the various work packages before the meeting and so far the project seems to run smoothly and on time. The two major issues that were discussed in Utrecht were the questionnaires which will need to be answered by leaders of relevant integrated care projects and a draft dissemination strategy. The discussion of the questionnaire was intense but rather technical, because we will have to take into account that the situation and the concepts used in the various countries are quite different. Many questions will need an explanation in order to make sure that respondents understand correctly what the issues are we are trying to explore. Already in this early stage, plans are being made to inform a larger circle of potentially interested people of the project, of its aims and possibilities and in a later stage of its outcomes. Different channels of communication were discussed, including social media. A representative of BMJ (*British Medical Journal*) was invited for part of the meeting and he advised how ICARE4EU can use the various possibilities for dissemination that BMJ offers.

A final point on the agenda was finding experts in all 30 countries who can identify the integrated care projects in their country and invite them to fill in the questionnaire. In many countries such an expert has already been found, but there are still a few outstanding, like finding someone in Iceland.

Request to Eurocarers members: if you happen to know of any project of integrated care for people with multi-morbidity, please inform ICARE4EU. You can get in touch with the project via the contact form on the website www.icare4eu.org. I would appreciate it if you would copy me in on this information: marja.pijl@socialpolicy.nl.

The KEYFORA PROJECT

By Brigid Barron

The development of the knowledge society is increasing demand for key competences in personal, public and professional spheres. Competence is a combination of knowledge, skills and attitudes appropriate to a particular situation. The aim of the **KEYFORA** project (run within the “Leonardo da Vinci” EU Programme) is to develop and transfer an innovative method to allow the identification and measurement of key caring skills and competences, as identified in the European Framework of Key Competences, to benefit Family Carers, Home Care Workers and Migrant Care Workers.

Caring for Carers Ireland, one of six partners in this project, provided this training for Family Carers, Home Care Workers and Migrant Care Workers. The project enabled participants to enhance learning and identify key personal competences in the field of personal care, as follows:

- Build Personal and Professional Confidence
- Promote Employability Skills
- Identify strengths and weaknesses of beneficiaries before/or in the workplace
- Increase and improve key skills, essential to all businesses and jobs and increase mobility of all beneficiaries of the Keyfora Project.

The **KEYFORA** partnership aims to create a set of tools for identifying strengths and weaknesses of the candidate for employment, vis-à-vis their professional competence, but also to measure the path that lies ahead before entering the world of paid work. This information was gained through a Traffic Light Self-Assessment Skills Audit.

The ultimate beneficiaries of the project are Family Carers, Home Care Workers and Migrant Care Workers who, despite not having a formal qualification, want to increase their employability skills in terms of their core competencies and skills extending across all employment opportunities. In the table below you find an outline of the course contents.

Caring Skills & Competencies: Course Outline

Session 1	Personal Skills & Competences Self Assessment of Interests and Personality Traits
Session 2	Self Assessment & Personal Skills Audit Completion of Self Assessment from Session 1, showing strengths, weaknesses, interests and suitability for Caring Role
Session 3	Learning to Learn / Communication Learning Styles – VAK, Verbal / Non-Verbal, Visual, Written 3 Basic Communicative Skills – Empathy, Active Listening, Assertiveness
Session 4	Caring Skills for Older People Facial Expressions, Eye Contact, Alzheimer’s, Dementia and Therapeutic Hand Massage
Session 5	Role & Responsibilities of a Carer at Work / Risk Assessment Development of Caring Role Responsibilities and discussion and completion of Risk Assessment in the home

Session 6	Problem Solving Step by step IDEAL Model of Problem Solving. How to deal with difficult situations
Session 7	Teamwork Characteristics & Elements of Teamwork. Completion of Traffic Light Skills Audit
Session 8	Project Work Using TRACE Tool and Teamwork, produce "Spud Head" Painting

The partners from France, Belgium, Spain, Ireland, Italy, Slovakia bring together all the skills necessary to raise public awareness. They include training organisations, family carer organisations, personal and household service providers, local community organisations. These group partnerships will further diversify and ensure the relevance, feasibility and sustainability of actions taken.

Caring for Carers Ireland: visit of Board Member to training session



Thearapeutic hand care



SUPPORT WORKING CARERS TO HELP BUSINESSES AND BOOST THE ECONOMY **By Madeleine Starr, Carers UK**

This landmark report from Government, Employers for Carers and Carers UK argues for more support to help carers juggle work and care. Better support for working carers would give businesses and the UK economy a much needed boost and would save taxpayers £1.3 billion a year, according to a new joint report published today by the Government, employers and Carers UK. The report warns that as well as losing money, businesses risk losing valuable, experienced employees if action is not urgently taken to enable people with caring responsibilities to remain in work.

There are more than three million employees who currently have to balance their work commitments and their family caring responsibilities; almost two million of those people work full time. The report includes new evidence from over 200 employers which shows that providing these carers with better support in the workplace can result in cost savings for businesses. This is because better support of working carers:

- Improves staff productivity;
- Improves staff retention;
- Reduces sick leave and absenteeism rates among staff.

Carers already have a legal right to request flexible working hours after 26 weeks of continuous employment, and a Bill is going through Parliament that will give everyone that same right. This will reduce the stigma among carers when discussing this issue with their place of work. The Westminster Government is also exploring other ways of supporting carers who want to stay in work or are trying to return to employment. The Care Bill will give carers new rights to support that put them on the same footing as the people they care for – they'll have the right to get support from their local authority for the first time and councils will have to consider how they can work with providers to develop care and support services that enable people, including carers, to work.

But the report highlights the need for a cultural shift among businesses towards this issue; workplaces and services have shifted to help working parents to juggle family responsibilities and this shift in attitude now needs to take place for carers of older and disabled loved ones. This report recommends that:

- Employers renew their commitment to flexible working and actively promote the benefits of this approach with other businesses;
- Businesses “carer proof” their policies and procedures to ensure they are fit to deal with the UK’s growing care responsibilities; and
- Local authorities support the development of a care market that offers more flexible and affordable care and support services that enable carers to stay in work.

With a rapidly ageing population, the number of people who will face the challenge of balancing work and caring responsibilities is set to grow; this is therefore a growing challenge that businesses will need to address. Download the full report or read the report summary here: <http://www.employersforcarers.org/resources/research/item/808-supporting-working-carers-the-benefits-to-families-business-and-the-economy>

IN BRIEF

A New Vision for Care Nurse-Led Carers Clinic Evaluation: This report was recently produced by the Work Research Centre, Dublin, and Caring for Carers Ireland. It examines the support provided to family carers by a nurse-led carers clinic in County Clare, and can be accessed via the following link:

<http://www.eurocarers.org/userfiles/file/presentations/Nurse%20Led%20Carers%20Clinic%20Report.pdf>

CARER: Emilia Romagna Association of Family Caregivers: CARER is an Italian carers organisation for carers in the Emilia Romagna Region of Italy (centre-north). The organisation intends to act in synergy with all the associations that pursue similar goals and jointly promote policies to support caregivers. In particular, the Association will aspire to best practices developed at European level, and support shared objectives and proposals towards stakeholders and policy makers in Europe. Further information can be found on these two websites:

www.associazionecarer.it

www.caregiverfamiliare.it

Social Connectedness and use of Technology amongst Older Persons and Family Carers of Older Persons in County Clare (Ireland): This 2011 Caring for Carers Ireland report documents an exploratory study of the level of social connectedness experienced by older people and family carers from seven locations through County Clare, Ireland. It can be accessed via the following link:

<http://www.caringforcarers.ie/wp-content/uploads/2012/06/Social-Connectedness-and-Family-Carers-in-County-Clare.pdf>

Carer's Resource Allocation Systems: Local Authority Implementation in England:

This short study is an extension to a larger project about personalisation and carers. The extension will develop the evidence base surrounding the introduction and implementation of carer resources in English local authorities. It will begin to scope the different mechanisms and approaches local authorities have developed or are planning to use when allocating resources to carers. For information about the extension (and main) study, use this link: <http://php.york.ac.uk/inst/spru/research/summs/personalisationC.php>

Care Alliance Ireland Exchange: The summer edition of the Care Alliance Ireland Exchange newsletter can be downloaded using this link:

<http://www.carealliance.ie/userfiles/file/Care%20Alliance%20Exchange%20Summer%202013.pdf>

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.

Since then the association has increased remarkably, especially in the last year, and includes now over 60 organisations and several individual associates from all 27 European Member States. Members of the current (2013-14) Executive Committee are: Frank Goodwin (President), Hanneli Döhner (Vice President Carers Associations), Giovanni Lamura (Vice President Research), Licia Boccaletti, Marijke Steenbergen, Helle Lepik and Marja Tuomi. In addition, the Executive is supported by two advisers, Christine Marking and Marja Pijl. For more information on the members of the Executive Committee: 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>.

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EUROCARERS is an NGO & non-profit organisation registered in Luxembourg in 2006 (registration no. F6854).

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