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# EUROCARERS

### EUROPEAN ASSOCIATION WORKING FOR CARERS

#### Dear readers

Welcome to the Spring edition of our newsletter. This is the start of a new season of activities for our network and we are delighted to confirm that we will be able to rely on the European Commission's support this year (and beyond) since our annual work programme has now been approved and our partnership agreement was signed a few days ago. This will not only contribute to structuring our work at EU level up to 2021, it will also allow us to play an active role in the implementation of the "Pillar of social rights" which – as you know – aims to deliver new and more effective rights for citizens and, in doing so, provides a renewed positive environment for our mission. The equality of treatment and opportunities between women and men, equal opportunities of under-represented groups, the provision of work-life balance mechanisms for parents and carers as well as the development of a coordinated approach to affordable long-term care services of good quality, home care and community-based services are among the principles of the Pillar which we can use to make the case for carers across the EU. Money is nevertheless the sinews of war and we it will therefore be important to keep an eye on the ongoing negotiations regarding the next Multi-Annual Financial Framework 2021-2028 (MFF) since none of the ambitions defined in the Social Pillar will be achieved without the allocation of adequate resources. We therefore collaborate with fellow EU umbrella organisations to monitor this crucial process and advocate for a socially inclusive Europe. You can therefore expect more details about the next MFF in our next publications and at the AGM.

In this newsletter, you will find our now customary update on the EC proposal regarding work-life balance for parents and carers, which – among other things - has been the subject of interesting exchanges in the European Parliament's committees in charge of employment and social affairs as well as gender equality. You will find a detailed summary of these discussions below as we believe that they provide a very clear and comprehensive overview of the approach adopted by each political party and country. You will also find information about the country reports recently published by the EC in the framework of the European Semester which now systematically capture policy developments in the field of long-term care, or lack thereof.

We hope that you will find the newsletter useful and interesting and – as always – we remain at your disposal should you have questions or require additional information. The next edition of our newsletter will be circulated at the end of June 2018.

All the best,

Alemany

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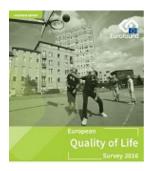
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### **EU Policy Developments**

#### Informal care and work-life balance: increasing pressure on carers



Eurofound's European Quality of Life Survey (EQLS) 2016 highlights that informal carers face an ever heavier burden. According to the EQLS, over half of respondents have problems in reconciling work and family life, a significant increase since 2007. While this particularly affects younger and mid-age women, his also is true for older workers (50-64): 60% of women and 53% of men declare difficulties to perform household work because of employment. The report also highlights the contribution of older people to caring for grandchildren and disabled family members.

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## European Semester Winter Package: reviewing Member States' progress on their economic and social priorities

The European Commission today publishes its annual analysis of the economic and social situation in the Member States, including progress in implementing country-specific recommendations and an assessment of possible imbalances.

The European economy is expanding robustly and the positive economic outlook is matched by an improved labour market and social situation. This reflects the reforms undertaken by Member States in recent years and provides a window of opportunity to further strengthen the resilience of the EU's economies and societies. Nevertheless, the recovery is not benefitting everybody in society equally and structural weaknesses are holding back growth and convergence in some Member States. That is why EU countries should use this momentum to further strengthen the foundations of their economies



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### EP EMPL - Work-life balance for parents and carers – consideration of draft report



On March 27, the EMPL Committee met for a consideration of its draft report on Work-life balance for parents and carers. The rapporteur, David Casa (EPP, MT), explained that in the draft report he focused on finding a balance between protecting the rights of parents and carers and not placing too much of a burden on SMEs and microenterprises. He also seeks to change leave remuneration from sick pay level to a percentage (75%) or gross salary. His proposals were seen favourably by most of the MEPs present but calls were also made to place a focus on workers' rights and ensuring that existing national benefits will not be reduced following the introduction of this directive. Please see below for a summary of the debate.

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### EP FEMM - Work-life balance for parents and carers – Consideration of draft opinion

On March 27, the FEMM Committee held a debate on the work-life balance for parents and carers dossier. The rapporteur for the FEMM opinion, Ms Agnieszka Koz?owska-Rajewicz (EPP, PL) focused on the objective of the Directive to increase women's employment and to well reflect its legal basis. Two crucial pillars of the proposal which the rapporteur considers fundamental for achieving these objectives are: non-transferability of parental leave and sick pay level of compensation during leaves. The rapporteur introduced several modifications with the intention of making the proposal responsive to the demands of the EU economies.



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#### Trade unions reiterate their support for the directive on work-life balance

The European Trade Union Confederation (ETUC) reiterated its support for the proposal for a European directive on work-life balance for parents and carers at an ETUI Monthly Forum on 17 April. The main results



of a comparative study of the systems already in place in the Member States, which the ETUI had requested from the European Social Observatory, were presented at the Forum.

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## GUE/NGL Group - Macron must unblock Work Life Balance Directive for sake of equality

Ahead of his appearance at the European Parliament on the 18th April, MEPs from four different political groups have urged Emmanuel Macron to push in favour of legislative proposal that would improve parental leave standards across Europe.

Members from GUE/NGL, S&D, Greens/EFA and ALDE have joined forces to call on the French President to unblock the Work Life Balance Directive at the EU Council - one of the key elements in the European Pillar of Social Rights. By hindering the Directive, Macron could very well torpedo the continuity of the entire political initiative - a key priority for the European Commission during this legislature.



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### The FEMM Committee of the European Parliament approves a Pilot Project on young carers



Following up on the last meeting of the European Parliament Interest Group on Informal Carers, the MEP Sirpa Pietikainen has submitted a pilot project proposal on young carers. Pilot projects are designed to test the feasibility and usefulness of specific activities. They are used to identify good practices and provide policy guidance for the benefit of possible future initiatives.

Eurocarers has been in contact with the MEP office and has contributed to the development of an abstract.

The title of this pilot project is: Young carers in Europe: Who are they and what support do they need?

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## DG Justice Newsletter on rights of the child includes a whole section on young carers

The latest issue of the DG Justice Newsletter on the Rights of Child features a whole section dedicated to Raising awareness on the issue of young carers! It includes a report of the Interest Group on Informal Carers, held on 6th March, as well as a clear reference to the Me-We and Edy-Care Projects and to Eurocarers activities on young carers in general.



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#### OECD - Which policies increase value for money in health care?



The incentive structures produced by different institutional arrangements in health systems are important determinants of their performance and can explain some of the differences in cross-country performance patterns.

This paper proposes an approach and quantitative method to investigate how different policies and institutions helped achieving better value for money across 26 OECD countries for the period of 2000-2015.

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### ECB - The economic impact of population ageing and pension reforms

This article examines the macroeconomic and fiscal implications of population ageing in the euro area and looks at how pension reforms can help to address these challenges. According to Eurostat's latest projections, population ageing is set to continue and even intensify in the euro area over the next few decades. This ongoing process, which stems from increases in life expectancy and low fertility rates, is widely expected to lead to a decline in the labour supply and productivity losses, as well as behavioural changes, and is likely to have an adverse effect on



potential growth. Furthermore, euro area countries are also projected to experience further upward pressure on public spending on pensions, health care and longterm car as their populations age.

#### Health Systems in the EU: Commission publishes report on Primary Care

On the 5th March, the EU Expert Group on Health Systems Performance Assessment (HSPA) published its report "A new drive for primary care in Europe: rethinking the assessment tools and methodologies" to help policy makers and health practitioners to set objectives and measure progress towards improving primary care services for the benefit of patients.

The report examines core aspects of well-performing primary care systems, focusing on their key functions such as access, coordination of care and continuity of care.



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### The impact of Brexit on patients and public health should be prioritised in 2nd phase of negotiations

Eleven organisations including the European Heart Network (EHN) representing patients across the UK and Europe have alerted EU negotiators to the risk of drugs getting stuck at borders, regulatory systems for medicines splintering and potential breakthrough research collaborations being forced to stall.

In a joint letter to Brexit negotiators Michel Barnier and David Davis, the organisations make a plea to both sides of the negotiations not to forget about patients.



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### Research in Action

Update on the Me-We Project – towards improved resilience and enhanced social support for adolescent young carers

The Me-We project brings together Eurocarers and 9 of its members, with the aim to strengthen the resilience of Adolescent Young Carers in transition to adulthood (15-17 years old), in order to impact positively on their mental health and well-being. This ambitious research project –funded by the European Union under the Horizon 2020 Programme- only started in January 2018; yet, many tasks have already been carried out, thanks to the great commitment and hard work of the project partners.



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#### The European Social Network publishes new toolkit 'Towards more independent lives for people with disabilities: Reflections from social services across Europe'



in Europe

The European Social Network's (ESN) new toolkit 'Towards more independent lives for people with disabilities: Reflections from social services across Europe' showcases steps that can be taken by social services to promote the independence and autonomy of people with disabilities. It is based on the results of ESN's working group on disability which brought together ESN members to share and discuss innovative practices and policies from their own services for people with disabilities. The toolkit is divided into different thematic chapters each providing overviews of national policies, detailed descriptions of local practices, and key challenges and opportunities for disability services planners and providers.

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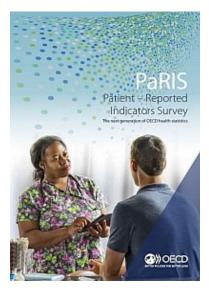
## Eurocarers' contribution to the work of the ROSEnet consortium on reducing social exclusion in old-age

How are older people and ageing positioned within European and international policies? How the existing policy frameworks, such as the European Pillar of Social Rights or Sustainable Developments Goals can be effectively applied to combat and reduce oldage social exclusion? How more effectively support and empower older persons, in particular those in vulnerable situations, to fully participate in society?



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#### OECD - Patient-Reported Indicators Survey (PaRIS)



Health care seeks to improve people's well-being and their ability to play an active role in society. Yet health systems know very little about how often they achieve this. The success of health care is typically measured by survival rates, or rates of cure, after treatment. Often, though, differences between the best- and worst performing hospitals are small. It is only when we measure outcomes reported by patients themselves – such as quality of life – that important differences in the outcomes of care emerge.

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## mHealth Economics – How mHealth App Publishers Are Monetizing Their Apps

This is the 2nd report of the mHealth Economics 2017/2018 program. The second report " How To Monetize Mobile Health Apps " gives detailed insights into download numbers, monthly active users, app marketing, revenues, business models and development costs of mHealth apps. The report shows the best ways to monetize mobile apps and how much money app publishers in healthcare are making.



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Impact of EU-funded Research & Innovation on ICT for active & healthy ageing



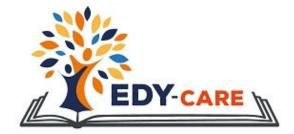
Ageing poses one of the biggest economic and social challenges for this century. It is estimated that by 2025, more than 20% of Europeans will be 65 or over. A selection of the top 25 most relevant projects has been identified in agreement with the EC to extract the key findings on results achieved. The study results will be used for the further development of priorities under the EU Horizon 2020 Societal Challenge 1 Health, demographic change and wellbeing1 and as input for the further implementation of the policy initiative on a 21st century blueprint of digital solutions for AHA.

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## Update on the Edy-Care project: your support is needed to help young carers to enjoy their right to education

On 5 and 6 April, the Edy-Care project partners met in wonderful Ljubljana for the second transnational project meeting.

The main focus was the finalisation of the first project output: a self-assessment questionnaire to be filled in by students, in order to identify those who have caring responsibilities and the perceived impacts of the caring role on their education. This new tool builds on the MACA-YC18 (Joseph & Becker), but it also includes additional questions suggested by the partners during previous project meetings. University of Ljubljana coordinated the efforts of developing, piloting and testing the new assessment tool for identifying young carers.



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## Care4Dem partners discuss a review of relevant practices and policies (Madrid, 27 April)



What is the state of play regarding ICT-based mutual support groups for carers in the EU? This was the topic discussed by Care4Dem project partners during their second meeting, on the basis of a review of evidence coordinated by Instituto de Salud Carlos III between September 2017 and March 2018.

### Events and Calls for proposals

## Conference of Partners EIP on AHA: 'Digital transformation of health and care for active & healthy ageing in Europe'

370 participants attended the 6th Conference of Partners of the European Innovation Partnership on Active and Health Ageing (EIP on AHA) held on 27 and 28 February. The EIP-AHA partners discussed how to align themselves to the actions of the Digital Single Market and the future Commission Communication on Digital Transformation of Health and Care.



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### News from the network

### The EP Interest Group on Informal Carers meets to discuss "Young carers – challenges and solutions", 6 March 2018, Brussels

Meeting on 6 March in the European Parliament in Brussels to discuss on "Young carers – challenges and solutions", the European Parliament Informal Carers Interest Group addressed the challenges and issues faced by young carers, i.e. children and young persons under 18 who provide care, assistance or support to another family member – a parent, sibling or grandparent affected by chronic physical or mental health conditions.



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#### Update on the Eurocarers Young Carers Working Group

The Eurocarers Young Carers Working Group has been established in May 2017, building on the



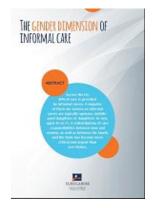
incredible energies shared during the International Young Carers Conference (Malmo, Sweden). The group currently consists of 21 members from 11 States (Australia, Belgium, Denmark, Finland, France, Germany, Italy, Netherlands, Norway, Scotland/UK, Sweden) and it is constantly open to new members, as long as they are young carers, former young carers or organisations dealing exclusively on young carers. On 6 March, the members met in Brussels, to agree on the next steps of its work.

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### Eurocarers launches a publication on "The gender dimension of informal care"

Across the EU, 80% of care is provided by informal carers. A majority of them are women, as informal carers are typically spouses, middle-aged daughters or daughters-in-law, aged 45 to 75.

EIGE's Gender Equality Index shows that the unequal distribution of care and domestic responsibilities between women and men remains the most problematic area in the EU in terms of gender equality. Eurocarers' recent publication on "The gender dimension of informal care", launched at the occasion of International Women's day 2018, aims to underline the causes, consequences and possible solutions to the of the gender dimension of informal care.



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## Eurocarers contribution to a symposium on gender equality in the workplace: the role of unpaid care work



On 10th April 2018, Eurocarers – represented by Francesca Centola- participated in a symposium on Fostering Gender Equality in the Workplace, in Brussels.

This symposium - organised by Public Policy Exchange- provided a timely opportunity for experts, national authorities, social partners and other key stakeholders to discuss the latest policy developments at EU level to tackle gender-based discrimination in the workplace. It also allowed delegates to analyse the different drivers of

inequality between men and women at work and to identify priorities for future policy actions in order to remove the remaining barriers to women's access to the labour market.

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#### Eurocarers participates in the WHO High-level regional meeting, 'Health systems respond to Non-Communicable Diseases: Experience of the European Region, Sitges, Spain 16-18 April

Over 200 delegates from 39 Member States, non-state actors and other United Nations agencies met to discuss how best to accelerate health system transformation for faster reductions in premature NCD mortality, otherwise known as 'leapfrogging'. If current trends continue it will take another six decades to close the gap between 'high burden' countries and those in the original EU-15 countries. Hans Kluge, Director, WHO Regional Office for Europe made the case for a more comprehensive and aligned health systems response to NCDs.

Elizabeth Hanson, Eurocarers VP Research, participated in a session on how to make the strategies of people centred integrated services happen!



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#### Eurocarers calls upon French President Macron to support the Work-life Balance Directive



#### Together with our French member organisations, l'Association Française des Aidants and La Compagnie des Aidants, as well as 51 EU and national organisations, Eurocarers signed an open letter to the French President ahead of his address to the European Parliament on the 17th April.

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Greece - Intervention for children entitled "Who am I, grandpa?"

The project entitled "Who am I, grandpa?" is an experiential workshop for children and adolescents, which has designed and accomplished by Alzheimer Hellas.

Three psychologists specialized in dementia, have conceived and realized this intervention, which is taking place either in Elementary schools in order to raise children's awareness of dementia or in the framework of Alzheimer Hellas in order to inform grandchildren (6-12 years old) about people with dementia. The attitude of the children towards patients with dementia is possible to change when they have the opportunity to understand the symptoms, causes and prognosis of dementia and also, to learn new ways of interaction with the demented grandparents.



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#### Resource for Former Carers in Ireland Launched



In collaboration with a number of former family carers and other not-for-profit organisations including the Irish Hospice Foundation, University College Cork, and West Cork Carers Support Group, as well the Health Service Executive. Care Alliance Ireland has produced a booklet aimed at former family carers. The target audience is family carers who are no longer providing care (in any way), generally due to the death of a loved one. Since its launch in March 2018, 2,000 hard copies have been distributed across Ireland and beyond, whilst there have been over 3,000 direct downloads of the booklet.

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## Care Alliance Ireland launches new Discussion Paper on the topic of difficult relationships and family caring

The latest in their ongoing Discussion Paper series, this discussion paper, entitled Difficult Relationships and Family Caring, continues the series' goal of introducing some lesser discussed topics which may affect family carers.

Caring for a 'loved one' has long been acknowledged as having real implications for family carers' physical and mental health, along with economic, employment and other impacts. Not all of these impacts, however, are negative. The positive impact of providing care – often significant levels of care – has been well researched.



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#### Swedish minister highlights the needs of carers



On 23-24th April, Eurocarers member "The Swedish Family Care Competence Centre" (SFCCC) arranged a two day national conference "Life's Opportunities – carers of children with multiple and profound disabilities" in Stockholm, Sweden.

A national conference with the aim to offer an arena for knowledge exchange between carers, staff, representatives from civil society, researchers and decision makers so that they can work together for an improved carer support that meets their needs both now and in the future.

The opening speaker was Lena Hallengren, the Swedish Children, Older People and Gender Equality Minister.

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