EUROCARERS

EUROPEAN ASSOCIATION
WORKING FOR CARERS

# The relevance of EU policy development to carers and vice versa

## An overview

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Eurocarers receives support from The European Union through the programme for Employment and Social Innovation (EASI Programme 2014–2017)

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# I.
# INTRODUCTION

This document aims to emphasize both the political and societal relevance of carers as well as the need to specifically include carers in current EU policy development. It was elaborated by Eurocarers in cooperation with the European Parliament Interest Group on Carers, as part of a 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, and highlights those issues on the current agenda that have a bearing on carers – thus providing a practical guide on how to better take account of carers in current and future EU policy development.

# II.
# CARERS – WHAT ARE THE ISSUES?

Carers are persons of all ages who provide care (usually unpaid) to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal employment framework. Research has pointed out that approximately 80% of care across the EU is provided by families (spouses and children) and friends. Even in countries with a well-developed supply of formal long term care, the number of informal carers is estimated to be at least twice as large as the formal care workforce.

Estimates also suggest that the economic value of unpaid informal care – as a percentage of the overall cost of formal long-term care provision – in EU Member States ranges from 50 % to 90 %. For example, in the UK, it has been calculated that the value of informal care equals £ 119 billion (€141.2 billion) – a huge contribution in times of austerity and tight health and social budgets.

From the above, it is clear 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.

However, this precious resource is under pressure: the combination of various demographic and socio-economic developments – such as lower birth rates, the trend towards smaller families, increasing mobility (leading to greater physical distances between relatives), the rising number of women entering the labour market and a prolonged working life due to delayed retirement (partly following explicit policies aiming at increasing labour force participation of women and older workers) – is rapidly leading to increased strain on carers, as a direct result of the decreasing unpaid care potentials. In addition, in many countries, governments aim to decentralise care provision, and count on society to step up to the challenge. Moreover, these developments are being compounded by increasing shortages of formal caregivers, and this is rapidly becoming a major issue in the majority of EU Member States.

While caring for a loved one can be a source of personal satisfaction and emotional gratification. Caring can have – if not adequately supported – many challenging consequences for carers:

- It can impact on the (physical and mental) health and well-being of carers themselves;
- It can have consequences in terms of social participation, integration and inclusion, especially in cases where their care is needed around the clock;
- It can lead to financial difficulties and poverty, due to cut backs in social provision and direct costs of care (e.g. medication, heating, special diet), medical devices, home adaptations and payments for formal care;
- It can lead to difficulties in relation to balancing paid work with care responsibilities, which can impact on labour market participation. Many carers of working age (mainly women) cannot cope with these multiple pressures and are forced to reduce or give up work – which has a negative impact on their social protection rights and hence, their financial situation later in life.
- With respect to young carers, caring can have a negative impact in terms of the natural socialisation processes as well as their formal education, significant impact on family relationships and employment prospects in later life.

Caring can also have negative consequences for society and the economy, as informal care provision can result in lower productivity for those carers that combine care and work in an unsupportive environment. It can also lead to increasing health and welfare costs, due to carers' physical and mental health problems.

The above underlines the urgent need for actions aimed at building and strengthening carer resilience and putting support in place that enables them to continue to care.

All Member States are facing comparable challenges in terms of long-term care provision, both with respect to the development and implementation of effective care provision models as well as in relation to financial sustainability. While care provision differs greatly between (and sometimes within) Member States, it is clear that all countries need the resource provided by informal carers to prevent a collapse of the entire care system.

# III.
# RELEVANT EU POLICY DOMAINS WITH A BEARING ON CARERS

Despite the obvious importance of the contribution of carers as outlined above – both to care supply 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 and across-the-board manner: health, social, education, employment, social security, transport and housing policies, all come into play in different ways. This chapter lists the various current policy initiatives that have a bearing on carers, thus underlining the potential to address carers issues more strongly on the one hand side while providing a practical guide of how and where to take better account of carers on the other.

## 3.1 SOCIAL POLICY

### Europe2020

Europe 2020, the EU's ten-year jobs and growth strategy, addresses a number of specific policy targets, also related to education, social inclusion and poverty reduction. Progress towards the Europe 2020 targets is encouraged and monitored throughout the European Semester, the EU's yearly cycle of economic and budgetary coordination.

As part of the efforts to achieve Europe2020's objectives, the Commission proposes integrated guidelines – broad guidelines for the economic and employment policies. Health is recognized as an important condition for economic growth and prosperity.

### The European Semester

As part of the European Semester, the yearly cycle of economic policy coordination, the Commission carries out a detailed analysis of EU Member States' plans of budgetary, macroeconomic and structural reforms and provides them with country-specific recommendations for the next 12-18 months. Health and long term care provision are one of the elements addressed.

The Semester should take carers-related issues into account, as part of its work on health and long term care.

### Communication on the European Pillar of Social Rights

Proposed by the Commission in April 2017, the European Pillar of Social Rights sets out a number of key principles and rights to support fair and well-functioning labour markets and welfare systems. It will serve as a compass for a renewed process of convergence towards better working and living conditions among participating member states. It is primarily conceived for the euro area, but is applicable to all member states wishing to participate.

There are 3 main categories of the Pillar:

- Equal opportunities and access to labour market
- Fair working conditions
- Social protection and inclusion

Carers should be explicitly addressed by the Social Pillar as many of their concerns and issues directly relate to social policy and social rights.

### The Employment Guidelines and strategy

The European Employment Strategy (EES) aims to create of more and better jobs throughout the EU. As part of this strategy, the Commission issues a set of guidelines, approved by the Council, presenting common priorities and targets for national employment policies. They frame the scope and direction for Member States' policy coordination and provide the basis for Country Specific Recommendations (as part of the European Semester). Fairness, combating poverty and promoting equal opportunities are part of the guidelines.

The Employment Guidelines should have a stronger focus on work/life balance in order to enable carers

to combine work and care responsibilities and ensure continued activity in the labour market.

## The EaSI Programme

The Employment and Social Innovation (EaSI) programme is an EU financing instrument to promote a high level of quality and sustainable employment, guaranteeing adequate and decent social protection, combating social exclusion and poverty and improving working conditions.

The programme provides financial support to Eurocarers.

## The European Social Fund (as regards training)

The European Social Fund (ESF), the EU's main financial instrument for supporting employment and promoting economic and social cohesion, helps people get a (better) job, integrating disadvantaged people into society and ensuring fairer life opportunities for all – mainly by investing in skills.

Training for carers (care skills) as well as re-training for paid employment after a period of absence from work due to care responsibilities are relevant in this respect.

## The Disability Strategy

The EU promotes the active inclusion and full participation of disabled people in society, in line with the EU human rights approach to disability issues. The EU European Disability Strategy 2010-2020, builds on the UNCRPD. Amongst its eight priority areas are accessibility, participation, equality, social protection and health.

Those who care for people with disabilities should be considered by the Strategy as well.

## Gender Equality Initiatives

Equality between women and men is one of the EU's founding values and a number of initiatives to improve equality have been taken in recent years, such as equal treatment legislation, gender mainstreaming and specific measures for the advancement of women.

However, gender gaps remain; in the labour market, women are still over-represented in lower paid sectors and under-represented in decision-making positions. Current initiatives include the Strategic engagement for gender equality 2016-2019, setting the framework for the EU's future work towards improving gender equality.

As most carers are women, equality initiatives should take carers into account, especially with respect to their employment situation and possibilities to combine care and work.

## Social Investment Package

The Commission's Social Investment Package:

- Guides EU countries in using their social budgets more efficiently and effectively to ensure adequate and sustainable social protection;
- Seeks to strengthen people's current and future capacities, and improve their opportunities to participate in society and the labour market;
- Focuses on integrated packages of benefits and services that help people throughout their lives and achieve lasting positive social outcomes;
- Stresses prevention rather than cure, by reducing the need for benefits. That way, when people do need support, society can afford to help;
- Calls for investing in children and young people to increase their opportunities in life.

Carers are an inherent part of social policy and many of the areas addressed by the Social Investment Package have a direct or indirect impact on them.

## Social Innovation

Social innovation relates to developing new ideas, services and models to better address social issues. It invites input from public and private actors, including civil society, to improve social services.

Social innovation is part of the social investment package. Social policy experimentation tests the validity of new innovative policies by collecting evidence about the real impact of measures on people.

Carers are an inherent part of social policy and should benefit from social innovation.

## Demography Initiatives

The EU is facing unprecedented demographic changes (an ageing population, low birth rates, changing family structures and migration). In the light of these challenges it is important, both at EU and national level, to review and adapt existing policies. Key policy responses to manage demographic change include supporting demographic renewal through better conditions for families and improved reconciliation of working and family life and ensuring sustainable public finances to guarantee adequate pensions, health care and long-term care.

Demographic change has an important impact on the informal care resource (e.g. more people in need of care, smaller families, increased mobility, increasing numbers of women entering the labour market…). Carers should therefore not be forgotten in policies addressing demographic change and its consequences.

## European Platform for Investing in Children

The European Platform for Investing in Children (EPIC) is an open platform where stakeholders and interested users can submit innovative and effective practices in the area of child and family policy.

It took over the work done by the Group of Experts on demographic issues for the European Alliance for Families, which ended in December 2012.

Young carers may have to skip school because of their care responsibilities, which impacts on their chances later in life; the Platform could take young carers into account.

## Social Protection

The main policy framework in the field of EU social protection is the Europe 2020 strategy and the open method of coordination for social protection and social inclusion ('Social OMC'), which aims to promote social cohesion and equality through adequate, accessible and financially sustainable social protection systems and social inclusion policies. Through the Social OMC – and in collaboration with the Social Protection Committee – the EU provides a framework for national strategy development for social protection and social investment, as well as for coordinating policies between EU countries on issues relating to poverty and social exclusion, health care, long-term care and pensions.

The social OMC could pay specific attention to carers and their role in long-term care provision as well as the impact of caring responsibilities on their social protection rights.

## Actions on Corporate Social Responsibility

The European Commission believes that CSR is important for the sustainability, competitiveness, and innovation of EU enterprises and the EU economy. Companies can become socially responsible by integrating social, environmental, ethical, consumer, and human rights concerns into their business strategy and operations. The Commission promotes CSR in the EU and encourages enterprises to adhere to international guidelines and principles.

Employers should be stimulated to enable carers to combine work and care (e.g. respite care, flexible working hours)

## Youth Policy

The EU Youth Strategy sets out a framework for cooperation covering the years 2010-2018 with two main objectives, i.e. to provide more and equal opportunities for young people in education and the job market and to encourage young people to actively participate in society. Initiatives are being proposed in eight areas including education & training, employment & entrepreneurship, health & well-being and social inclusion.

Young carers should be taken into consideration.

## 3.2 HEALTH

### The EU Health Programme

The EU Health Strategy «Together for Health» supports the overall Europe 2020 strategy. The EU's third health programme (2014-2020), is the main Commission instrument to implement this strategy and seeks to promote health, prevent diseases and foster supportive environments for healthy lifestyles, contribute to innovative, efficient and sustainable health systems and facilitate access to better and safer healthcare. It is implemented by means of annual work plans which set out priority areas and the criteria for funding actions under the programme.

Carers are at risk of stress, burn-out and physical illness as a result of their caring responsibilities: they should be explicitly targeted by the Health programme.

### Mental Health Compass

In November 2005, the Commission published a Green paper - Promoting the Mental Health of the Population, focusing on mental health in older people, in young people and in employment; and on prevention of depression and suicide and stigma. Following this, a Joint Action Mental health and Well-being was launched in 2013, with the aim to develop concrete recommendations for actions in the fields addressed by the Pact as well as on mental health in all policies. The Joint Action has come to an end in February 2016; EU level activities on mental health are now being taken by means of the European Compass on Mental Health, a mechanism to collect, exchange and analyse information on policy and stakeholder activities in mental health. This will disseminate the European Framework for Action on Mental Health and Well-being resulting from the Joint Action and it will monitor mental health and wellbeing policies and activities by Member States and non-governmental stakeholders.

Carers taking care of people affected by mental health conditions are even more vulnerable to (mental) health problems, if only due to the stigma attached to mental health; future EU action on mental health should explicitly include a focus on carers, not least because of the growing trend towards community mental health care.

### CHRODIS + (September 2017 – August 2020)

Between 2013 and 2016, the EU Joint Action on Chronic Diseases and promoting healthy ageing across the life-cycle (JA CHRODIS) aimed to address the potential to reduce the burden of chronic disease by bringing together and making better use of existing knowledge. Its successor, CHRODIS PLUS Joint Action of the European Union, supports Member States through cross-national initiatives identified in the JA-CHRODIS to reduce the burden of chronic diseases. CHRODIS PLUS promotes the implementation of policies and practices with demonstrated success in closely monitored implementation experiences. A total of 42 beneficiaries representing 20 European countries will collaborate to implement pilots and generate practical lessons in this Joint Action.

If carers provide 80% of the care for people affected by chronic conditions, it is obvious that the Joint Action should take account of carers and their need for support.

### AHA-EIP

The European Innovation Partnership on Active and Healthy Ageing was put in place as a result of the recognition of the Commission that active and healthy ageing is a major and common societal challenge and an area which presents considerable potential for Europe to lead the world in providing innovative responses to this challenge. The Partnership pursues a triple win for Europe:

- enabling EU citizens to lead healthy, active and independent lives while ageing;
- improving the sustainability and efficiency of social and health care systems;
- boosting and improving the competitiveness of the markets for innovative products and services

This will be realised in the areas of prevention and health promotion, care and cure, and active and independent living of older people.

The AHA-EIP is one of the first EU initiatives that explicitly takes account of carers; this focus should be expanded and not be lost in the vast number of activities being carried out.

## 3.3 INFORMATION AND COMMUNICATION TECHNOLOGIES

The Commission's Information and Communication Directorate General is leading a programme of research to map and develop more systematic and scientific evidence on ICT-based services for independent living and elderly care at home. This programme aims to help European policy makers make decisions on how to design, implement and transfer successful strategies for long-term care, based on technological solutions.

Carers could benefit from home based ICT care solutions and should therefore be explicitly targeted and involved with the development of this type of solutions. The Ambient Assistive Living Programme is highly relevant in this respect.

## 3.4 RESEARCH

### Horizon 2020

Horizon 2020 is the biggest EU Research and Innovation programme ever, as research is seen as a means to drive economic growth and create jobs. Horizon2020 brings together research and innovation, and focuses on three specific research sections, i.e. excellent science, industrial leadership and tackling societal challenges.

The specific action 'health, well-being and demographic change', as part of the section 'societal challenges, Responding to this challenge, research and innovation (R&I) under Horizon 2020 is an investment in better health for all. It aims to keep older people active and independent for longer and supports the development of new, safer and more effective interventions. R&I under Horizon 2020 also contributes to the sustainability of health and care systems.

More research is needed on the actual and practical needs of carers; Horizon2020 could contribute to this knowledge base.

## 3.5 JUSTICE

Communication: An initiative to support Work-Life Balance for Working Parents and Carers

One of the deliverables of the European Pillar for Social Rights is the 'New Start' initiative to address the work-life balance challenges faced by working parents and carers. After the withdrawal of the Maternity Leave Directive, the Commission has decided to take a broader approach in order to address women's underrepresentation in the labour market.

This new initiative takes into account the developments in society over the past decade in order to enable parents and other people with caring responsibilities to better balance their work and family lives and to encourage a better sharing of caring responsibilities between women and men.

Legislative measures: besides the introduction of paternity leave (at least 10 days) and strengthening parental leave a proposed Directive on Work-Life Balance for Parents and Carers introduces carers' leave for workers caring for seriously ill or dependent relatives. Working carers will be able to take 5 days per year, compensated at least at sick pay level. It also includes the extension of the right to request flexible working arrangements (reduced working hours, flexible working hours and flexibility in place of work) to all working parents of children up to 12 and carers with dependent relatives.

Non-legislative measures include ensuring protection against discrimination and dismissal for parents (including pregnant women and workers coming back from a leave) and carers, encouragement of a gender-balanced use of family-related leaves and flexible working arrangements, better use of European funds to improve long-term and childcare services and the removal of second earners which prevent women from accessing the labour market or working full-time.

The work-life balance initiative addressed carers directly. It should be implemented as soon as possible; following implementation, its impact should be monitored and evaluated and adapted where required.

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