



## 'ENABLING CARERS TO CARE'

### Proposal for an EU-level initiative in support of informal care provision

#### 1. Introduction

This document contains the rationale and framework for an EU-level initiative on carers. 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, makes the case for the added value of EU-level initiative, proposes areas where action is most urgently required and sets out tools and ways to address these issues.

#### 2. What are the issues at stake?

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)<sup>1</sup> – 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<sup>2</sup> 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 result of the decreasing unpaid care potentials. The increasing demand for care results in more and more of us becoming carers. When there were more

<sup>1</sup> Royal College of Practitioners report 2013

<sup>2</sup> Actively encouraged by the EU itself, with its target of a female employment rate of 75 % by 2020.

children in the family one (youngest daughter) often became the main carer; now when there are only one or two children it is more likely that we will have to take on caring responsibilities.

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<sup>3</sup>.

While caring for a loved one can be a source of personal satisfaction and emotional gratification. Caring it 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 cannot cope with these multiple pressures and are forced to reduce or give up work. They are more vulnerable to suffer stress, depression, social isolation and financial hardship;
- This in turn can lead to precarious financial circumstances: direct loss of income as well as limited access to social security and pension entitlements in later 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
- The onset severe disability or illness, leading to long term care needs often impacts negatively on other family members, especially children or other vulnerable adults, as the family tries to adjust to their new circumstances.

All of the above underline the need for actions aimed at building and strengthening carer resilience.

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.

Despite the obvious importance and contribution of carers - 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.

Addressing future challenges in long term care will require a comprehensive approach covering both policies for informal carers, and policies on the formal provision of LTC services and its financing. To date, policy attention has focused excessively on paid care systems with little attention being given to the services and supports required by families and communities in the provision of LTC. To meet this aim, policies which promote partnership and empowerment of carers should be developed.

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<sup>3</sup> <http://ec.europa.eu/social/BlobServlet?docId=8233&langId=en>

### 3. Rationale for an EU-level initiative

All Member States are facing the same 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.

Fortunately, recognition of the importance of carers and their contribution to care and well-being, society and the economy as a whole, is slowly on the increase: some EU member states now have specific policies for carers or carers' strategies in place<sup>4</sup>.

At EU level, the European Parliament has supported direct references to carers under the EU's PROGRESS programme budget lines since 2011; the European Parliament Interest Group on Carers is continuing to act as a forum for discussion on EU policy, assessing the impact of EU policy developments on carers.

As far as the European Commission is concerned, three recent and major initiatives refer explicitly to carers, i.e.:

- The European Innovation Partnership on Active and Healthy Ageing<sup>5</sup> : this Partnership explicitly targets carers as one of the main stakeholder groups;
- The Employment Package<sup>6</sup>, more notably the Staff Working Document on the employment potential of household and personal services, which contains a number of relevant statistics on carers and the need to ensure high quality and sustainable care provision;
- The Social Investment Package and its Staff Working Document on Long Term Care<sup>7</sup> explicitly recognise the huge contribution of carers and acknowledges their main issues and challenges.

These three initiatives contain many references to carers, which highlight:

- That a substantial part of long term care is provided by mostly untrained informal carers, and that long-term care provision should be seen as a combination of informal and formal care;
- The strong gender issues in relation to long term care provision, since women are the main recipients as well as the main providers of care;
- The increasing need for long-term care, on the one hand, and a shrinking informal care potential, on the other;
- The need for better and more comparable European data on the current provision of formal and informal long-term care;
- That informal care provision involves costs for the economy and the public budgets: informal carers may not be able to find or stay in formal work, which means that they do not contribute to taxes and social contributions;
- Some of the issues and challenges faced by carers, as already outlined above in section 2.

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<sup>4</sup> E.g. UK, Ireland, The Netherlands, Belgium

<sup>5</sup> [http://ec.europa.eu/research/innovation-union/index\\_en.cfm?section=active-healthy-ageing&pg=about](http://ec.europa.eu/research/innovation-union/index_en.cfm?section=active-healthy-ageing&pg=about)

<sup>6</sup> <http://ec.europa.eu/social/main.jsp?catId=1039&langId=en>

<sup>7</sup> <http://ec.europa.eu/social/main.jsp?catId=1044&langId=en&newsId=1807&moreDocuments=yes&tableName=news>

Importantly, the Commission underlines the ‘huge potential benefits of EU-level collaboration and policy coordination in this complex area’<sup>8</sup>; in other words, the added value of EU-level action in this field is acknowledged. The fact that great variation exists between Member States in terms of care provision models and the roles of formal and informal care within these means that there is a huge potential for exchange of experiences and ideas and good (as well as bad) practice.

#### 4. Potential areas for action<sup>9</sup>

As the impact of being a carer can be felt in many different areas and at different times of life and work, a comprehensive EU level carers initiative should be multi-dimensional and longitudinal.

The following areas are all highly relevant to enable European citizens to continue caring during their life course in the future:

- Awareness and recognition of the contribution and the resource represented by carers for the entire society. Research should help build a more comprehensive picture of carers and their issues throughout Europe.
- Social inclusion and societal participation of carers in different fields (see below) and throughout the life course.
- The preventative aspects of well-trained and well-supported family care to avoid or delay hospital admission and long-term institutional care
- Accessible and reliable information and advice to promote self-care and self-management solutions in family care
- Emotional support and counselling to alleviate the emotional impact of caring and the impact on changing relationships.
- Measures to offer practical support to carers.
- Respite breaks for carers, essential both to the carer and the cared-for-person, especially where care is provided for most of each day of the week.
- Health promotion and protection for carers in health services and delivery (e.g. need for a systematic health and social assessment of carers and of their care burden).
- Measures that enable working carers to combine their care and work responsibilities, so that carers can continue to contribute to the economy, the labour market and can earn their own living.
- Measures to ensure that carers do not lose their financial and social security rights as a result of their caring responsibilities, e.g. by losing out on pension rights when giving up paid employment to care (leading to poverty in old age), or suffer financial hardship through out of pocket expenses related to the person cared for.
- Possibilities and facilities for carers of working age who have left the labour market in order to care to update their professional qualifications when they are ready to re-join the labour force.
- Training, especially in core caring skills e.g. manual handling, coping with caring, knowledge of conditions and in situations where carers need to administer and monitor complex medication prescriptions, implement and manage complex medical procedures.
- Assisted Ambient Living (AAL) and Information and Communication Technology (ICT) products and services that support carers, e.g. to decrease the care burden, to contribute to a higher quality of life and increase the independence of the persons cared for.

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<sup>8</sup> Staff Working Document on Long Term Care 2013

<sup>9</sup> Based on Eurocarers’ 10 guiding principles to strengthen the position of carers in Europe.

- Integrated provision of services at home as well as in care institutions and hospitals, but also between health and social care systems. Privately-hired domestic care workers can provide an important support to carers; training is important in this respect.
- Recognition by and training of formal care service (including homecare) providers with regard to the central role of carers and acknowledgment of them as equal partners in care.
- Empowerment and capacity building of carers and of their representative organisations.
- Take account of the variety of different situations e.g. specific needs and challenges of the many young carers as well as those that are very old, mostly partners.

## 5. Implementation of the initiative

This section lists the instruments the EU level could use to underpin the initiative.

### a. Inclusion of carers issues in health and social policy development: mainstreaming

The fact that the Commission is referring to carers in the Active and Healthy Ageing Partnership, the Social Investment Package and the Employment Package is a useful start. Nevertheless, carers and their issues could be included more explicitly in a number of further outstanding and future programmes and initiatives, such as the following:

- The Employment Guidelines and strategy
- The PROGRESS Programme
- The Health Programme
- The Joint Action on Mental Health
- The chronic disease reflection process
- The European Social Fund (as regards training)
- The Ambient Assisted Living Programme (ICT)
- The disability strategy
- Gender equality initiatives
- Demography initiatives
- The social Open Method of Coordination
- Horizon 2020
- The European Semester
- Actions on Corporate Social Responsibility
- Youth Policy
- Procurement policies

Eurocarers and the European Parliament Interest Group on Carers would be happy to provide details on how this mainstreaming could be achieved.

### b. Awareness-raising

A specific EU action programme on carers could be put in place, based on previous action programmes e.g. on ageing, disability etc. This could ensure and coordinate an effective exchange of information, experience and good practice between relevant stakeholders in relation to the topics listed under section 4.

Another option would be to consider designating one of the coming years as the European Year of Carers.

### c. Financial support

A number of the above initiatives hold the potential for funding. This funding could contribute to capacity building of carers in relation to provision of support (e.g. emotional support, exchanges, information) and advocacy (e.g. policy development, practical solutions). It could also support exchange of information, research and networking.

d. Data collection and monitoring

The Horizon2020 programme could include research on carers in future calls for proposals under the action 'Tackling Societal Changes', section 'Health, demographic change and well-being'. This research could be built on earlier major EU-funded research projects such as EUROFAMCARE10 , thus allowing for an updated picture of the achievements and challenges characterizing this crucial area of EU-citizens' life<sup>11</sup>.

e. Legislative measures

While most of the legislative competence in the relevant areas lies at the national level, there are some areas where legislative action could be taken, such as legislation relating to carers leave and retraining and re-entry into the labour force. Action in other areas could be explored and experiences disseminated between countries, while recognizing and respecting the principle of subsidiarity.

f. Inclusion of carers in relevant consultations, fora and advisory boards

Carers and their representative organisations could be included in social and health consultations as well as in relevant fora and advisory boards as a relevant stakeholder. This could help assess proposed policies and initiatives for their impact on carers and their cared for persons.

## 6. Conclusions

As the information and data reported above clearly show, sustainable health and care provision systems simply do not work without carers.

This clearly makes the case for the fact that carers are:

- A highly relevant stakeholder group in society, providing day to day care provision for those in need of care (of all ages) and, at the same time,
- The largest contributors to the sustainability of our health and social security systems.

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.

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<sup>10</sup> <http://www.uke.de/extern/eurofamcare/>

<sup>11</sup>As suggested also by the EU-funded Road Map for European Ageing Research (esp. on pages 48-49 and 53-57): <http://futuraage.group.shef.ac.uk/road-map-flip-book.html>