

**Report of the Social Protection Committee:  
Adequate social protection against long-term care needs in an ageing society**

***Comments from Eurocarers***

**Introduction**

Eurocarers is the European association working for informal carers. It aims to:

- Raise awareness of the significant contribution made by carers to health and social care systems and the economy as a whole, and of the need to safeguard this contribution;
- Ensure that EU and national policies take account of carers, i.e. promote social inclusion of carers, develop support services and enable carers to remain active in paid employment and maintain a social life.

This document provides our initial feedback on the report of the Social Protection Committee entitled 'Adequate social protection against long term care needs in an ageing society'. It was prepared as part of our work programme under the Commission's PROGRESS Programme, which is partly funding Eurocarers' activities during 2014 and the coming three years. Providing input in policy debates by means of feedback anchored in 'grassroots' experience is one of our core activities, and this SPC report provides an excellent opportunity for direct cooperation and input.

This document is the first of two parts: as part of its detailed review of each national profile set out in the appendices to the report, Eurocarers hopes to propose a draft typology capable of accommodating the spectrum of models for the delivery of long-term care throughout the EU in close cooperation with its members. In consulting our membership we intend to make use of the basic questions put forward by the report in terms of what needs to be done to improve long term care provision, as it was felt that this would deliver the most practical and concrete feedback to the SPC and Commission i.e.

- Do those in need get the help they need?
- Is this achieved without impoverishing the person needing help or their family?

and related questions, as listed in the report as follows:

- Whether (and how much) help and care is available to people who suffer a loss of autonomy and become dependent on LTC;
- Whether this care (which may include non-institutional care such as tailor-made support for independent living) is of sufficient quality;
- Whether and what help is available to family carers; and
- What degree of means-testing is applied before the social protection system will bear the costs of care.

We aim to deliver this comprehensive feedback by the end of 2014.

## General comments

### ***The report underlines the importance and urgency of addressing long term care***

Eurocarers warmly welcomes the work carried out by SPC-WG-AGE. The fact that this report is directly based on the 2013 Staff Working Document on long term care is a strong indication of the Commission's and SPC's belief that long term care provision is indeed

- A topic which requires urgent further thought and policy action;
- An area where cooperation and exchange between Member States is highly useful.

The EU can truly add value in this area by supporting exchange and cooperation between Member States in order to find common solutions.

### ***Positive common objectives: access, quality and sustainability***

Eurocarers also warmly welcomes the Commission and SPC's agreement on the three common objectives for Member States to strive for in relation to long term care, i.e.

- Guarantee access for all to adequate health and long-term care and ensure that the need for care does not lead to poverty and financial dependency;
- Promote quality in health and long-term care and adapt care to the changing needs and preferences of society and individuals;
- Ensure that adequate and high quality health and long-term care remains affordable and sustainable by promoting healthy and active life styles, good human resources for the care sector and a rational use of resources.

These objectives have guided all of the work of the SPC in the area of health care until now and it is gratifying to note the explicit interest in long term care, next to health care.

### ***The report recognises and outlines the current situation and threats in relation to long term care***

According to the report, three major, related and simultaneous, challenges will need to be addressed:

- a huge increased requirement for long term care services;
- the threat to the supply of formal as well as informal carers due to various demographic developments;
- a threat to care quality, care standards and public expenditure as a consequence of the rapid growth in demand.

Eurocarers agrees that, if not addressed properly, this three-fold challenge will lead to a major gap between needs and available services; and this in turn will have a profound impact on those in need of care and their informal carers. Cooperation and exchange between Member States, involving relevant stakeholders, can support the development of effective frameworks to address the situation and prevent this gap across the EU.

***Informal care is part and parcel of care delivery***

Far from being a matter of “kin and chance” informal/family care is an appropriate and important element of the response at different points in an individual’s health trajectory. Equally, the “health, dignity and quality of life of frail older people” is only put at risk when families are left “to carry the heavy burden of care responsibilities alone and unsupported” which suggests that any EU-level activity to address long term care must include consideration of how best to support such families. Work is ongoing in a number of Member States in relation to the development of carers assessment tools (e.g. a Carer Needs Assessment module for InterRAI in Ireland) and may result in important new healthcare management tools.

***Immediate support action to carers required: need for an EU level carers’ strategy***

The report builds on the framework for thought set out in last year’s Staff Working Document, making the case for two main strands of action:

- prevention of ill health and disability;
- making more effective use of resources.

As already outlined in our comments on the Staff Working Document, these two strands of action – while fully valid – will only have an impact in the medium to longer term. As informal carers need support now – *as underlined by the SPC report itself* - Eurocarers would recommend *immediate action* to ensure support for carers as well.

**If carers are expected to continue to care – and they are – measures should be taken to enable them to do so as a matter of urgency.**

Eurocarers believes that there is a need for a **comprehensive European Carers Strategy**, implemented by means of an action programme which would support:

- The exchange of information, experience and good practice between Member States;
- Mainstreaming of carers issues in EU policies, e.g. Employment Strategy, Health programme, AAL, Equal Opportunities, Social exclusion, Research, Justice.....;
- Putting in place policy measures (e.g. a carers leave directive);
- Empowerment of carers and their representative organisations;
- Collection the information on care provision that is currently lacking;
- Research activities.

Eurocarers has developed a proposal for such a Strategy<sup>1</sup> in cooperation with the European Parliament Interest Group on Carers. This was launched in October 2013 and welcomed by a number of main EU umbrella organisations<sup>2</sup>.

---

<sup>1</sup> See appendix 1

<sup>2</sup> European Patients Forum, COFACE, Platform of European Social NGOs, EUFAMI and Alzheimer Europe.

This type of Strategy/action plan is not new at the EU-level; it has been undertaken before in other social policy areas, e.g. disability and ageing. Moreover, such a Strategy would fit well with the current priorities and thinking of the SPC-WG-AGE as outlined in this report; Eurocarers would be pleased to cooperate with the SPC and the Commission to help develop and implement such an initiative across the EU.

#### Specific comments

#### ***The report reflects Eurocarers' priorities and main issues in the field of informal care***

As was the case with last year's Staff Working Document on Long-term care, Eurocarers is delighted to note the report's recognition of the role and huge contribution made by carers, as well as of the challenges they face. The report echoes many of the issues raised by Eurocarers over recent years – most recently in our draft proposal for an EU level Carers Strategy and our comments on the recent Commission Communication on effective, accessible and resilient health systems<sup>3</sup> - such as:

- In most European countries informal caregivers provide a great deal of the long term care for older people: the number of informal caregivers is estimated to be at least twice as big as the formal care workforce in many EU member states; therefore, most care across the EU is provided by informal carers;
- The report refers to the economic value of unpaid informal care as a percentage of the overall cost of long-term care in EU Member States ranges from 50% to 90%. The total value of unpaid family caregiving ranges between 20.1% and 36.8% of EU GDP;
- The carers resource is shrinking due to a combination of demographic developments such as smaller families, greater distances between families, women entering the labour force, extended length of time in the labour market and rising retirement ages;
- Without access to quality long term care, the affected person's well-being, dignity, health or even survival may be endangered;
- The fact that improving and maintaining the quality of long term care and long term carers is a challenge for all EU Member States. Currently, there is no consensus about the most appropriate quality indicators or how best to do it. Indicators of formal long term care need to include carer outcomes that also take into account their needs, preferences and quality of life and well-being.
- The fact that, in most countries, long-term social care is treated differently from health care, with the primary responsibility for financing of long term care remaining with the people in need of care and their families;
- The impact of meeting the cost of professional care, which can lead to substantial reductions in disposable income both to carers and those cared for;

---

<sup>3</sup> See appendix 3



# EUROCARERS

EUROPEAN ASSOCIATION  
WORKING FOR CARERS

- The fact that those paying for care, and family carers who have to give up or cut back paid employment as a result of their caring responsibilities, risk falling into poverty. This, in turn, could have a negative impact on labour supply and the economy;
- The potential income loss as a direct result of providing care- both current and future (as pension rights may be affected as a result of cutting back or leaving paid employment);
- The heavy workload and social isolation faced by many carers and lack of equal opportunities such as access to education, training and leisure;
- Relying on relatives to provide care, regardless of suitability, training or motivation, can be economically inefficient as a way of allocating people to caring jobs, delivering care and ensuring quality standards;
- Among carers, young carers are a particularly vulnerable category and research has proven that providing care might have a relevant negative impact on their transition to adulthood
- The 'underdevelopment of formal long term care provision remains a major impediment to female employment and economic growth, and reduces women's chances of labour market participation';
- The risk of negative impact on the health and wellbeing of informal carers (e.g. the prevalence of mental health problems among informal carers is 20% higher than among non-carers and research has also found various adverse effects on physical health) and particularly for those carers providing intensive amounts of care;
- Reliance on informal carers creates inequities as not everybody has a family from which to resource informal care, neither does everybody have family members that live close by, making daily caring impracticable;
- The risk of poverty of informal carers who have to drop out of the labour market, especially women, also in old age.

While we recognise the limited EU remit in the area of care provision, Eurocarers warmly welcomes the SPC's comprehensive recognition of the issues faced by carers. This recognition could (and should) pave the way for concrete and coherent (policy) action and guidelines.

### ***Positive approach to improving the long term care situation across the EU...***

Eurocarers is also pleased to note a number of elements to guide a successful approach to ensuring quality, access and sustainability of long term care put forward by the report, including:

- Preventing people from becoming dependent on care from others, by promoting healthy life styles and tackling the major causes of dependence;
- Improving understanding and awareness of the pathway from health to frailty and disability, and identifying risk factors at an early stage;
- Improving arrangements for rehabilitating people whose health and fitness are impaired;
- Making cost-effective use of technology to remove obstacles to independent living;

EUROCARERS – Association européenne travaillant pour les aidants non professionnels,  
EUROCARERS is an NGO & non-profit organisation registered in Luxembourg since 2006. Registration No: F6854.

Registered Members are: John Dunne: President, Hanneli Doehner: Vice-President, Elizabeth Hanson: Vice-President,  
Marijke Steenbergen: Treasurer, Licia Boccaletti, Helle Lepik, Marja Tuomi.

- Creating more age-friendly environments to facilitate independent living of people with impaired health;
- Improving the efficiency of long-term care services, by ensuring better care coordination, raising the productivity of services, improving recruitment and retention in the long-term care workforce, improving support for family carers and making it easier for them to reconcile family and care responsibilities.

We fully believe that the report's focus on "shifting care from the informal to the formal sector to raise the productivity and quality of care delivery systematically" would benefit from being located in a wider policy framework that has regard to sustainable (focused on prevention and delaying progressive dependency) and co- healthcare.

***...and the extensive listing of measures that could support carers, such as***

- The lack of EU objectives in relation to access to long term care, similar to the Barcelona objectives/targets for child-care as well as a lack of monitoring in relation to coverage, access and affordability;
- The recommendation for Member States to define and agree an adequate level of social protection and properly measure and monitor this;
- The need for more information on long term care provision across the EU as the current information is patchy and insufficient;
- The high potential for useful exchange of experience, good practice and ideas because of the differences between Member States in the way long-term care is provided;
- The need for carers to have access to training and information;
- The need for carers need to have access to respite care and care breaks;
- The need for employers to put in place carer-friendly measures;
- The potential of technology and IT services, developed with the input from carers and those cared for to ensure practical uptake;
- Access to counselling and support.

***Data gathering: use national Census to gather information on informal carers***

The annex lists a number of suggestions for further work, underlining the role of the EU in helping to highlight the social challenges posed by dependency. A number of these relate to gathering better information, by means of

- EU-SILC, the LFS and SHARE (dependency and social protection)
- MISSOC (looking at the support that is available to informal carers, the obligations of relatives and the extent of means-testing),
- the Commission/OECD Joint Action, "Measuring Effective Social Protection in Long-Term Care (methodology for estimating the costs of long-term care (including informal care), as a basis for assessing the costs and benefits of new technology, innovative care practices and measures designed to improve productivity in the care system, and assisting cross-country exchange of data, information and experiences).

- Eurostat (long-term care spending)
- EU funding (establishment of a network of institutions that can develop and spread expertise in assessing the cost-effectiveness of various ways of tackling long-term care needs)
- Horizon2020 programme (to gather more evidence on the main causes of dependency and on the best ways of preventing or mitigating its effects).

While all of these are useful (and existing) sources of information, Eurocarers would like to suggest adding questions on carers and their situation to the Census held at national level as this will be an easy as well as an effective way to generate data on the number and situation of informal carers.

Eurocarers welcomes the suggestion to promote age-friendly environments, and would like to underline that the EU's AHA-EIP was the first EU-level initiative that explicitly addressed carers. The Partnership's actions on integrated care and age friendly environments can also support exchange of good practice and data generation.

Eurocarers also welcomes the suggestion to encourage a systematic and integrated approach to implementing strategies for the secondary and tertiary prevention of frailty to reduce disability in older people. Eurocarers would like to suggest also including health promotion, including routine screening and health maintenance measures to optimize the mental and physical health status and well-being of carers and reduce associated health and social care costs associated with carer burden.

### **Conclusions**

Eurocarers agrees with the SPC that

- There are solid equity and efficiency reasons for establishing collective social protection against the risk of LTC dependency, and for ensuring that societies provide adequate access to affordable quality care;
- Member States need to move from a primarily reactive to an increasingly proactive policy approach, which seeks both to reduce care demand and to boost efficient, cost-effective care provision.

The report's focus on the quality of care (related to safety, taking into account well-being, needs and preferences of those cared for, and coordination with other services) is also warmly welcomed.

The report makes a clear case for the action that needs to be taken by Member States in relation to long term care – in terms of quantity as well as quality – and that this is a matter of urgency. Eurocarers believes that a specific EU-level coordinated initiative in this field could considerably boost Member States' efforts in this field; this could provide a framework for the exchange experience and ideas in order to develop guidance, cooperation and in the longer term, solutions.



# EUROCARERS

EUROPEAN ASSOCIATION  
WORKING FOR CARERS

Our proposed Carers' Strategy contains some of the elements which could either be a stand-alone initiative as well as be part of a wider EU action programme on long term care provision.

Once again, Eurocarers would like to thank the SPC and the Commission for its interest in this area. We will be happy to cooperate on any further initiatives in this area, to ensure fair, equitable, accessible and high quality long term care, which takes account of the needs and preferences for both carers and their cared for.

EUROCARERS – Association européenne travaillant pour les aidants non professionnels,  
EUROCARERS is an NGO & non-profit organisation registered in Luxembourg since 2006. Registration No: F6854.

Registered Members are: John Dunne: President, Hanneli Doehner: Vice-President: Elizabeth Hanson: Vice-President,  
Marijke Steenbergen: Treasurer, Licia Boccaletti, Helle Lepik, Marja Tuomi.