Family carers are non-professional persons who provide primary assistance with activities in daily life, either in part or in whole, towards a dependent person in their immediate circle. In most Member States, the lack of a network of close-to-home services often leaves family members with no other option but to provide informal care for close relatives who have a disability or serious illness and/or one or more care needs from growing old. This care provision, which, often impinges on their family, personal and working lives, can be very difficult for many family carers. The lack of appropriate support and recognition of social security/employment rights means that these family carers may accumulate physical and mental stress that will badly damage their quality of life and well-being as they themselves get older.

Family carers are over-represented among part-time workers, and “intensive carers” are more likely to stop working. All these factors adversely affect the accrual of pension rights and may heighten the risk of old-age poverty. Also, there is an unquestionable gender dimension to family caregiving – a recent OECD study found that close to two-thirds of informal carers aged over 50 are women.

And when they are gone?

A big concern for ageing family carers is what will happen to the disabled/dependent person when they are too old to look after them or they will not be there anymore. Those who have not received sufficient support or help during their lifetimes may be out of touch with the available main sources of information and networks and so be unaware of the existence of local services and other assisted living opportunities. Abiding uncertainty and anxiety about the future are major sources of anxiety and concern for family carers: it is vital to begin discussions at national and European level on this as a matter of urgency.

Growing old together: but how?

Without a proper monitoring system to pick up any change in the family’s health and living conditions, the situation may gradually deteriorate to the point of putting the family carer and cared-for person’s health and well-being at risk. On the other hand, moving towards independence can be particularly difficult for people with disabilities who have been cared for by their parents for a long time. It must be planned and prepared for to enable a smooth transition taking into account all the relevant psychological factors. Attempts must be made to find innovative solutions, like multi-generation living services as part of a process of living in the community.
Recommendations

COFACE recommends that the Member States should:

- Create a wide range of accessible, affordable, good quality local services for long-term care that are available as required and appropriate to the needs of the intended recipients;
- Focus on prevention and forward planning to promote active ageing and carers’ quality of life, including by recognizing their rights through according them official status and the provision of appropriate support throughout their working lives;
- Establish and facilitate the implementation of employment policies designed to help family carers keep their jobs while caring for a dependent person (work/life balance measures), and to find a new job if they choose to return to work after a long career break;
- Ensure that public policies take proper account of the different needs of age groups and that gender equality is mainstreamed across all policies;
- Encourage effective channels of information to be established between providers of social support services to family carers.

COFACE also recommends that the European Union and the Member States should:

- Include the issue of older family carers in the framework of 2012 European Year for Active Ageing and Solidarity between Generations;
- Use the Open Method of Coordination on social protection and social inclusion and the European Alliance for Families as platforms for exchanging good practices and promoting policies to support older family carers;
- Encourage the creation of local services and other forms of support to older family carers, ensuring that appropriate use is made of the EU’s Structural Funds, including by funding innovative solutions for assisted living and multi-generation living;
- Mainstream the rights of family carers across all European disability, ageing, health and intergenerational solidarity initiatives.

What is COFACE-Disability? COFACE-Disability was founded by the Confederation of Family Organisations in the EU (COFACE) in 1998 in order to better represent the people with disabilities and their families.

COFACE-Disability’s mandate is to help people with disabilities achieve fulfilment throughout their entire lives, in particular within the family context. Its member organisations actively work together to see that a policy for family carers is mainstreamed across all EU policy spheres. COFACE-Disability advocates that families are given a central place in policy on disability.

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