

The European Charter for Family Carers is written in light of the provisions of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) and other major international conventions and documents drafted under the auspices of the United Nations, the Council of Europe, the European Union, and the European Disability Forum, as regards the life, dignity, rights and full citizenship of persons with disabilities and their families. The European Charter addresses the needs of family carers irrespective of the cause of the person's support need (impairment, age, illness, accident etc.).

The Charter is developed as a reference tool to be implemented by various organisations representing persons with disabilities and/or complex needs and their families in the European Union, as well as by the European Union's institutions.

The Charter is a deliverable of the 'Help to Family Carers' project that was carried out by some member organisations of COFACE Disability between 2005 and 2006. The project received full support from the Administrative Council of COFACE Families Europe on 16 March 2009. The Charter was updated in March 2017.

ABOUT COFACE FAMILIES EUROPE

COFACE Families Europe has been involved for 60 years in building a strong social, family friendly Europe. It brings forward the voice of millions of families, gathering 60 organisations from all over Europe. COFACE Families Europe advocates for strong social policies that take into consideration family needs and guarantee equal opportunities for all families.

ABOUT COFACE DISABILITY

COFACE-Disability was founded by COFACE Families Europe in 1998 to better represent persons with disabilities and their families. COFACE Disability's mission is to promote the interests of disabled people, their families and caregivers and to support the enjoyment of their rights throughout their lives.

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This publication has received financial support from the European Union Programme for Employment and Social Innovation «EaSI» (2014-2020).

This document is produced with the support of the European Commission but does not necessarily express its views.



EUROPEAN CHARTER FOR FAMILY CARERS

FOREWORD

In most EU countries, there is a lack of adequate community-based services to support persons with care, or support needs. In many cases, this gap is filled by family members – mostly women.

However, informal care provided by family members should not replace the duty of Member States' public authorities to provide high-quality, accessible and affordable support services to ensure people's full participation in society.

COFACE Disability is convinced that family carers must be recognised and provided with support to maintain and/or improve the quality of life of care-givers, the person with care needs and the family as a whole. Formal recognition would ensure the physical and mental health of carers, help to avoid poverty of the family, enable work-life balance for both men and women and protect the rights of all family members.

COFACE Disability advocates for adequate community-based support services for persons with disabilities. That should include personal budget and assistance, housing, mobility and transport, education and training, employment, healthcare, resources and appropriate services. At the same time, COFACE Disability also finds it crucial to recognise family carers through a certain number of rights. Family carers are often providing care without being paid, or being entitled to social benefits. These rights should enable them to make an informed choice in agreement with the person with support needs on whether becoming a carer, or not.

A family carer is therefore anyone, woman or man, who is not a professional caregiver, but by default or choice cares for a person with care or support needs in his/her immediate circle.

This Charter aims to give recognition to family carers and to raise awareness on the disadvantaged situation they often face in their personal and/or work life.

The ultimate purpose of the Charter is to ensure that family carers can enjoy the same rights and opportunities, as anyone else.

1 DEFINITION OF FAMILY CARER

A family carer is 'a non-professional person, who provides primary assistance with activities in daily life, either in part or in whole, to a person with care, or support needs in his/her immediate circle. This regular care, or support may be provided on a permanent or temporary basis and can take various forms, including nursing, care, assistance in education and social life, administrative formalities, travelling, coordination, vigilance, psychological support, communication, or domestic activities.'

2 CHOICE OF FAMILY CARER

Persons with disabilities and/or complex needs should always choose the person in their family, or immediate circles from whom they want to receive support. If a person has limited verbal skills, all efforts should be made to ensure their will is respected. Similarly, family carers should also have the opportunity to decide whether they want to fulfil caring duties full-time, or part-time and to reconcile it with their work, or personal life. Such choice of both the care-givers and care receivers must be free, informed and open to reassessment.

3 PUBLIC SOLIDARITY

The fact that persons with disabilities and/or complex needs may choose their own non-professional carers, and the effective solidarity within the family, in no way releases the national and local public authorities from their respective obligations towards those receiving and those providing care. Furthermore, such care provision should meet official recognition in terms of social rights and all kinds of social support. There should be a legal provision ensuring that the care work is financially compensated.

4 FAMILY SOLIDARITY

Family environment is the primary socialisation area for children and the natural environment for the growth and well-being of all its members. Solidarity within families should be complementary to public solidarity.

5 THE PLACE OF THE FAMILY CARER WITHIN THE HEALTH SYSTEM

The needs of family carers should be recognised and taken into consideration in the development of health and social protection policies. Family carers must receive adequate support themselves, including health care, or psychological support.

6 OFFICIAL STATUS OF THE FAMILY CARER

Family carers should benefit from resources, social rights and benefits when they provide support, or assistance to persons with disabilities. Family carers should have full access on an equal basis with others to:

- ▶ labour market and employment: working time arrangements, holidays, leaves, return to work support, accessing health and social protection schemes;
- ▶ transport, housing, culture, built environment, communication;
- ▶ retirement benefits through official recognition of their status, as carers;
- ▶ recognition of experience and skills in the open labour market achieved through caring and supporting.

7 QUALITY OF LIFE

The person, who is receiving care, or support from a family member and his/her caregiver are interdependent in terms of the quality of their life. It is therefore necessary to develop preventive measures to avoid exhaustion, psychosocial risks, illness, burnout, or any abuses. Community-based services and facilities play a key role in contributing to the well-being of persons with support needs and their family members.

8 RIGHT TO RESPITE

Respite is a fundamental requirement that can take various forms, including occasional and/or emergency assistance, substitution services and/or high-quality temporary care centres during various periods of time depending on the needs (holiday, rest, health etc.). Providing family carers with respite is extremely important to avoid the deterioration of their physical, or mental health condition.

9 INFORMATION/TRAINING

Family carers should be informed about their rights and duties. They should have access to all information that will help them to fulfil their role as carers. They should also have access to special training programmes aimed at improving their knowledge about support giving. A training system should be set up by public authorities in full consultation with the representative bodies. Professional carers should be trained and be aware of the needs and challenges of families.

10 ASSESSMENT AND MONITORING

Public authorities should continuously assess and monitor the local situation with the involvement of persons with support needs and family carers:

- ▶ assessment of the needs of both the supported person and the carer;
- ▶ assessment of the quality, affordability and accessibility of community-based services (social and health) for persons with disabilities and their family members to ensure public authorities can further improve such services.

Persons receiving care, or support and their family members are the best to determine their needs for support. Therefore, they should be closely involved and fully participate in the assessment process and in the development of community-based services, or be represented by a person of their choice.