

ABOUT THE CHARTER

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, equality, non-discrimination, access to services and full citizenship of persons with disabilities and their families. These include the UN Convention on the Rights of the Child, the United Nations Convention on the Elimination of All Forms of Discrimination against Women, the European Convention on Human Rights, and the Charter of Fundamental Rights of the European Union.

The European Charter addresses the needs of all family carers* irrespective of the reason for the person's care needs (disability, age, illness, accident, etc.). The Charter is developed as a reference tool to be implemented by decision makers at all levels of governance in Europe, as well as for service providers and organisations representing or working with persons in need of care and their families.

The Charter was first developed in 2005 by the COFACE Disability Platform for the rights of persons with disabilities and their families. Its current version was adopted in 2024.

ABOUT COFACE DISABILITY PLATFORM FOR THE RIGHTS OF PERSONS WITH DISABILITIES AND THEIR FAMILIES

COFACE-Disability was founded by COFACE Families Europe in 1998 to better represent and advocate for the rights of persons with disabilities, their families, and family carers. Its mission is to ensure the full enjoyment of their rights across the life course.

ABOUT COFACE FAMILIES EUROPE

COFACE Families Europe has been involved for over 65 years in building a socially inclusive and family-friendly Europe. It brings forward the voice of millions of families, gathering 50+ organisations from all over Europe. We advocate for strong social policies that address the diverse needs of families and guarantee equal opportunities for all families.

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* For simplification only the term "family carer" will be used hereafter, even though other terms are in use such as "informal carer" or "non-professional carer"



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EUROPEAN CHARTER FOR FAMILY CARERS

FOREWORD

In most European countries, there is a lack of adequate community-based services for persons with care and/or support needs (due to disability, age, illness, accident). In many cases, this gap is filled by family members – mostly women, which reinforces gender inequalities and the gender care gap.

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

COFACE Disability considers that family carers must be formally recognised and provided with social protection rights to maintain a decent quality of life. This is essential for carers themselves but also for the person(s) under their care and the family as a whole. Formal recognition would ensure the physical and mental health of carers, mitigate the risk of family poverty (short-term and long-term for retirement), enable work-life balance and protect the rights of all family members.

COFACE Disability advocates for adequate community-based support services for persons with care needs, whether for reasons of disability, age or illness. This includes personal budgets and assistance, access to housing, universal accessibility, mobility and transportation, education and training, employment and healthcare. COFACE Disability also finds it crucial to recognise family carers through a certain number of social protection rights. Only a combination of services provided to persons with care needs and rights given to family carers will enable the latter to make an informed choice to become family carers or not, in agreement with the person with care needs.

Access to these social protection rights is essential for society as a whole, since caregiving activities often prevent carers from fully participating in the labour market and can lead to adverse physical and mental health outcomes.

This Charter aims to promote the formal recognition of family carers and to raise awareness about the negative health impacts and disadvantaged situations they often face in their personal, family and/or work life.

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 (due to disability, age or illness) in their immediate circle. This regular support may be provided to persons in need of care at any age and can take various forms, including nursing, assistance in education and social life, in administrative formalities, in travelling, vigilance, coordination, psychological support, assistance in communication, or in domestic activities.

2 CHOICE OF FAMILY CARER

Persons with care needs should always, and at any age, have the choice of receiving support from a family or a professional carer. If a person has limited verbal capacity, all efforts should be made to ensure their will is respected. Similarly, family carers should also have the opportunity to decide whether to fulfil caring duties or not, full-time or part-time, and to reconcile it with their work and personal life. Such choices for both the caregivers and care receivers must be free, informed, and open to reassessment. As concerns children or young people, whether with care needs or providing care, their views should be fully acknowledged.

3 FAMILY AND PUBLIC SOLIDARITY

The 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 underpinned and complemented by public solidarity. The fact that persons with care needs may choose a non-professional carer and benefit from the effective solidarity within the family, in no way releases the national and local public authorities from their obligations towards those receiving and those providing care. Furthermore, such national solidarity in care provision should be tailored to the needs of those being cared for and entail full social recognition and access of family carers to social rights and all kinds of social support. There should also be a legal provision ensuring that care work is financially compensated, should the family carer choose this.

4 THE INCLUSION OF THE FAMILY CARER WITHIN THE HEALTHCARE SYSTEM

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

5 RECOGNITION OF THE SOCIETAL ROLE OF THE FAMILY CARER

Family carers should benefit from resources, social rights and financial benefits when they provide support to persons with care needs due to disability, age or illness. Their role of family carer should be taken into account in terms of access to:

- the labour market and employment: working time arrangements, holidays, leaves, return to work support;
- health and social protection schemes;
- retirement benefits, through their formal recognition as carers;
- the recognition, in the open labour market, of the experience and skills learned through caring and supporting;
- transport, housing, culture, built environment and communication when supporting the person in need of care.

6 AGE DIMENSION OF CARE

Since caring can occur at any point in a lifetime, it is also crucial to consider the age dimension of care, distinguishing between the challenges faced by younger and older carers.

For young carers, the challenges include the impact on education, training, social life, mental health, and the lack of knowledge of their rights. In addition to youth-friendly social protection rights, they should have access to flexible school policies, tutoring, counselling, mental health services, time for leisure and social interactions. For older carers, the challenges include poor or deteriorating health conditions, social isolation, financial difficulties, and lack of capacity to manage administrative burdens. Social protection rights should be tailored to these realities, through accompanying measures aimed at preventing the escalation of needs.

7 QUALITY OF LIFE

The quality of life of the person receiving care and the family carer are interdependent. 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 care and/or support needs, their carers, and their family members.

8 RESPITE BREAK

Respite is a break from caring, while the person cared for is looked after by someone else. Respite is a fundamental necessity that requires the development of regular support solutions that can take various forms, including occasional and/or emergency assistance, substitution services and/or high-quality temporary care centres during varying periods of time depending on the needs (holiday, rest, health). Providing family carers with respite breaks is extremely important to prevent the deterioration of their physical or mental health.

9 INFORMATION/AWARENESS/TRAINING

Family carers should be informed about their rights. They should have access to all the information that will help them fulfil their role as carers. They should also have access to special awareness-raising and training programmes aimed at improving their capacity to provide care. A training system should be set up by public authorities in full consultation with family organisations, which play a fundamental role in supporting family carers. In this sense, information, training and support programmes, as well as peer programmes run by family organisations should be supported and funded. Furthermore, professional carers should be trained and be aware of the needs and challenges of families; and awareness-raising/training involving peer carers should be prioritised.

10 ASSESSMENT AND MONITORING

Public authorities should, with the involvement of persons in need of care, family carers, and family organisations, continuously assess and monitor:

- the needs of both the person in need of care and their family carers;
- the implementation of measures;
- the quality, affordability and accessibility of community-based services (social and health) for persons with care needs and their family members;
- the continuous improvement of services based on the assessments carried out;
- the implementation and effectiveness of social rights.

Persons receiving care, family carers and family organisations are the best placed to determine the needs for support and how to answer them. Therefore, they should be closely involved and fully participate (or be represented by a person of their choice) in the assessment process of their support needs, in the development of community-based services, and in the evaluation of the measures developed.