



**LONG-TERM CARE:
THE FAMILY DIMENSION**
KEY RECOMMENDATIONS FROM COFACE
FAMILIES EUROPE TO SHAPE LONG-TERM
CARE SYSTEMS *FOR AND WITH* FAMILIES



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I. BACKGROUND AND DEFINITIONS

Long-term care (LTC) addresses people needing support in many aspects of living over a prolonged period of time.

LTC differs from other types of health care in that its goal is not to cure an illness or an impairment, but to keep a good quality of life, to prevent institutionalisation and/or manage the deterioration in health status for people with a degree of long-term dependency.¹

Individuals need LTC when at birth, or during life, when a chronic condition, trauma, or illness limit their ability to carry out basic self-care tasks, called activities of daily living (ADLs) such as bathing, dressing, eating, communicating or to practice domestic activities, called instrumental activities of daily living IADLs, such as household chores, meal preparation, or managing money. LTC helps them in their basic care and in their independent living and it can include rehabilitation, basic medical treatment, home nursing, social care, housing and services such as transport, meals, occupational assistance and help with managing one's daily life.

The need for long-term care touches a large portion of the European population and it is increasing: it is estimated that one in two women and one in three men will come to need intensive LTC as they age.² According to Eurostat, between 2017 and 2080 the share of those aged 80 years or above in the EU-28 population is projected to more than double and those aged 65 years or over will likely move from 19.4 % to 29.1 %, while the population of working age is expected to decline.³ The current social and demographical changes,

such as changing family structures, the situation of intergenerational families, women's increased participation in the labour market and the growing ageing population are affecting LTC provision in terms of size and practices.

Families are and will be affected by growing LTC needs as many of them provide care informally. COFACE Families Europe promotes a holistic approach to long-term care taking into account roles, needs and rights of both care recipients and caregivers.

Informal care, also known as unpaid care or family care, according to the OECD⁴, is based on the informal nature of the relationship between care recipients and carers.

COFACE Disability's **European Charter for Family Carers**⁵ defines a family carer as a non-professional person, who provides assistance with activities of daily life, either in part or whole, to a person with care, or supports needs in his/her immediate circle.

Family care constitutes a significant share of the total LTC provision in European countries. Estimates suggest that **80% of all long-term care in Europe is provided by informal carers.**⁶ The available appraisals of the number of informal caregivers ranges from 10% up to 25% of the total population in Europe.⁷ The average varies significantly between countries, groups of countries and depending on how informal care is defined and measured.

Long-term care is a highly gendered issue as women are the majority of care recipients (due to their higher life expectancies) and are also the majority of both formal and informal carers. Moreover, a large share of informal LTC is provided by people who are older than standard retirement age. **Women often leave the labour market to take care of dependent family members or they are likely to accept lower qualified positions to accommodate their family duties upon their return.**⁸ According to Eurostat, in 2016, the gender pay gap was at 16.2% and one of the reasons for its existence and size was that women more often take career breaks or part-time work due to caring responsibilities and decisions in favour of family life. According to Eurofound, about 7% of male workers and 11% of female workers are providing regular care and among those with caring responsibilities, 90% of men work full-time, compared to only the 50% of women.⁹ The gender gap is very pronounced regarding inactivity due to caring responsibilities: in 2017, 31% of women reported caring responsibilities as the main reason for them not being part of the labour force, which was the case for only 4,5% of inactive men. Informal care is likely to become even more important in the future due to demographic change, health care advances, and LTC policy and cost-containment pressures leading to the

favouring of community care options over institutionalisation.

Leaving family carers to provide almost all the care to their relatives in need, without giving them recognition, social protection and appropriate working arrangements risks undermining the social inclusion, the health and the gender equality of their families.

According to the **European Social Policy Network (ESPN) Study on LTC**,¹⁰ most EU countries face issues relating to access to and financing of LTC systems, due to the institutional and geographical fragmentation of LTC provision. The report also highlights the consequences of the common trend towards prioritising home care: underdeveloped home care services and community-based care are the most difficult to access in many countries, but the availability of residential care has been decreasing in several countries over the past 25 years.

The ESPN Study underlines that **the main reasons of expansion of informal care are the lack of accessible formal LTC facilities, the poor quality and the high cost of LTC** as well as the persistent traditional model of intergenerational and familial relations. Unfortunately, only a limited number of countries have well-developed services such as training, counselling, respite services tailored to informal carers. Finally, domestic workers, often migrant women, play an increasingly important role in informal care in many countries: the issues of their qualifications and working conditions need policy responses in many countries.

II. EU/INTERNATIONAL LEGAL AND POLICY CONTEXT

The EU perspective on Long-Term Care is strongly linked with the issue of ageing societies, the **Europe 2020 Strategy** for a smart, sustainable and inclusive growth emphasises the need to promote active ageing policies meaning social engagement of older people in the community and the adaptation of working practices to the age of the employees. Long-Term care is relevant for many of its objectives, including sound public finances in ageing societies, a high level of employment and the reduction of poverty.

Twenty-twelve was proclaimed the **European Year for Active Ageing and Solidarity between Generations**. Its objectives were to raise awareness about what population ageing means for individuals, families, the economy and society and to demonstrate how older people can contribute to the economy and society.

In 2013, the Commission published a Communication called **Social Investment Package** (SIP) in order to respond to the worsening social situation and problems of sustainability

of social protection across Europe. The SIP guides Member States to modernize their welfare systems and included the Staff Working Document '**Long-term care in ageing societies – Challenges and policy options**'. This paper calls for social innovation and social investment to develop new ways of closing the gap between long-term care needs and provision and presented examples of good practices from across Member States.

In 2014, the European Commission and the Social Protection Committee published a **Joint Report on Adequate social protection for long-term care needs in ageing society**,¹¹ addressing the growing gap between the need and the supply of long-term care and ensure that adequate provisions for long-term care needs can be organised in a sustainable way even at the height of population ageing.

In September 2015, the United Nations world leaders adopted the **2030 Agenda for Sustainable Development** and its **17 Sustainable Development Goals (SDGs)**. These goals touch a number of issues relevant for long-term caregivers and care recipients:

GOAL 1 about **ending poverty** refers to the implementation of nationally appropriate social protection systems and measures for all;

GOAL 3 on the **promotion of healthy lives and well-being at all ages** refers to the promotion of mental health and well-being for all;

GOAL 5 about **gender equality and empowerment of all women and girls** tackles the issue of informal carers in its target 5.4: “recognize and value unpaid care and domestic work through the provision of public services, infrastructure and social protection policies and the promotion of shared responsibility within the household and the family as nationally appropriate”;

GOAL 8 on **economic growth and employment** target 8.8 is relevant for formal carers, in particular migrant women, rights aiming to “protect labour rights and promote safe and secure working environments for all workers, including migrant workers, in particular women migrants, and those in precarious employment”.

In November 2017 the EU proclaimed the **European Pillar of Social Rights**, about delivering new and more effective rights for citizens. Long-term care is specifically addressed under **Principle 18** on long-term care services and **Principle 9** on work-life balance for people with caring responsibilities.

PRINCIPLE 18: “Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services.”

PRINCIPLE 9: “Parents and people with caring responsibilities have the right to suitable leave, flexible working arrangements and access to care services. Women and men shall have equal access to special leaves of absence in order to fulfil their caring responsibilities and be encouraged to use them in a balanced way.”

One of the deliverables of the European Pillar for Social Rights is the ‘New Start’ initiative to address the work-life balance challenges faced by working parents and carers and to modernise the existing EU legal framework in the area of family-related leaves and flexible working arrangements. The **Proposal for a Directive on Work-Life Balance for Parents and Carers** defines «carer» as a worker providing personal care or support in case of a serious illness or dependency of a relative (Art. 3) and includes the possibility for carers to adapt their working schedule to their needs and to take periods of leave in case of serious illness or dependency of a relative to improve the work-life balance of carers and avoid their exit from the labour market.

In the framework of the 2021-2027 Multiannual Financial Framework, in May 2018, the Commission issued its **Proposal for a Regulation of the European Parliament and of the Council on the European Social Fund Plus (ESF+)**. The Proposal makes references to long-term care, the modernization of social-protection systems, family and community-based services in its preamble and in its article 4 on specific objectives:

(18) The ESF+ should be also used to enhance timely and equal access to affordable, sustainable and high quality services such as healthcare and long-term care, in particular family and community-based care services. The ESF+ should contribute to the modernisation of social protection systems with a view in particular to promoting their accessibility

(21) The ESF+ should support policy and system reforms in the fields of employment, social inclusion, healthcare and long-term care

(28) The ESF+ should also promote the transition from residential/institutional care to family and community-based care, in particular for those who face multiple discrimination. The ESF+ should not support any action that contributes to segregation or to social exclusion

4(IX) enhancing the equal and timely access to quality, sustainable and affordable services; modernising social protection systems, including promoting access to social protection; improving accessibility, effectiveness and resilience of healthcare systems and long-term care services

The **European Semester 2018 Employment Guidelines** adopted by the EPSCO on June 2018 include in the Guideline 8 that 'Member States should ensure the right to timely access to affordable health care and long-term care of good quality, while safeguarding sustainability in the long run. **The Joint Employment Report 2018** highlights that 'the sufficient provision of formal, accessible, high-quality and sustainable long-term care services remains a challenge in several Member States'

In 2018 long-term care was included in four Country-Specific Recommendations to Austria, Belgium, Finland and Slovenia, not addressing quality, affordability and availability of services but only their financial aspect, calling for cost-containment (BE), sustainability (AT), reform to improve cost-effectiveness and equal access to social and healthcare services (FI) and reform of long-term care sector (SI).

The above-mentioned ESPN report “**Challenges in long-term care in Europe. A study of national policies**” provides a description of the main features of national LTC systems in Europe and analyses the challenges of national LTC systems in 35 countries.

The ESPN study includes some recommendations regarding informal carers, European challenges, domestic workers’ rights and quality of care:

STRONGER SUPPORT FOR INFORMAL CARERS SHOULD INCLUDE:

- **Information, training and counselling** (tele-assistance services might be an effective tool);
- **Respite care**, to allow informal carers to take a break from caring tasks;
- **Regular checks on the ability and willingness of informal carers to bear the burden of care** as well as meeting their own needs;
- Improved ways of **sharing care tasks** among more than one informal carer;
- Improved **social (security) rights for informal carers**, enhanced possibilities to remain in the labour market (e.g. part-time carers’ allowances) and to return to it;
- The development of adequate **LTC arrangements** in order to support the labour market participation of informal carers (mostly women);
- **Adequate leave** to take care of dependent relatives, currently not available in all countries, so that carers (mostly women) are not obliged to work part-time or leave

the labour market. **Flexible working arrangements and reduced working hours** should be available to people with caring responsibilities to prevent them having to leave the labour market.

CHALLENGES IN LONG-TERM CARE IN EUROPE:

- Possible enhanced **LTC benefits in kind and carers’ leave** in order to achieve a high level of employment and a sustainable work-life balance for middleaged workers with dependent relatives.

DOMESTIC WORKERS:

- Specific attention should be paid to the role and situation of **migrant domestic workers**, especially their status, qualifications and working conditions.

ENHANCING QUALITY OF CARE:

- Countries should apply stricter standards to the various providers and above all should extend their scope to cover home care. Effective checks on and supervision of the quality of care should be reinforced.

III. COFACE FAMILIES EUROPE

POLICY ACTIONS ON LONG-TERM CARE

As founding members of the **European Expert Group on the Transition from Institutional to Community-based Care**, COFACE Families Europe is advocating for public and private investment in community-based services that would provide person-centered support for all people with care, or support needs.

Long-term care should not take place in institutional settings, but in the form of accessible, affordable and good-quality home-based care, or community-based care. At the moment, many family members fill a gap in the social care system by leaving their jobs and providing often very intensive support to their children with multiple disabilities, or to their older parents with support needs. This is an important role to prevent the institutionalization of people with support needs, however it is not a sustainable solution taking into account the growing ageing population.

In 2007, the COFACE Disability Platform for the rights of persons with disabilities and their families published the **European Charter for Family Carers**, a reference tool that contributes, inter alia, to reconciling family and working life by allowing an informed choice by both the person with care needs and the carer, as well as providing carers with adequate financial compensation, working-time arrangements, social rights and benefits such as pensions and respite care. The Charter highlights the right of choice of both the family carers and care recipients, which can only happen if affordable community-based services are in place.

In 2012, COFACE published a study **on transnational families and the impact of economic migration on families**,¹² which underlined that the care sector is the one where transnational families are overrepresented and recommended the recognition of diplomas and skills acquired through informal education in the country of origin and to allocate EU funds to develop migrants' competences.

As stated in COFACE's **preliminary assessment of the European Pillar of Social Rights**¹³ principle 18 on long-term care reflects well our priorities, namely the need for community-based solutions, including home-based care, as well as a flexible system in which people with care needs can use a combination of formal and informal care to decrease the current pressure on family carers.

In 2017, COFACE published a **study of the challenges and needs of family carers in Europe**¹⁴ collecting the testimonies of 1,160 family carers from 17 countries. The study 'Who Cares?' examined the characteristics of family carers and the main

challenges they face in their access to resources, services and flexible time arrangements.

The gender dimension of informal caring was confirmed by the study, where 85% of respondents were women aged between 35 and 64 (sandwich generation), 27% of whom providing care for multiple people. Moreover, 1 of every 3 caregivers provided 56 hours or more of care per week, making it almost impossible to be economically active and 13% did not receive any help in their caring tasks.

The main findings of the 'Who Cares?' Study are the following ones:

- 1. Lack of social protection and community-based services:** 73% of the respondents did not receive any financial compensation for their caring role and 2/3 of them didn't have access to any kind of social benefits and only 11% of the respondents said that there are sufficient community-based services available where they live. Many highlighted the complete lack of personal assistance and person-centred solutions.
- 2. Lack of good examples to follow:** no countries seemed to lead by example in the provision of adequate resources, quality support services, flexible time arrangements to better reconcile professional, care and personal life of family carers.
- 3. Isolation and social exclusion:** 1 of every 3 respondents reported financial difficulties as a consequence of their caring role and most of them signaled isolation, lack of time to leave their house and be part in social activities. Moreover, caring has often a strong impact not only on the carer's life, but also on other family members.
- 4. Need for person-centred, flexible solutions:** some of the respondents are willing to return to the labour market while others would prefer staying at home, if their work as carers was recognised and financially compensated. Choices and preferences of family carers should be at the core of policies regarding them.

The Study calls for targeted measures addressing the needs of family carers to enhance the quality of life of all family members.

IV. RECOMMENDATIONS FROM COFACE FAMILIES EUROPE

ACTIONS NEEDED AT NATIONAL AND LOCAL LEVEL

➔ **Provide access to community-based services:**

Affordable and high quality long-term care services need to be available in the community as well as in-home with a tailored-made approach in order to allow a full choice of both the caregiver and of the person in need of care. Respite services and daycare centers are fundamental tools to ensure the psychological and physical well-being of the caregiver and of its family members.

➔ **Right of choice:**

Choice of person with special needs and of carers must be an important element in planning long-term care systems. People with care needs should be provided with a flexible system in which they can use a combination of informal and formal care, with the possibility to access personal budget and personal assistance systems. These initiatives should be combined with checks on the ability and willingness of informal carers to bear the burden of care as well as meeting their own needs.

➔ **Health prevention:**

Considering the impact of caregiving on family carers' physical and mental health, it is crucial to apply preventive health measures. Informal caregivers especially demand access to psychological support, recreational activities, regular health checks and telephone help for situation of mental stress.

➔ **Legal recognition and social security:**

Recognising caregivers legally is the precondition for them to be covered by social security and have access to an adequate pensions. A form of financial contribution to the carer is indispensable, to compensate for the financial consequences of career breaks or part-time work. Measures should include the assimilation of the periods spent caring to employment in the calculation of pensions and for their access to specific medical and social support. National policies should foster the inclusion of working carers in collective agreements and include practical measures that employers could implement at company level.

➔ **Work-life balance policies to address the care penalty:**

Providing reconciliation policies are essential to allow carers, and in particular women's, economic empowerment and to close the gender-pay gap. Additional days of leave, flexible working hours and the possibility to telework would improve their situation. It is important to offer flexible solutions to caregivers, since their needs and the needs of their relative may vary significantly from family to family.

➔ **Workforce in the care sector:**

Effective checks on and supervision of the quality of care, skills, trainings and working conditions should be reinforced. Working conditions should be improved, also through social dialogue, to enhance the attractiveness of the sector for young people side by side with the development of trainings and specific career with a special attention to the role and situation of migrant domestic workers, in terms of status, qualifications and working

conditions.

➔ **Administrative changes:**

A central focal point could be a valuable solution to provide the necessary information to persons with special need and their family members, who often do not know about their rights or existing services. Family carers should be provided with trainings and counselling including peer-support. Fast and simplified structures need to be put in practice, so bureaucracy will not create an additional burden to families.

➔ **Involvement, inclusion and awareness raising:**

Family carers and persons with special needs should be involved in policy making and in the evaluation of services. Awareness raising campaigns should address the discrimination and isolation of persons with support needs and their families and gender stereotypes, encouraging men to take their share in family care.

RECOMMENDATIONS AT NATIONAL AND LOCAL LEVEL

ACTIONS NEEDED AT EUROPEAN LEVEL

Kick-start the implementation of the European Pillar of Social Rights principle 18 on Long-term Care, in line with the United Nations Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals by promoting the actions which follow.

➡ **Driving policy reform towards more holistic long-term care**

Policy reforms are needed to ensure that all persons with care or support needs can access services in the community. Fragmentation between long-term care and disability services, thus between the health and social sector, must be addressed in such reforms. Policy reforms should be built in a more integrated and holistic way with a lifecycle approach tackling needs and rights of formal carers, family carers and persons with long-term needs and should be accompanied by a European Recommendation on Family and Informal carers.

➡ **Mainstreaming long-term care in current and future European policy initiatives**

Long-term care should be mainstreamed in European policy initiatives such as the next European Disability Strategy, pushing social investment in community-based long-term care services, in collaboration with the EU Social Protection Committee (SPC), using key references such as the Guidelines of the European Expert Group on De-institutionalisation, the EPSCO Council recommendations adopted in December 2017 on Enhancing Community-Based Support and Care for Independent Living, and the 2018 ESPN Study on challenges in long-term care in Europe.

➡ **Adopt and consolidate legal measures to improve the social protection of family carers and of persons in need of care**

The Proposal for an EU Directive on Work-Life Balance for Parents and Carers addresses the obstacles to the labour market participation for people with caring responsibilities, setting minimum standards for policies such as carers leave and flexible work arrangements. We call for adoption of this proposed Directive by end 2018 and effective implementation in the EU Member States, with strong minimum standards for working carers.

➔ **Data collection and adequate indicators**

We urge the European Commission to start the process of developing harmonized definitions, indicators and corresponding targets on long-term care to assess the affordability, the accessibility, the quality and the availability of care and support services. Due to the strong gender dimension of LTC, it is important to include gender disaggregated data, with a specific attention to informal care and its impact on labour market participation, gender-pay gap and gender-pension gap. LTC must be included in the monitoring and review of the European Semester process and in the Annual Report of Gender Equality.

➔ **Research and innovation**

We call on the European Commission to use the Horizon2020 Programme and the EU Programme for Employment and Social Innovation (EaSI) to research the different types of services that are offered and needed, including home-based support. Furthermore, the EaSI Programme should launch transnational social experimentation projects to test new ways of working and introducing community-based methods and integrated services at local level.

➔ **Monitoring and evaluation of national reforms**

COFACE considers it essential to monitor progress on driving national long-term care reforms and prepare recommendations for corrective actions if needed for and with families, making this a reality through the European Semester process. This means developing strong Country Specific Recommendations (CSRs) on long-term care, addressing not only the financial sustainability but also the access to and the quality of long-term care services.

➔ **Transformative EU funding investments**

More funding opportunities should be provided to support local-level organisations including civil society and local authorities in building holistic long-term care services for families. This means a better use of EU funds such as the European Fund for Strategic Investment (EFSI) and the Structural funds (mainly the ESF - European Social Fund, and the ERDF - European Regional Development Fund). The Agricultural Fund for Rural Development (EAFRD) should be used to support the provision of long-term care services in rural areas.

RECOMMENDATIONS AT EUROPEAN LEVEL

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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 Platform for the rights of persons with disabilities and their families

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 persons with disabilities, their families and caregivers and to support the enjoyment of their rights throughout their lives.



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