



# WHO CARES?

STUDY ON THE CHALLENGES AND NEEDS  
OF FAMILY CARERS IN EUROPE



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We would like to thank all members and friends of the COFACE network, who helped with the translation and the dissemination of the questionnaire. Special thanks goes to all the family carers who took part in the European consultation.

Throughout the report, we are using the following country abbreviations:

Austria	(AT)
Belgium	(BE)
Estonia	(EE)
Finland	(FI)
France	(FR)
Greece	(GR)
Germany	(DE)
Hungary	(HU)
Ireland	(IE)
Italy	(IT)
Malta	(MT)
Netherlands	(NL)
Portugal	(PT)
Spain	(ES)
Sweden	(SE)
Switzerland	(CH)
United Kingdom	(UK)

COFACE Families Europe is a pluralistic network of civil society associations representing the interests of all families without discrimination. With 58 member organisations in 23 Member States of the EU, COFACE Families Europe represents more than 25 million families in Europe. It advocates at the European level for policies of non-discrimination and equal opportunities between persons and between family forms, and specifically supports policies aimed at increasing equality between women and men, with a special focus on reconciliation between work, care and family life. COFACE is supported under the European Union Programme for Employment and Social Innovation (EaSI).

COFACE Disability was founded in 1998 to improve the representativeness of people with disabilities and their families at national and European level. Its mandate is to help persons with disabilities to enjoy their rights throughout the life cycle and in particular within their family context. COFACE Disability fights for sufficient, appropriate care provision and community-based services (close-to-home, in-home help services) for people with support needs in all Member States, as well as for resources, assistance and provision to be harmonised within the EU.



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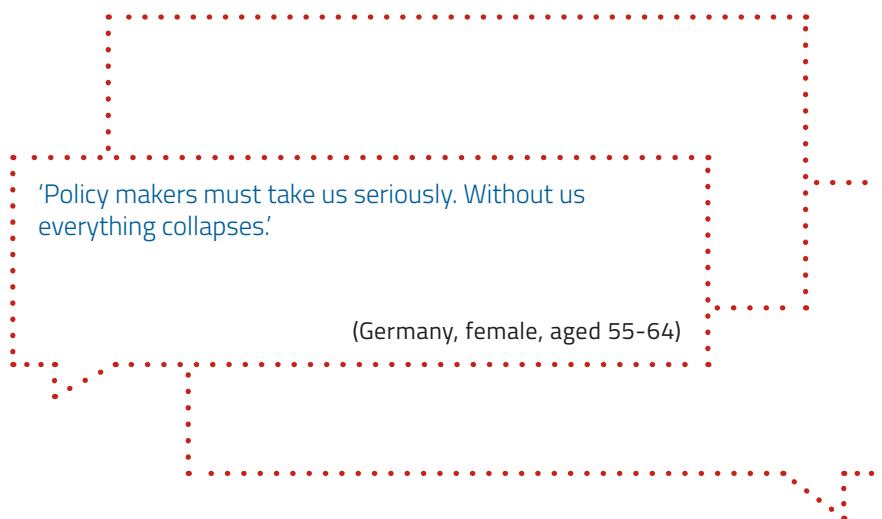
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# EXECUTIVE SUMMARY

This report summarises the findings of a major data collection COFACE Families Europe carried out to take stock on the needs and challenges of family carers in Europe in 2017. With more than 1,000 answers from family carers from 16 European countries, the study provides a better understanding of the situation in Europe and offers policy recommendations from family carers to better meet their needs and tackle their social exclusion. Family carers are Europe's invisible workforce, and they represent one of the most silenced, socially excluded groups. This study takes a closer look at who family carers are, and what are the main challenges they face, when it comes to accessing resources, services and flexible time arrangements.

Family carers fill an important gap in the social care provision and provide primary assistance on a long-term or temporary basis to one, or more family members, or to someone in their immediate circle. Persons needing care, or support include children and adults with disabilities, or mental health problems, older persons with support needs, people who suffer from a chronic disease, or addiction. Current social and demographical changes, such as the growing ageing population, changing family structures, the situation of intergenerational families, or women's increased participation in the labour market greatly affect all families in Europe.



**One thing is clear: the current situation, in which 80% of care work in Europe falls on family carers, who are left without adequate financial compensation, social rights, or a pension scheme, is simply not sustainable.**

Family carers are mostly women (85%), aged between 35 and 64, who are often part of the 'sandwich generation' and provide care for multiple people (27%). In our study, 1 of every 3 carers provide very high intensity care of 56 hours per week, or more, which explains that 43% of the family carers are economically inactive. There is often no one who would help them in fulfilling the caring role (31%). The testimonies given by family carers provide a comprehensive overview and also point to some core common messages:

1. Family carers face significant challenges when it comes to reconciling their professional and personal life, accessing community-based services, their financial situation, health, administrative procedures, and social recognition. It is especially concerning that 73% of the respondents do not receive any financial compensation for their work, as carers and almost of them don't have access to any kind of social benefits.
2. There are no countries in our study that would do significantly better than others in terms of providing adequate resources, high-quality support services, or flexible time arrangements to family carers to better reconcile their professional, care and personal life.
3. Being a family carer often results in isolation and social exclusion: 1 of every 3 respondents said that they are having a hard time to make ends meet, as a consequence of their caring role. In most countries, carers reported that they felt isolated with no time, or possibility to leave their house, or take part in social activities.
4. In-home support services, in-home nursing care, respite, or personal assistance are preferred forms of support service provision by family carers. Respondents mentioned that the availability of such services would relieve them from the intensive care responsibilities and would ensure that their relatives can live independently in the community while receiving high-quality support.
5. There is a great demand towards person-centred, flexible solutions: Some family carers expressed their intention to return to the labour market, whilst others would not mind staying at home, if their work as carers was recognised and financially compensated. Policy makers should take into account the choices and preferences of family carers and their relatives with care needs.

Meeting the needs of family carers through targeted measures contributes to the quality of care, or support and also helps to preserve a quality family life. Investment in 21st century community-based support services and family support measures, with special regard to work-life balance policies would contribute greatly to the social inclusion and wellbeing of all families.

# I. INTRODUCTION AND BACKGROUND TO THE STUDY

COFACE Families Europe and its members representing persons with disabilities and their families, have been advocating for many years for the recognition of family carers who provide care to their relatives with support needs, through a number of rights and social benefits. According to research, 80% of care in Europe is provided by informal carers, including family members (spouses, children, parents and other relatives) as well as friends.<sup>1</sup>

In 2007<sup>2</sup>, COFACE Disability published the **European Charter for Family Carers (hereafter the Charter)** a reference tool that contributes to reconciling family and working life by allowing an informed choice by both the person with care needs and the carer, and provide them with adequate financial compensation, as well as social rights and benefits (pension, respite care etc.).<sup>3</sup> The Charter emphasises that the rights and choices of persons with disabilities and other support needs should be respected and they should be able to choose from whom they want to receive care, or support. The EU and up to date 27 of its Member States ratified the UN Convention on the Rights of Persons with Disabilities (CRPD), the major international human rights treaty protecting the rights of persons with disabilities and their families. Among others, it includes provisions on the right to live independently and be included in the community (Article 19), respect for home and family (Article 23), rights of children with disabilities (Article 7), adequate standard of living and social protection (Article 28).<sup>4</sup> Family carers of children with disabilities play a particularly important role in realizing children's rights to grow up in a family environment.

Similarly to persons with support needs, 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 caregivers and care receivers must be free, informed and open to reassessment.<sup>5</sup> We note with concern the lack of adequate, accessible, community-based support services for persons with disabilities in most Member States, with special regard to person-centred schemes, like personal budget, or personal assistance. In some countries, there have been major cuts on personal assistance services due to the 2008 economic crisis and the recession. Family carers are often filling the gap of social service provision, however, relying on their unpaid workforce is not a sustainable solution to create inclusive and prosperous societies in Europe. COFACE therefore advocates for both the investment in community-based, good quality, accessible social services and for the legal, financial and social recognition of family carers.

Besides advocating for the rights and recognition of family carers, COFACE Families Europe has been actively working on providing adequate work-life balance measures for family carers, so they can better reconcile their care, work and personal life. Among other initiatives, COFACE published the European Reconciliation Package<sup>6</sup>, which is the main policy outcome of the 2014 Year of Reconciling Work and Family Life in Europe and one of its chapters is focusing on reconciliation for carers.

Family carers, or more generally informal carers, have not received until recently much attention in academic research. Statistics on informal carers are slowly growing in numbers and reveal tendencies in Europe. For instance, caregiving has a strong gender dimension: two thirds of family carers are women, whereas men often become carers only at an older age.<sup>7</sup> When it comes to intensive and highly demanding caregiving, the involvement of women is even more prevalent.<sup>8</sup>



It remains unclear in which European countries caregiving for a family member is more frequent than in others.

Findings from a 2011 Eurobarometer survey on employment and active ageing reveal that around 16% of Europeans provided full-time (3%) or part-time (13%) care in 2011, of which 40% reported that they had to provide care for an adult with care, or support needs.<sup>9</sup> According to Eurofound's third European Quality of Life Survey (EQLS), 12% of men and 16% of women aged 18–64 in employment, care for an elderly or disabled relative less than once a week, and 8% of men and 9% of women care for an elderly or disabled relative at least once or twice a week. Among workers aged 50–64, 18% of men and 22% of women provide care at least once a week.<sup>10</sup>

Family carers take over a significant share of care provision in Europe and also indirectly make an economic contribution through their work. It has been estimated that the economic value of informal care accounts for 40% to 90% of the overall cost of long-term care.<sup>11</sup> Thus, family carers can be considered as the backbone of the long-term care sector. Also, other calculations amount the value of unpaid family caregiving to between 20% and 36% of the GDP of the European Union.<sup>12</sup> However, this economic contribution is only one side of informal caring.

In several studies, it has been highlighted that caring also has a strong impact on the caregiver's life, i.e. in terms of financial or health problems due to their responsibilities. Statistics show that caring for a highly dependent person often involves the reduction of working hours or rates of employment.<sup>13</sup> Consequently, carers in working-age are at a higher risk of poverty with women being the most vulnerable. Furthermore, studies find that there is a relation between intensive care and a worsening of the caregiver's mental health.<sup>14</sup> In order to support family carers and to ensure their psychological well-being, different services, for instance respite care, need to be in place. Yet, less than one third of family carers reported in a pan-European study that they had used a support service in the last six months. It was pointed out that more services for family carers were needed with different forms of services according to the respective country.<sup>15</sup> **Having this context in mind, we developed our research methodology to collect first-hand testimonies of family carers on the existing gaps and challenges regarding their access to resources, services and time arrangements, as well as the impact of caring on their life.**

Some European non-governmental organisations produced reports relating to family carers, but with a different or more specific focus, including EUFAMI<sup>16</sup>, EURORDIS<sup>17</sup>, Eurocarers<sup>18</sup> or AGE Platform Europe.<sup>19</sup> For instance, EUFAMI and EURORDIS specifically addressed caregivers for persons with mental illness or persons with rare diseases as well as their carers. Eurocarers focused on the socio-economic impact of care provision, but did not build their study on testimonies from family carers themselves. Also, the study of AGE Platform was conducted with a specific focus on persons with incontinence and their carers.

In 2017, responding to the **lack of information on what family carers consider as most useful measures, or policies to better reconcile their work, care and personal life whilst respecting the choices and rights of the person they care for**, the COFACE network decided to launch a major data collection. The target group of this study is specifically family carers from different EU Member States, who are fulfilling a caring role towards a member of their family, or someone in their immediate circle. We find that the voice of family carers is often missing from policy discussions. COFACE Families Europe sees this study as a great opportunity to channel the voice of family carers directly to European level policy-making and build an evidence-based advocacy strategy for the rights of family carers and persons with support needs in the future.

## II. METHODOLOGY

### 1- Research Objectives

The aim of this study is to take stock of the challenges and needs of family carers in Europe and search for any good examples of work-life balance policies that support their social, or labour market inclusion. Families in Europe are greatly affected by current social and demographical changes, such as the growing ageing population, changing family structures, or the situation of intergenerational families. Leaving family carers to provide all the care for dependent elderly people, or their relatives with a disability, undermines the social inclusion (poverty risk), health (physical and/or mental exhaustion) and gender equality (most family carers are still women) of these families. Furthermore, we find the persistent existence of institutional care another problem, as they isolate people with care needs from their families and communities, instead of supporting their social inclusion and autonomous life.<sup>20</sup>

The purpose of this data collection was twofold:

1. To explore some of the challenges faced by family carers in accessing adequate resources, services, or time arrangements in different EU Member States.
2. To collect recommendations and good policy practices from national, or local level that help family carers to balance their work, family and personal life.

The target group of this study are family carers and informal carers from different EU Member States, who are fulfilling a caring role towards a member of their family, or someone else in their immediate circle. We are aware that international studies use different definitions of family carers, depending on the caring activities included, who is the recipient of care and other factors. In this study, we will use the definition of the European Charter for Family Carers, that states:

A family carer is 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.<sup>21</sup>

This definition allows us to have a broad perspective on the care provided by a non-professional person, including support, or assistance in many different areas (e.g. assistance in education and social life, administrative formalities, traveling, psychological support, communication, or domestic activities etc.). It is important to take a flexible approach and consider also the needs of those who provide care part-time, or on a temporary basis. The group of care recipients includes children with special needs, persons with disabilities, older people, or people with any other support needs (e.g. a person with chronic disease, or addiction). We acknowledge that persons with disabilities is a heterogeneous group and not everyone needs intensive care, or support. However, we should keep in mind the care needs of persons with multiple disabilities, or complex support needs, which should be met by respecting their rights, choices and needs.

The study covers all family carers regardless of who they provide care for and how many hours they spend with their caring duties. A few respondents asked us why parents of children in general are not covered by our study, as they often face exhaustion and challenges while bringing up their children (lack of childcare, work-life balance policies etc.). While acknowledging these challenges, we also find important to make a distinction between parents and family carers, as supporting a child with a complex impairment, or a chronic disease goes beyond parental duties. Our purpose was to collect first-hand experiences from family carers, a group that is often forgotten in political, human rights and social policy discourses on issues that directly affect their lives.

This study will provide a great understanding of the situation of family carers in Europe and offer policy recommendations to better meet the needs and tackle the social exclusion of this marginalised group. COFACE Families Europe will use the results of this study to carry out more targeted advocacy at European level when representing the interests of family carers.

## 2- Main research questions

Our study aims to answer six main research questions. These questions were developed in cooperation with our members, mostly family organisations and family carers from the national and local level. The questions build not only on the firsthand experiences of our members, but are driven by the current legal, political and social context and challenges in Europe.

Table 1: **Research questions and hypotheses**

Questions	Hypotheses
<p>1. Do our collected data align with the general trend regarding family carers (see European Reconciliation Package), e.g.:</p> <ul style="list-style-type: none"> <li>■ More women than men</li> <li>■ Age groups are affected differently: the highest share of care is provided by women aged 50 or older (despite a growing number of young carers)</li> <li>■ the more care responsibilities are left on families, the higher the gap of the division of care responsibilities between men and women</li> <li>■ Lack of services and support to those with family needs have a strong impact on employment of family carers, especially for women.</li> </ul>	<p>The data we collected in 17 countries (16 EU Member States+CH) will reflect the general trend regarding family carers:</p> <ul style="list-style-type: none"> <li>■ More women family carers than men</li> <li>■ Highest number of answers are from 50+ women (sandwich generation)</li> <li>■ Among those who care for more than 1 person with support needs, or spend the most hours with caring, we will find even more women than men.</li> <li>■ Family carers are out of the labour market. Women are more likely to be unemployed beside their caring role than men.</li> </ul>
<p>2. Is the work of family carers recognised? (legal recognition, social rights, adequate resources, skills for formal employment)?</p>	<p>Family carers are not recognised when it comes to:</p> <ul style="list-style-type: none"> <li>■ financial compensation for the work as a family carer</li> <li>■ access to social benefits and social insurance</li> <li>■ value of their work</li> </ul>
<p>3. Are there services in place to support family carers and their relatives with support needs to live their lives in dignity and independently?</p>	<p>There is a lack of adequate services that would support persons with support needs and their relatives.</p>
<p>4. Are there flexible time arrangements in the labour market to support family carers in reconciling their care and work life?</p>	<p>There are no flexible time arrangements that support family carers in reconciling their care and work life.</p>
<p>5. How did the caring role impact the quality of life of the family carer (financial, physical health, mental health etc.)?</p>	<p>Being a family carer impacts the quality of life of the family carer negatively, including:</p> <ul style="list-style-type: none"> <li>■ physical and mental health</li> <li>■ financial situation</li> <li>■ quality of life</li> <li>■ family relations</li> </ul>
<p>6. Which are the countries that do better in supporting family carers (resources, time, services)?</p>	<p>Western European countries (e.g. BE, FR, DE) do better than Southern European countries (PT, IT, ES) in supporting family carers when it comes to providing them with resources, services, or time arrangements.</p>

## 3- Development of the research plan

### 3.1. PRINCIPLES

A questionnaire was created with the R-S-T (resources, services, time arrangements) framework in mind, in line with COFACE's vision that the best way to achieve a reconciliation economy and society, is through a mix of legislative and non-legislative measures linked to these three pillars.<sup>22</sup>

**Resources** refer to a number of elements that can support families to have decent living standards to live in dignity and avoid poverty, or social deprivation (e.g. wage, allowances, cash benefits, social benefits, pension etc.). The prospect of reconciling work and family life very much depends on the availability of accessible and affordable quality services, including child care, community-based support services for persons with disabilities, or home-based nursing support. 'Community-based services' refer to the spectrum of services that enable individuals to live in the community and in the case of children, to grow up in a family environment, as opposed to an institution.<sup>23</sup> The lack of accessible care services for children, elderly, persons with complex needs, or with chronic illness often hinders the labour market inclusion of family members, mostly women.<sup>24</sup> **Time arrangements** cover both leaving schemes (periods of time off from work for employed

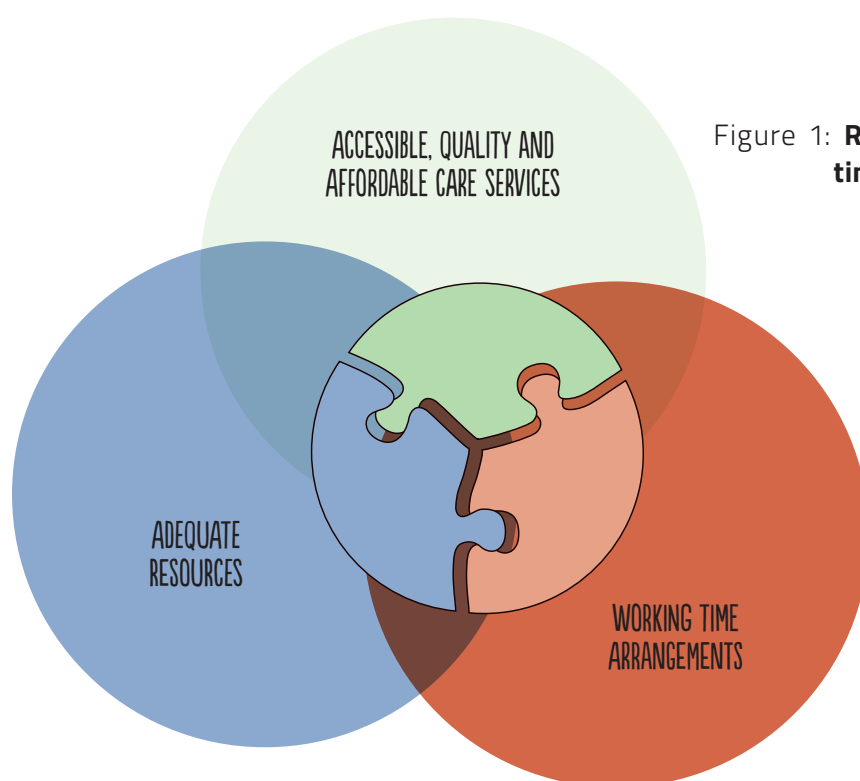


Figure 1: **Resources, services and time arrangements**

parents or other relatives) and flexible working arrangements (e.g. job sharing, tele-work, smart work, compressed working hours, possibility to swap shifts among employees etc.).<sup>25</sup> Flexible time arrangements at work could prevent giving up paid employment and the complete drop-out of the labour market in situations where it is necessary for a short, or medium-term to reduce, or interrupt work due to unexpected situations in one's family.

While the analysis of the collected data is carried out in an independent way, the structure and development of the questionnaire itself took into account the already adopted principles of COFACE Families Europe in the area of work-life balance policies. COFACE has been calling for work-life balance policies and legislation that support families along the life-cycle regardless of gender, or family status. The questions are specifically looking into whether a reconciliation policy mix is available in different countries and how that affects the employment situation and quality of life of family carers.

### 3.2. LIMITATIONS

The study does not offer a comprehensive analysis of the legislative, and policy framework, or the social protection system of each country, but aims to highlight some of the key challenges that family carers face in different EU Member States. The analysis solely relies on the information we received via questionnaires and it was not our intention to check their accuracy. Therefore, the available work-life balance measures may not be adequately reflected in our study. We believe that the lack of family carers' awareness of their rights, or existing work-life balance measures can also be an indication that policies do not always reach those who need them the most.

It is important to note that the study has some further limitations, and our analysis should be read with the following points in mind:

Table 2: **Limitations of the study and consequences**

Limitations	Consequences
The sample is not representative. The data was collected through online purposive sampling with the only requirement being that respondents must be family carers.	Our findings do not present the challenges of all family carers in Europe, but only the experiences of those, who filled out the questionnaire.
Besides online purposive sampling, we also used snowball sampling techniques when we encouraged COFACE member organisations at the national level, as well as our European partners to disseminate the questionnaire among their contacts.	The sample is heterogeneous, and its composition depends on which COFACE member mobilised family carers in the different countries (e.g. in AT most respondents care for children with disabilities, while in DE we mostly received answers from carers of older people). The situation and needs of these people may differ, therefore the comparability has limitations.
The data is not weighted.	We did not weight the data, despite receiving different amounts of data from some countries (e.g. 248 from BE vs 49 from IT), thus the data is not representative of the population of these countries.
The questionnaire was available in 8 languages (Dutch, English, French, German, Italian, Portuguese, Slovenian and Spanish), which had a negative impact on reaching carers from other countries (e.g. Baltic states, or Eastern European countries).	Not having the questionnaire available in other languages resulted in geographical imbalance in the sample, as we received the vast majority of data from Western and Southern Europe, and only very few answers from Eastern and Northern Europe. Another reason is probably that the COFACE network is stronger in Western and Southern European countries. Due to the geographical imbalance, the study cannot provide a comprehensive European picture, but reflect mostly on country differences between Western and Southern Europe.
The study does not take into account the regional differences within countries due to the lack of sufficient information in this regard.	The analysis will be unable to show potentially significant regional differences and will focus on presenting overall the main challenges for family carers. The results might be distorted, especially in the case of Federal States where social protection systems can differ significantly from one region to another (e.g. DE, BE).
Data collection targeted only family carers.	We do not have comprehensive information on the socio-economic situation of the whole family that may affect family carers in a positive, or negative way (e.g. if it's a single parent household). We don't have information on the preferences and needs of the person with support needs, which also limits the scope of our analysis.
The mobilisation happened online, through the COFACE membership.	The data collection could reach family carers linked to the COFACE network in one way, or another, but not necessarily those family carers who live in rural areas, without support, or any links to a local civil society organisation are probably. Furthermore, in some countries, the older generation is less active online. Their needs and challenges might differ from those, who could access our questionnaire online.

## 4- Data collection

A questionnaire was developed to collect data on the challenges and needs of family carers in Spring 2017.<sup>26</sup> The questionnaire included closed and open questions to gather both quantitative and qualitative data. The draft questionnaire was discussed with members of the COFACE network, with special regard to organisations that represent directly family carers. And was finalised upon receiving their feedback. Therefore, the research methodology includes some participatory elements. In order to maximise the number of respondents, the questionnaire was translated into eight languages.<sup>27</sup>

The launch of the data collection was linked to the United Nations International Day of Families that is observed every year on 15 May 2017.<sup>28</sup> The questionnaires were published on an online platform<sup>29</sup> and disseminated through various social media channels within the COFACE network.<sup>30</sup> The data collection took place between 15 May and 30 June 2017. As it was mentioned before, the data was collected through online purposive sampling with the only requirement being that respondents must be family carers. It is important to note that being a non-governmental organisation, COFACE Families Europe had no specific resources to reach family carers and we completely relied on our members' mobilisation efforts.

Initially, the data collection aimed to target only members of COFACE Families Europe (and their members), but we decided to open the data collection to the public and disseminate it widely. As a result of that, it is impossible to say how many answers we received from family carers linked to COFACE member organisations at national level. However, considering that the mobilisation happened mainly through our membership, probably most respondents are indeed linked to our national members.

## 5- Ethical issues

We included a disclaimer in the introductory part of the questionnaire that anonymity of the participants will be protected rigorously, and the collected data will be handled with high confidentiality. By filling out the questionnaire, we did not ask participants to share any of their personal information that would allow us to identify them, thus we fully respect their anonymity. In order to be able to provide respondents with a copy of the final study, they could leave their contact details (email address, or postal address) at the end of the questionnaire. COFACE Families Europe finds it important to channel the results of this study back to the local level and stir information and knowledge among family carers, so a copy of the study will be sent to those respondents who requested it and their email addresses will be then deleted from our data basis.



### III. MAIN FINDINGS

The following section summarises the main findings of our data collection, including both the quantitative and the qualitative data. The information we present in this study derives solely from our collected data and doesn't necessarily represent the views of all family carers in Europe. First, we present the general, socio-economic information of the respondents, the available work-life balance measures (resources, services, time arrangements) for family carers and the impact of caring on their quality of life. In order to put our findings into context, we will take into account data published by the OECD<sup>31</sup>, Eurofound<sup>32</sup>, the European Centre for Social Welfare Policy and Research and others.

We also provide a detailed analysis on the qualitative information we received from family carers regarding the main problems they face in their everyday life and the recommendations they give to policy makers on key matters that would improve their disadvantaged situation. Hopefully, our findings will feed into ongoing legislative and policy discussions both at EU and national level and will help policy makers to better understand the preferences of family carers when developing work-life balance policies and social services.

#### 1- General information

- We received 1160 answers in total, from 17 countries (16 EU countries+CH). For simplifying the analysis, the category 'Other' country was created to include the following:
  - Non-EU countries (CH);
  - All EU countries from where we received less than 30 answers (EE, FI, GR, HU, IE, MT, NL, SE);
  - Those answers who did not want to share what their country was (28 respondents).

The table below summarizes how many answers we received altogether from each country:

Table 3: **Absolute number of respondents per country**

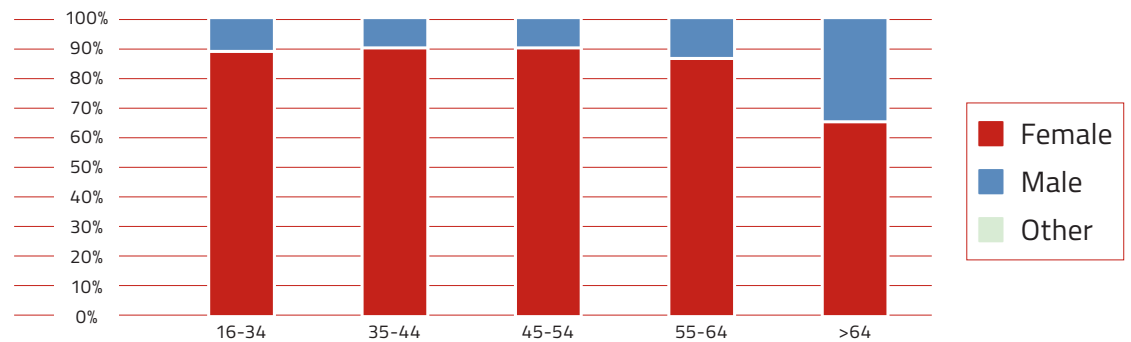
Country	Number of respondents/% of total
Austria (AT)	46 (4%)
Belgium (BE)	248 (21%)
France (FR)	246 (21%)
Germany (DE)	78 (7%)
Italy (IT)	49 (4%)
Portugal (PT)	234 (20%)
Spain (ES)	153 (13%)
United Kingdom (UK)	32 (3%)
Other	74 (6%)
<b>TOTAL</b>	<b>1160 (100%)</b>



## 1.1. GENDER AND AGE

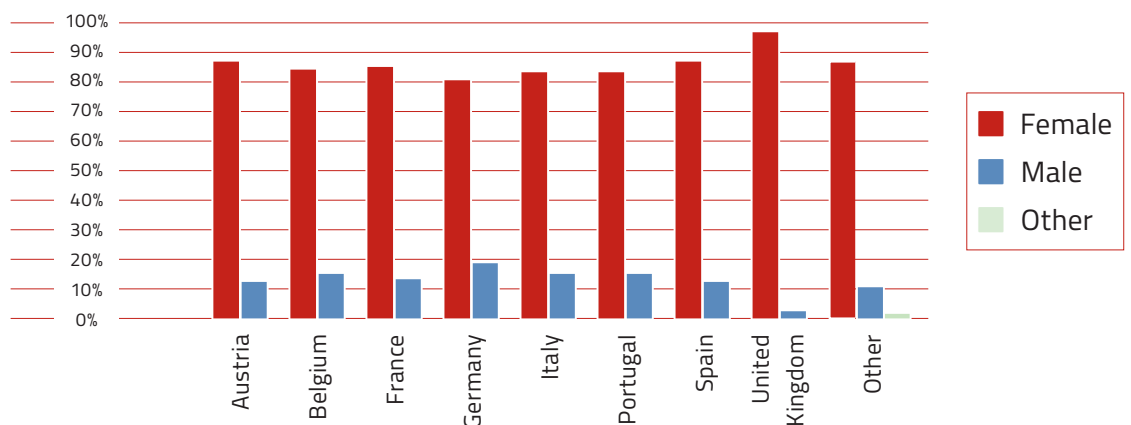
85% of the respondents are women, 14.6% are men and 0.3% marked their gender as 'other'. Despite the fact our sample is not representative, the high proportion of female carers is in line with the general trend that most of the informal care work is carried out by women. The highest proportion of male carers appeared in DE (19.23%) and the lowest in the UK (3.13%), but there were no major differences among the other countries (around 15% everywhere).

Figure 2: **Gender-Age ratio (total)**



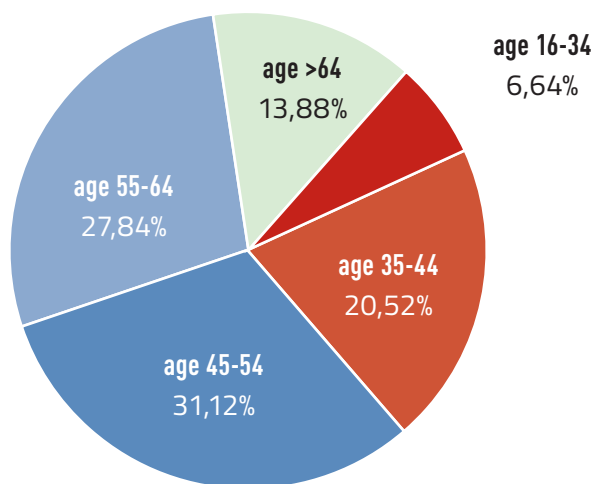
In our sample, we have 6.64% of young people (aged between 16 and 34), which signals the increasing number of young carers taking up an informal support role. Our data corresponds to the OECD's data that 75 to 80% of carers are aged 45 and above<sup>33</sup>, as in our sample 73% of the respondents belong to this age group.

Figure 3: **Gender ratio by country**



Looking at the gender-age ratio, we find that the total rate of men amongst carers is around 10% in all age groups until age 64+, where their proportion increases to 35%. It means that men take a bigger role in caring, once they are retired, but before that it mostly falls on women. This result is perfectly in line with the findings of OECD that the gender distribution of carers changes with the age and there are more male carers among the 75-years-old and above.<sup>34</sup>

Figure 4: **Age ratio (total)**



When we break it down to countries, the proportion of men among carers aged 64+ is at least 25% in each country, but in BE and DE it goes up to as high as almost 50%. Regarding other age groups, in AT, the proportion of men is also higher (45%) in the age group 55-64 and in IT we find more men in the age group 35-44 (30%). Nevertheless, we would need more data to draw any conclusions from these observations.

To assess whether our sample aligns with the general trend that there is a bigger gap in the division of care responsibilities between men and women when there are more care responsibilities, we look at two indicators:

- how many people they have to care for;
- how many hours of care they have to provide.

In our data, the gap in division of care responsibilities between men and women is about the same when there is 1 or 2 family members with care needs, but increases when there are 3 or more people needing care or support, from 85% to 90% women (see table below).

Table 4: **Division of care responsibilities between men and women by number of cared persons**

Number of cared person	1	2	>3
Female	84.33%	85.91%	90.40%
Male	15.31%	14.09%	9.60%
Other	0.35%	0.00%	0.00%

When we look at the hours of care provided (see table below), there was only a slight increase in the proportion of women when the hours of provided care is 40 or more hours per week (from 83% to 86-88%). We note that in our sample the gender gap in the division of care responsibilities doesn't change significantly when there is more hours of care to be provided, but the proportion of women indeed increases when there are 3 or more people to care for. Nevertheless, in general there is a big gap in the division of care responsibilities between men and women (85% vs 15%).

Table 5: **Division of care responsibilities between men and women by hours of care provided**

	<20 hrs/week	Around 20 hrs/week	20-40 hrs/week	40-56 hrs/week	>56 hrs/week
Female	82.37%	83.33%	83.53%	86.34%	88.17%
Male	17.27%	16.67%	15.88%	13.66%	11.57%
Other	0.36%	0.00%	0.59%	0.00%	0.26%

## 1.2. REASONS FOR CARE NEEDS AND RELATION TO THE CARED PERSON(S)

The questionnaire was open to any family carer, regardless of the support need of their relative. The three most common groups receiving care in our sample were:

1. Adults with disability (28,5%)
2. Older persons with support needs (22%)
3. Children with disability (20%)

Furthermore, chronic disease (11,7%), or mental health (7,7%) problems of adults are also common reasons for care needs.

Table 6: **Number of persons with care needs by reason (total)<sup>35</sup>**

Cared person	Number total (percentage)
Child with chronic disease	62 (4%)
Child with mental health problems	69 (4%)
Child with disability	320 (20%)
Adult with addiction problems	9 (1%)
Adult with chronic disease	188 (12%)
Adult with mental health problems	124 (8%)
Adult with disability	457 (28%)
Older person with support needs	351 (22%)
Other support needs	19 (1%)
<b>Total</b>	<b>1599 (100%)</b>

**Interestingly, 27% of the family carers in our study provide care for multiple people with care needs** (311 family carers in total). The proportion of those who provide care for 3, or more relatives is especially high in ES (12%) and PT (10%).

As a result of collecting data with non-probability sampling, the countries show diversity in the profiles of people cared for. Most respondents from AT (24%) and FR (32%), provide care for children with disabilities. The proportion of adults with disabilities who receive care is quite high in all countries, but in PT (36%), IT (40%), ES (42%) and the UK (27%) this is the most common group to whom family carers provide support. In contrast, most carers

from BE (35%) and DE (32%) provide support to an older relative with care needs. Interestingly, in a number of countries (AT, BE, DE, PT) adults with chronic disease appear as the third common group receiving care from a family member.

These national differences impact our study to some extent, especially when it comes to the needs for specific services (e.g. long-term, or temporary support needs), and leave schemes (e.g. care recipient is a child, or an adult). However, in each participating country, disability, age-related support needs and chronic disease were among the most common reasons to provide care for a relative.

### Informal care is mostly directed towards the carer's

1. child/children (35%);
2. parent(s) (28%);
3. spouse/long-term partner (11%).

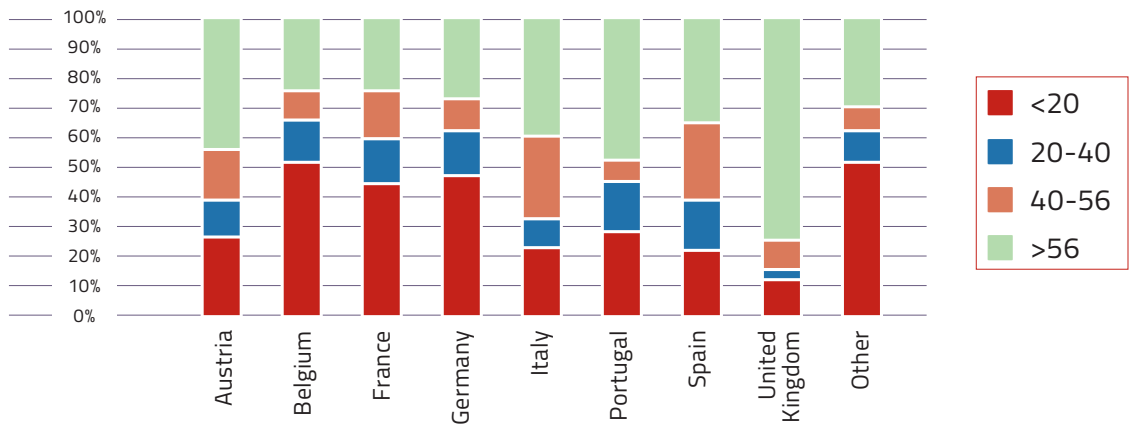
After that follows those who support their sibling (3%), grand-parent (2%), or another relative (3%). **72% of our respondents live together with the person they provide care to.**<sup>36</sup> The percentage of those who provide informal care to someone who is not their relative (friends, or neighbours) is 2%. To sum it up, people usually provide informal care to their closest relatives (child, parent, partner), and a few people also would support others, but then the family relation is not a distinguishing factor (siblings, friends, neighbours).

**31% of our respondents said that there is no one who would help them in fulfil their caring role.** Most carers receive support from their spouses, or long-term partners (22%), professionals (18%), the combination of the two, or multiple people. Spouses, or long-term partners play less of a role when family carers provide care to their siblings. It is also common that siblings share the caring responsibilities of their older parent, but interestingly, they are not much involved in sharing care responsibilities when one's child has disability. Contrary to our expectations, the involvement of friends, or neighbours was almost non-existent (less than 1%).

### 1.3. TIME SPENT CARING

According to the OECD, generally just over 50% of carers are involved in caring activities of less than 10 hours per week on average.<sup>37</sup> In our sample, the proportion of those who provide less than 20 hours of care per week is lower than the OECD data (38%). It is because 62% of our respondents are providing an 'intensive level of caring' (more than 20 hours per week).<sup>38</sup> Furthermore, **one third of our respondents provide very high intensity of caring of 56 hours or more per week**<sup>39</sup>. The proportion of those providing very intensive care (more than 56 hrs/week) is especially high in the UK (75%), PT (47.44%) and in AT (43.48%).

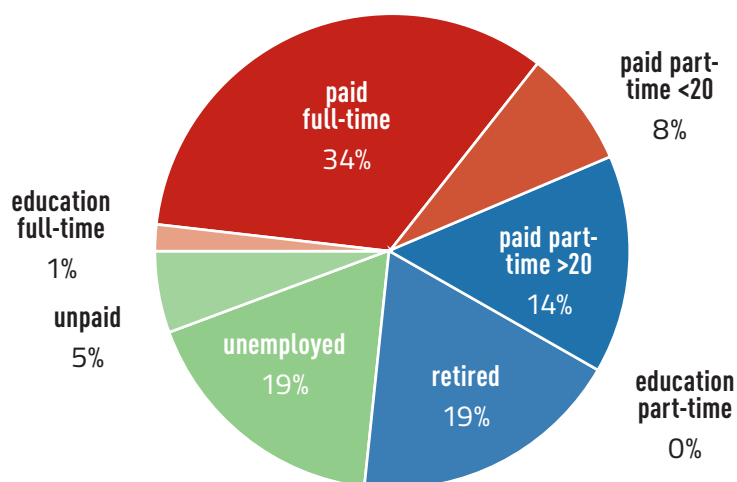
Figure 5: **Caring time (hrs/week) by country**



### 1.4. EMPLOYMENT STATUS OF RESPONDENTS

Respondents were asked what their current occupation (employment, or education) is beside their caring role. As studies show, providing care or support can be a demanding task that is incompatible with a full-time job, or with any type of paid employment.<sup>40</sup> Nevertheless, it is important to note that carers have different socio-economic characteristics and human capital levels, thus the decision of becoming a carer might be also related to labour market opportunities and earnings potential.<sup>41</sup> **Around half of our respondents have a paid full-time job (34%), or a paid part-time job (22%) besides caring for a family member. However, the proportion of retired (19%) and unemployed (18%) people are still significant.**

Figure 6: **Occupation besides caring role**



The group of unemployed consisted mostly of people aged between 35-54, with proportionally more women than men in this situation. Having some kind of unpaid occupation (e.g. being a housewife, or volunteering) is mostly common in age group 45-64. Interestingly, we find people attending full-time education in two age groups: 16-34 and 45-54. This shows that

some carers probably take part in education to have better perspectives when trying to return to the labour market after a longer break.

The proportion of those who hold a full-time paid job beside caring is the highest in PT (52%), then comes ES (45%) and 'other countries' (35%). The rate of unemployed carers is the highest in the UK (38%), ES (22%), FR (21%) and IT (20%).

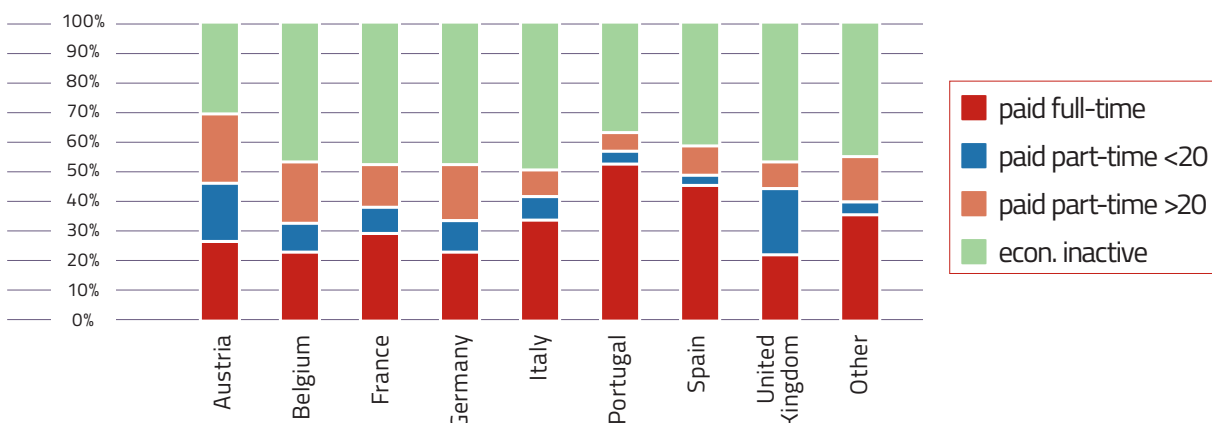
The greater the hours of care provided, the more likely carers are to give up paid employment. In our sample, the rate of unemployed carers is around 7% when 20 hours or less care is provided per week, but it increases to about 30% when 40 hours or more care is needed per week. **Those who provide 40 hours or more care per week are 4 times more likely to be unemployed than others.**

It is interesting to look at the proportion of economically inactive respondents in the whole sample. Based on the definition of Eurofound, 'economically inactive' comprises all persons who were neither «employed» nor «unemployed» during the short reference period used to measure «current activity».<sup>42</sup> This population is split into four groups: attendant at educational institutions; retired; engaged in family duties; other economically inactive.<sup>43</sup> Since all our respondents are engaged in family duties as family carers, we count everyone, who does not have a paying job beside their caring role, as 'economically inactive'. Therefore, in our sample, the 'economically inactive' group comprises the following categories:

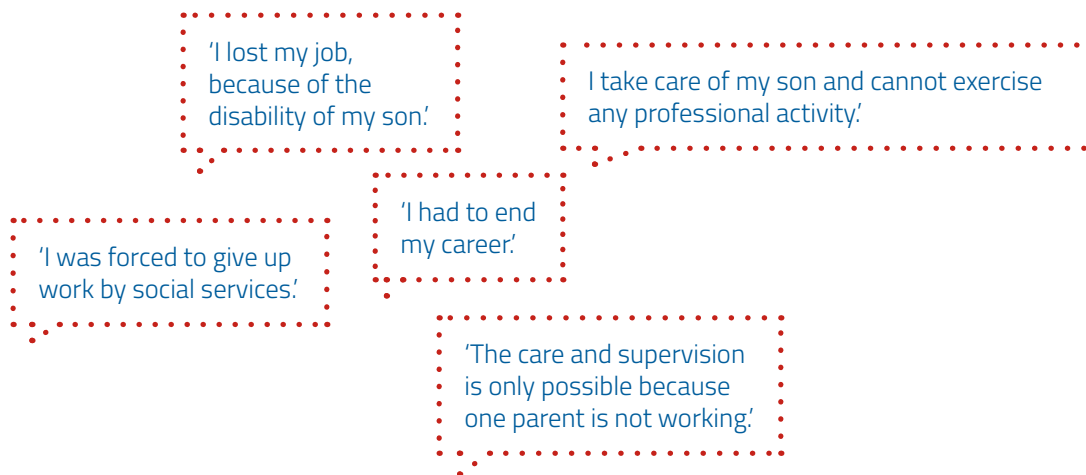
- Education full time (1%);
- Retired (19%);
- Unemployed (18%);
- Unpaid work (including volunteering, maintaining the household etc.) (5%).

As the diagram shows, the proportion of the inactive respondents is the highest in IT (49%), DE (47%), FR (47%), the UK (47%) and BE (46%), but it is above 30% in all the other countries. In this study, we cannot determine whether retired respondents receive a decent pension, or not. However, those carers, who provide long-term care and have been out of the labour market for a longer period of time, will likely have very low, or no pension

Figure 7: **Ratio of economically inactive by country**



at all. Respondents often mention that they had to give up their job against their will, either as a direct consequence of the need to care for their relative, or because of the way the social protection system is organised:



Some respondents who work as self-employed also highlighted some specific challenges they face in terms of the lack of available schemes, or rights. As one of them said:



Regarding the gender dimension, 42% of female carers and 51% of male carers in our study are economically inactive. This is because over one third of the male carers who responded to our questionnaire are retired. It is concerning that proportionally more female carers are unemployed (19% of women vs 12% of men), or engaged only in part-time work (25% of women vs 8% of men), than men beside caring. This will have a long-term negative impact on their pensions and put them in an economically disadvantaged and dependent situation towards their spouse who held a full-time job during the active working years. As one of our respondent underlines:



## 2- Available Work-Life Balance measures

'I cannot get a job with a schedule that would allow me to be a caregiver, because there is no flexibility with rotating shifts.'

(Portugal, female, aged 35-44)

As it was mentioned earlier, COFACE's vision is that the best way to achieve a reconciliation economy and society is through a mix of legislative and non-legislative measures to provide families with adequate resources, services and time arrangements. Therefore, this chapter is structured along these three pillars and looking into the experiences of family carers of accessing financial measures, support services and time arrangements in their home country.

### 2.1. RESOURCES

There are a number of elements that can support families to have decent living standards and avoid the risk of poverty, including:

- Labour related income: access to decent wages and tackling the gender pay gap;
- Fairer and more equitable tax systems;
- Removing implicit bias also from indirect taxation;
- Income support through benefits and allowances.<sup>44</sup>

In this study, we mostly focus on the availability of income support through benefits and allowances to family carers and to the persons with support needs.

### FINANCIAL COMPENSATION

'No job, no recognition from the State, therefore there isn't any remuneration.'

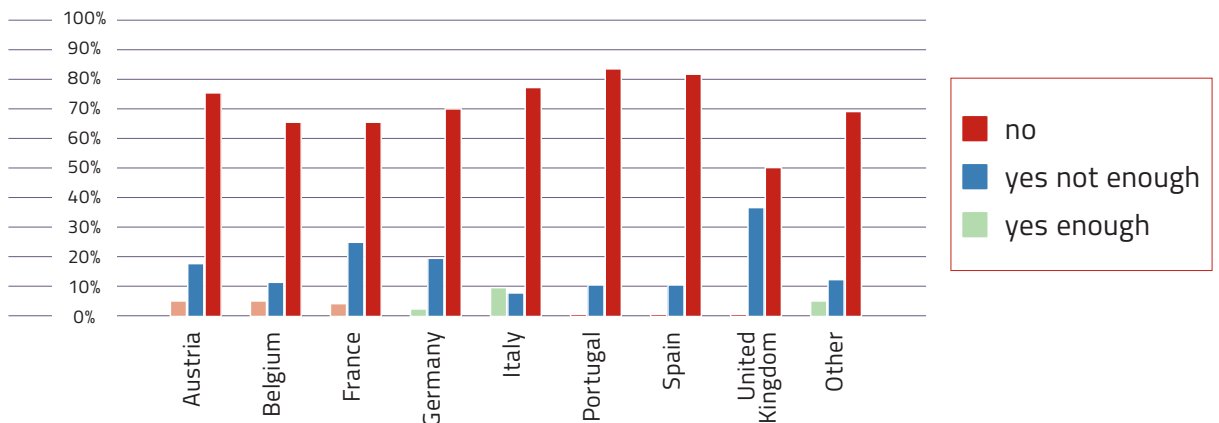
(n.a.)

Many of COFACE's members advocate at national level for the legal recognition of informal care work, as real employment and for getting financial compensation, for instance in a form of a paid carer's leave. Financial compensation is particularly important for those carers, who had to give up their full-time job, when one of their family members needed support and there were no alternative solutions available in the form



of community-based social services. Considering the great differences between wages in EU Member States, we simply asked respondents if they receive a payment or not, and whether this payment is enough to cover their needs. **73% of our respondents said that they do not receive any financial compensation for their work, as carers.** 1 of every 5 carers receive some kind of financial compensation, but only 3% of the total number of family carers finds the payment sufficient. In PT, ES and the UK literally no one said that they get sufficient payment for their work as carers.

Figure 8: **Financial compensation as family carer by country**



Regardless of the type of care, or support needs of their relative, the majority of family carers find available financial compensation insufficient. Carers of children with support needs (including disability, chronic disease, or mental health problems) more likely receive financial support than those who care for older people (30% vs 10.5%), but the vast majority of them would still find the payment too low to cover their needs. The rate of carers who receive some kind of payment is even lower, 1 of every 6 carers, when they support an adult with disability, or a chronic disease. **Carers who support an adult with mental health problems receive almost no financial support.**

When it comes to financial resources directed to people with support needs, the overall situation looks a bit better, as **58% of the total respondents confirmed that their relatives with support needs receive some kind of payment (personal budget, or care allowances).** The proportion of people with support needs who receive financial support to cover their needs was the highest in IT (77.5%), AT (76%), DE (74%), and ES (70.6%). Most commonly, children and adults with disabilities receive direct financial support ( of each group). The rate of those who receive financial support is much lower among older people with support needs, or adults with chronic disease. The vast majority of people with support needs received funding directly from State sources.

## SOCIAL BENEFITS AND INSURANCE

'Family carers should be given some form of financial benefit, because if I would not be taking care of my wife, I would have not yet retired.'

(Malta, male, aged 55-64)

After receiving some concerning news from COFACE's membership, we also wanted to know whether family carers have access to social benefits, including social allowances, carer's benefit, or pension. These instruments vary from country to country and this study will not detail all possible measures. However, it is important to recall that all families, without discrimination should be able to access the income support they need. Social benefits and extra ad-hoc support are especially important for families with a low income, or in a vulnerable situation. **Almost 2/3 of the respondents (63.7%) said that they do not have access to any kind of social benefits.** The situation is the worst in IT, where 86% of our respondents have no access to such benefits. The situation is similarly concerning in PT (70%), BE (64.5%), FR (64%). The only two countries where access to social benefits show a slightly more positive trend are AT and DE, but even in these countries only about half of the respondents said they access such benefits.

It is an extremely worrying trend in many EU Member States, that those family carers, who have been long-term unemployed to fulfil their caring duties may not get a pension when they will reach retirement age:

'I am retired without a pension.'

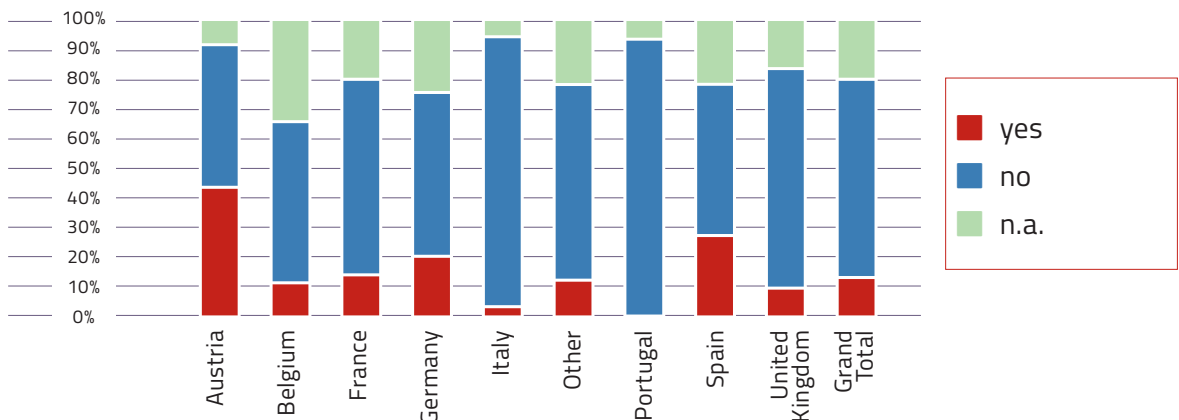
(n.a.)

One of our respondents suggested:

'Give a financial allocation for family carers, which accounts for calculating the pension. Caring for a family member should be regarded as a REAL job, even if it is done with LOVE.'

(Belgium, female, aged 65-74)

Figure 9: **Social insurance for carers by country**



In our study, the access rate to social insurance is even worse: **More than 2/3 of the family carers (68%) do not have social insurance**. The situation is especially striking in PT and IT, where over 90% of the respondents live without social insurance. The highest proportion of people who are covered by social insurance can be found in AT (43% covered), ES (26%) and DE (21%).

## 2.2. SERVICES

'Social services are less and less equipped, both financially and regarding the offered services. Thinking about the future of my son, when I won't be there, makes me anxious.'

(Spain, male, aged 45-54)

In this study, we generally distinguish between two main types of services:

- services that support directly the person with care or support needs;
- services that support the family carer in better fulfilling their caring role.

COFACE believes that there is a strong need to invest in both types of services to protect the rights, choices and improve the quality of life of carers and people with care needs. Therefore, in the questionnaire, we asked family carers on the availability of specific services available to support them, or their relative with support needs.

### AVAILABLE SERVICES TO PERSONS WITH SUPPORT NEEDS

'As an adult with disability, it should be possible to decide about your own life regarding your desires and choices and not be left as a dependent child with your family. Caregivers should also have the choice of the level of their involvement in caring.'

(France, female, aged 45-54)

As it was mentioned before, community-based services encompass a broad range of services, including early childhood care and education, in-home services, personal assistance, housing support services and other mainstream and specialised services to support the autonomy of persons with care, or support needs.

Only **11%** of the respondents said that there are **sufficient community-based services available where they live** (see table below). 35% reported that there are some services available, but they are not sufficient. The rate of carers who find available community-based services sufficient was the highest in BE (20%) and the lowest in IT (2%). Almost one third of

the Austrian respondents said that there are no such services available where they live. According to one of them:

'For young adults with multiple complex disabilities, who have the highest care needs, there is no person-centred support services in Lower-Austria that would take the individual needs into account.'

(Austria, male, aged 55-64)

Similarly, quite a few respondents in DE (21.8%), ES (19.6%) and PT (18.38%) reported the lack of community-based services. Notably, almost 40% of family carers did not know if such services are available, or not, where they live. Many family carers called for more information on the available services to be provided by the municipality. This may signal to policy makers that effort should be made to better reach family carers and increase their awareness of the variety of services available in the area where they live.

Community-based support services play a key role in relieving family carers from their caring duties and fostering the autonomy, quality of life and social inclusion of persons with care, or support needs. The following quotes illustrate the strong need for home-based support services:

'Association for home help for persons with disabilities. This allows me to keep working, knowing my child is supported by competent persons.'

(France, female, aged 35-44)

'We are in constant fear of losing the small bit of home help granted by the State.'

(Ireland, male, aged 55-64)

Respondents were also asked how could community-based support services be improved. First of all, many of them highlighted the **complete lack of personal assistance and person-centred solutions** and suggested making personal assistance available for persons with disabilities and other support needs. In order to improve the existing services and tackle long waiting lists, more places and trained staff is a first step. Many of them highlighted the need for a more needs-based, or person-centred approach:

'The services should be flexible: not every week the same number of hours'

(n.a.)

They also mentioned that community-based services are sometimes not accessible for all persons with specific support needs (e.g. no sign language interpreter available, or they do not accept young adults with multiple profound disabilities). The high cost of available services present another barrier for many people to frequently use them. Family carers suggested

**more public investment in community-based support services** to improve both their availability and quality.

Table 7: **Available community-based services by country (%)**

Available community-based services	Yes, sufficient	Yes, not sufficient	No	N.a.
Austria	13.04%	34.78%	30.43%	21.74%
Belgium	19.76%	35.08%	7.26%	37.90%
France	9.76%	33.74%	13.82%	42.68%
Germany	3.85%	26.92%	21.79%	47.44%
Italy	2.04%	36.73%	16.33%	44.90%
Portugal	4.70%	37.18%	18.38%	39.74%
Spain	10.46%	39.22%	19.61%	30.72%
United Kingdom	9.38%	40.63%	12.50%	37.50%
Other	17.57%	31.08%	10.81%	40.54%

**Only 18% of the respondents said that they had received professional help to fulfil their role as carers.** This professional help could come from various professionals (nurses, education professionals, housekeepers, daycare providers etc.) and take various forms (paid, unpaid, voluntary etc.). It was most often provided by the State, municipality, social service providers, or a church.

Indisputably, not all persons with disabilities have equally very high support needs. Many of them could be more included in the education system, or in the labour market, if person-centred support services were available. This would support their independent living and financial inclusion. As one respondent suggested:

'Offer concrete employment opportunities for people with disabilities, so that, within the limits of their ability, employ them in a paid job for a few hours weekly and consequently give a few free hours to caregivers.'

(n.a.)

### AVAILABLE SERVICES TO FAMILY CARERS

'The services must be further extended to specifically support the caregiver, because every situation is different and sometimes very complex.'

(Belgium, female, aged 55-64)

This section is looking at family carers' experiences about the availability and quality of some services that are meant to support them in fulfilling their caring role and in better reconciling it with their personal and professional life. **One does not prepare to become a family carer, but it often happens unexpectedly** due to an accident, diagnosis or complications at birth:

'You are not born a caregiver, you become one. You are responsible to provide care without any training and you and your family must pay the consequences of that.'

(n.a.)

People have to cope with a completely new situation from one day to another and this can be distressing physically and emotionally for both the person with care needs and the carer. There was a concrete proposal of introducing a European Card for carers and assistants of persons with disabilities, similarly to the European Disability Card<sup>45</sup> to support the mobility of the whole family and their access to services across Europe.

#### **a) Information on rights and available services**

The European Charter for Family Carers states that family carers should be informed about their rights and duties and they should have access to all information that will help them to fulfil their role as carers.<sup>46</sup> Therefore, we asked family carers if they received any information about their rights when they took up their caring role, or at a later stage. **30% of family carers received information about their rights, but less than half of them found the information useful (13%).** Surprisingly, over half of the respondents (54%) said that they did not receive and would not be interested in receiving information.

Nevertheless, calling municipalities to provide more information about services to family carers was one of the most common suggestions of our respondents on how to improve community-based service provision.

'Municipality must provide more information rather than withholding. Sometimes they do not know that some help, or support exist.'

(n.a.)

Providing families with information about the rights of persons with disabilities, would equip them better to stand up for the interest of their child with disability should a discrimination, or a human rights violation occur (e.g. in the education, or health system).

#### **b) Training to improve skills and knowledge as a family carer**

Altogether 16% of the family carers received some kind of training to improve their skills and knowledge on how to better provide care and support, as a carer, however, only 10% of them were satisfied with the training itself. **Almost two third of the respondents were never offered the opportunity to take part in any training, or skill development.** This is a pity, because family carers often have to provide medical support (e.g. tube feeding, dosing medicine etc.) or have to be able to notice change in the physical condition of their relative (e.g. sign of seizure for an epileptic person), whilst they are not necessarily prepared to that:

'I needed more training to be able to cope better with my son. I learned from mistakes.'

(Portugal, female, 65-74)

According to the European Charter for Family Carers, access to special training programmes aimed at improving knowledge about support giving should be provided. Furthermore, a training system should be set up by public authorities in full consultation with the representative bodies.<sup>47</sup> However, there were some respondents who said they would not be interested in such training (12%).

The rate of those, who received training and found it satisfying was the highest in ES (21%), FR (12%) and PT (11.5%).

**c) Psychological support, or counselling**

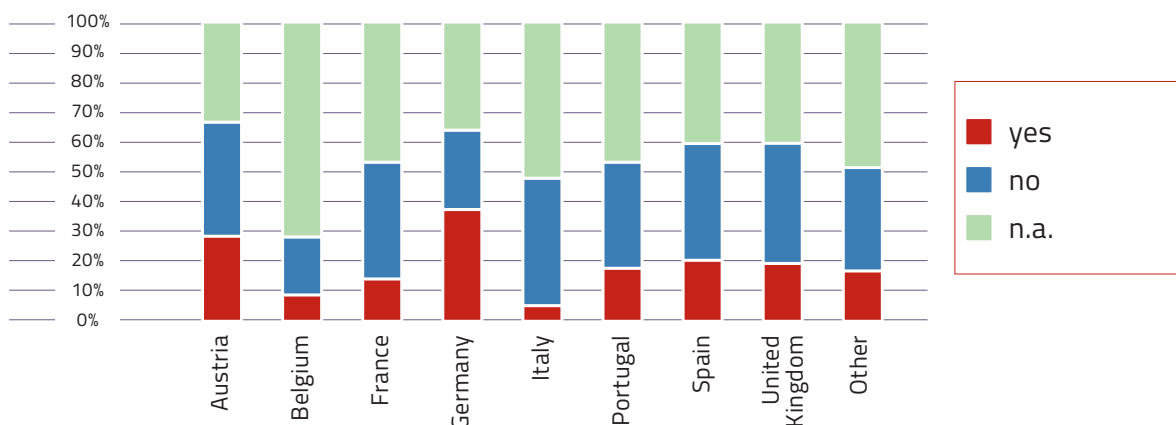
Becoming a family carer is often a consequence of an accident, or an illness of a close relative (child, parent, partner, siblings, or other relatives) and assisting someone in an extremely vulnerable situation can be very demanding both physically and emotionally. In order to successfully cope with the new life situation, often caused by shock, trauma, or depression, family carers should receive adequate health care, including psychological support.

From the support services that we examine in this study, the least available one is psychological support, or counselling to family carers. **Only 1.3 % of all respondents receive regular psychological support provided by the State, or local government, as a family carer.** Another 8.8% reported that they received counselling a few times, but not regularly. Two third of the respondents never received such support, but it seems, there would be a strong need to make counselling available (only 16% of respondents said they would not need it). There are no significant differences between the countries when it comes to providing psychological support to family carers.

**d) Respite care**

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.).<sup>48</sup> According to the European Charter for Family Carers, providing family carers with respite is extremely important

Figure 10: **Respite care by country**



to avoid the deterioration of their physical, or mental health condition. Regarding the availability of respite care, **only 1 of every 6 respondents said they can access respite care where they live**. There is presumably low awareness on what respite care is, given that half of the respondents skipped this question, or said they do not know if respite care is available. Many of them also could not specify how many hours of respite is available. Among those, who specified, the amount of available respite care showed great variety, e.g: 2 hours/month (GR), 20 hours/month (BE, FR); 28 hours/month (ES); 3 month/year (FR); 8 hours/month (AT); 12 hours/month (BE); 1 day/month (FR) etc.

Some respondents emphasised that more flexibility and especially the availability of respite during the nights would make their life much easier. Respite care is an area where we can see greater national differences. In IT, only 4% and in BE only 7.6% reported that respite care is available. The situation seems to be a lot better in DE (37%), AT (28%), ES (20%) and the UK (18.7%), however the coverage of respite care is below 50%, even in these countries.

#### ***e) Reintegration services to the labour market***

We also asked family carers if there are some measures, services, or public agencies in place to support their reintegration to the labour market after being unemployed for a longer period of time. Many family carers have to stop working completely and remain long-term unemployed, due to the lack of reconciliation policies, including flexible time arrangements at work. Our members reported that the longer someone stays away from the labour market, the harder it is to find a job again, because the labour market tends to penalise non-work periods very quickly. **Over 70% of the respondents were not aware/could not answer if such reintegration services to the labour market even exist in their country, or not**. Only 9% of the total respondents said that such service exists, and the highest proportion was in AT (28%), BE and IT (14%-14%). The European Commission identifies half of the total number of unemployed people in Europe as long-term unemployed, which means that they are unemployed for over 12 months. While family carers are not specifically addressed in the Council recommendation on the integration of the long-term unemployed into the labour market<sup>49</sup>, their needs and challenges should be taken into account in the implementation of this recommendation.



## 2.3. FLEXIBLE TIME ARRANGEMENTS

'I would not dare ask for time off (even unpaid) for fear of the recriminations. Not necessarily job loss, just being thought of as a less important team member and passed over for pay rises or promotions.'

(Portugal, female, 65-74)

The third important pillar of work-life balance policies is 'time' to better reconcile work, care and personal life. Measures include both leave schemes and flexible working arrangements.<sup>50</sup> We asked family carers about the available leave schemes to take time off from their work, or education to fulfil their caring role, and about flexible work arrangements in their countries. We also wanted to know how satisfied they are with these schemes, or arrangements and what kind of solution they finally found to reconcile their work, care and personal life. Some family carers felt that there is a lack of understanding about how difficult it is to reconcile these demanding responsibilities:

'Combining work with family care is very complicated. There is a rejection, and total incomprehension for the situation you are suffering from.'

(Spain, female, aged 35-44)

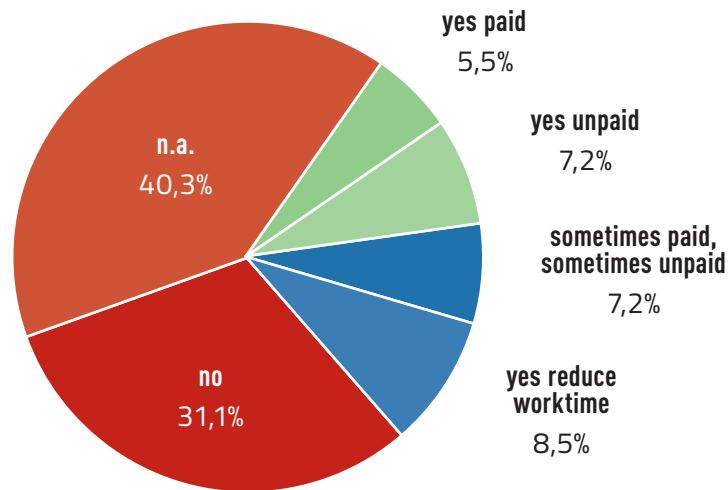
'Caring appropriately for a relative with special needs and working the same time is simply impossible in this country.'

(Germany, female aged 55-64)

### AVAILABLE LEAVE SCHEMES

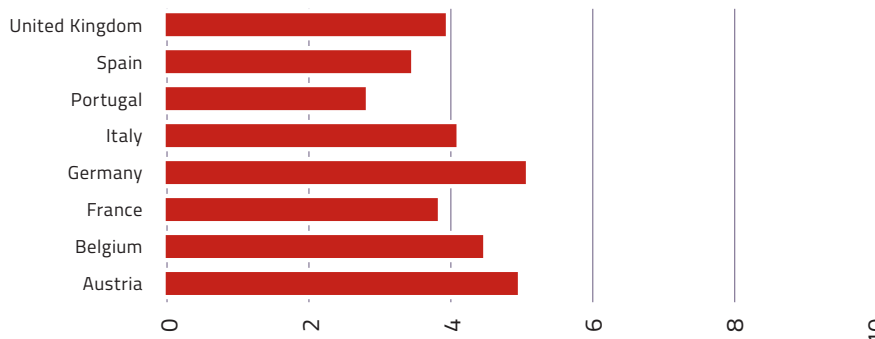
'Leave schemes' refer to the possibility of taking time off from employment to stay at home and look after a newborn, a baby, or child, or an ageing or disabled family member. Common leave schemes are for instance, maternity, paternity, parental, or carers' leave. The provided length and level of payment during leaves vary greatly across the EU and often depends on cultural and economic circumstances, as well as the level of gender equality. Leaves are still taken predominantly by women, due to economic (gender pay gap) and societal (dominance of traditional gender roles) reasons, but this has a long-term negative impact on women's employment and financial dependence on their spouses, or partners.

Figure 11: **Is it possible to take time off to fulfill caring role?**



When we asked about the available leave schemes in their countries, **a high proportion (30%) of carers reported that it would not be possible for them to take time off from work, when they need to provide care for one, or more of their relatives.** For many carers in our study, this was not a relevant question, or they could not answer it (40%), either because they are not active in the labour market, or because they have not tried to take time off from work. Only 5.5% of family carers said they could take a special paid leave at work. The rest can potentially reduce working hours to part-time (8.5%), sometimes take paid leave, but sometimes only unpaid one (7%), or take exclusively unpaid leave (7%).

Figure 12: **Satisfaction with available leave schemes**



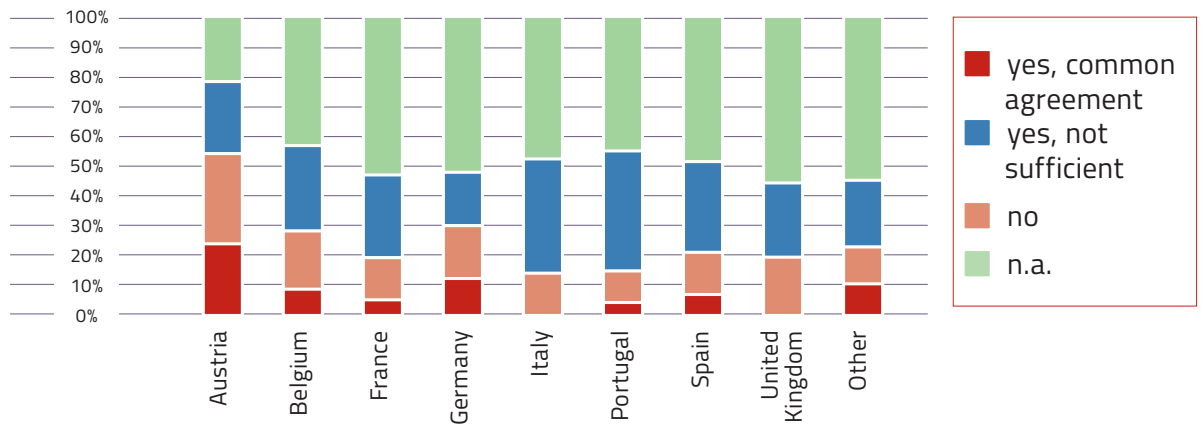
Taking paid carers' leave seems available mostly in BE (34%), IT (19%), or ES (17%). **Those who provide care for their children, or to their parent(s) could more likely take some kind of leaves than those who provide care to their spouses/long-term partners, siblings, or other relatives.**

We asked respondents **how satisfied they were with the available leave schemes**, including carers, maternity, paternity and parental leave. On a scale from 1 (=not satisfied at all) to 10 (=very satisfied), **respondents marked their satisfaction at a value of 3.9 on average.** The highest rate of satisfaction came from AT and DE, however these two countries scored also only 5 out of 10 in average. It is beyond the scope of the present study to describe what are the exact reasons for the low rate of satisfaction, however there are a number of factors that can play a role here, including the length of leave, the payment, administrative burdens, stigmatisation, or others.

## FLEXIBLE WORKING ARRANGEMENTS

We also wanted to know if flexible work or study arrangements were available, which cover a broad range of solutions, such as job sharing, telework, smart work<sup>51</sup>, compressed working hours, possibility to swap shifts among employees, among others. According to the OECD, flexible time arrangements are proven to be beneficial for both employees and employers, as they increase loyalty, dedication and reduce turnover.<sup>52</sup> Reconciliation measures also play an important role in bringing back and keeping women in the labour market. However, it is important to note that most part-time workers in Europe are women, and the available part-time jobs are on average low quality and do not support career progression.<sup>53</sup>

Figure 13: **Available flexible time arrangements at work/study by country**



Flexible time arrangements are mostly considered as common in AT (24%) and in DE (13%), but the access rate is still very low. Nobody from Italy, or the UK said that it is a common arrangement, and from Portugal and France the rate was less than 5%. The older the respondents are, the fewer of them have access to flexible time arrangements at work, but this may be related to the specific sectors they are working in and not necessarily to their age.

However, the most remarkable thing about **flexible time arrangements** is that a **significant proportion of the respondents do not even know, if such arrangements are available, or not in their country (47%)**. It would be useful, if future studies looked into any potential differences in the take-up of flexible work arrangements between employment sectors.

Some carers reported difficulties when they wanted to create more flexible working arrangements for themselves:

'There is also no support for the creation of self-employment in which the carer could manage free time to work.'

(Portugal, female, aged 35-44)

## SOLUTION FOUND TO RECONCILE CARE AND WORK LIFE

**The most common solutions family carers found was to either quit their job (21%), or to reduce their working hours (21%).** Quitting a job without having a perspective of a decent income is not only a traumatising experience, but also has long-term impact on the financial and social situation of family carers:

'I had to stop working after thirteen years of work, I will have no right to a pension, that includes my contributions, which will be then lost. I am very saddened by this injustice.'

(Italy, female, aged 45-54)

Only few family carers (4%) managed to go on paid leave. Respondents, who reduced their working hours, most commonly provide care for their child, or their parent. They considered reduced hours a good system, if it was ensured that they do not lose future perspectives for promotion, benefits, or bonuses.

'The fact that I can reduce my working hours and still receive a premium from the Flemish government does help me to spend more time with my father.'

(Belgium, female, aged 35-44)

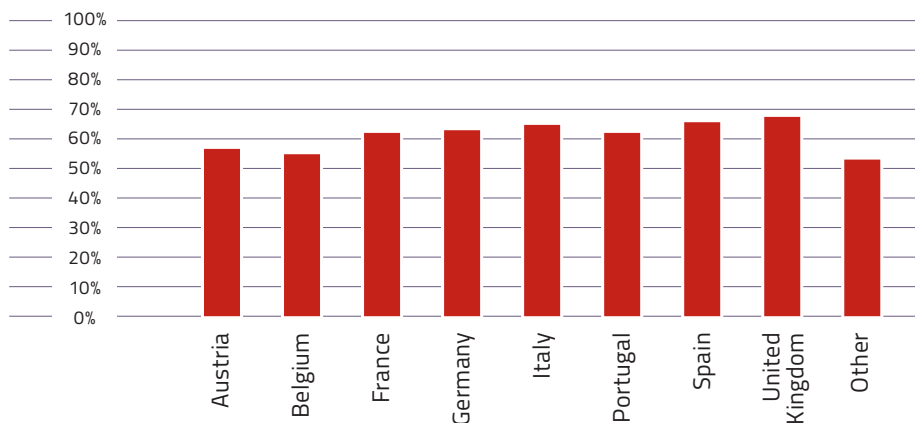
It is important to acknowledge that **carers often have no choice in the way they want to reconcile work and care life:**

'I was forced to take unpaid leave, because I could not fully meet my work.'

(n.a.)

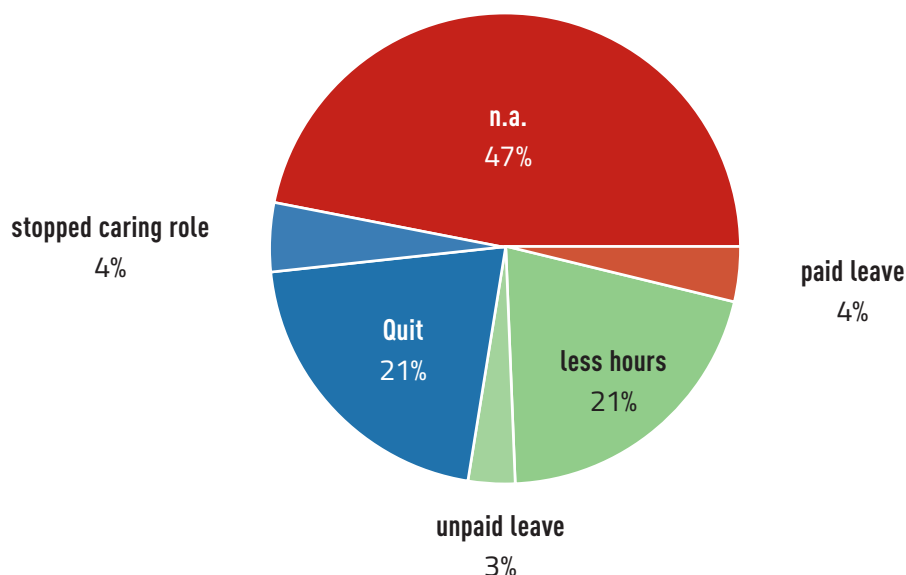
## 3- The impact of being a carer on quality of life

Figure 15: **Has the quality of your life deteriorated due to caring?**



This section looks at how the caring role impacts the quality of life of the family carer along two dimensions: financial situation, and physical and mental health. Our working hypothesis is that being a family carer impacts the quality of the life of the carer negatively and that they face vulnerable situations when it comes to facing poverty, or developing physical or mental health problems. During the analysis of the qualitative data, the negative impact of caring on family relations in general also emerged, therefore we find it important to look into this aspect later in the analysis as well.

Figure 16: **Solution for reconciliation**



On a scale from 1 to 10, respondents marked that their quality of life deteriorated at a value of 6 in average. Unsurprisingly, the more hours of care provided the more negative impact the caring role has on someone’s life (from 5 to 6.7). The negative impact is also higher than the average in cases when someone supports their spouse/long-term partner, child, or multiple relatives. Those who support a child with mental health problems reported the most severe impact of care duties on their life quality (7.45).

### 3.1. PHYSICAL AND MENTAL HEALTH

‘The conditions, in which my house is due to the fact that I cannot work and don’t have money, seriously contributes to the deterioration of our health.’

(Portugal, female, aged 35–44)

**43% of the respondents said that they have developed health problems, including physical, or mental health, due to their caring role.** Furthermore, 24% of them don’t know if they have already a problem, or not. The highest rate of those who encounter health problems can be found in ES (59%), FR (52%) and DE (45%).

The intensity of care has an impact on developing physical, or mental health problems, as there is a steady increase (from 30% to 55%) in the rate of health problems in line with the increasing hours of support provided. Interestingly,

the reported health problems decrease a bit, when it comes to the highest care provision (56 hours, or more/week), however the rate of reported health problems in this group is still around 50% too. Having said that, our study only provides a snapshot of the current situation in some countries and if carers receive no support, the mentioned health problems will likely get worse.

There was no correlation between access to social insurance and developed health problems, nevertheless the lack of social insurance can prevent family carers from taking part in prevention programmes, medical check-ups, or regular screenings that are key to protect them from more severe health issues. Carers are aware of the importance of preserving their physical and mental health:

'The biggest challenge we face is the constant fear of getting sick and not having anyone to replace me.'

(Portugal, female, aged 35-44)

It is clear from our results, that respondents who are unemployed, or have some unpaid occupation besides their caring role, more likely develop health problems than those who have a full-time, or even a part-time paid job (44% vs 53%). Probably, this has to do with the lack of resources, or time to take care of their health, which can result in accumulated health problems in the future:

'We are exhausted, our health is affected and we do not take time to look after ourself. Respite is impossible when you have no family support and this becomes increasingly difficult, as we get older and as the batteries are never recharged.'

(France, female, aged 35-44)

As the second diagram shows, developing care-related physical, or mental health problems do not only affect the older generation, but in our data, actually it was even more prevalent for the younger generation, and especially for carers aged between 35 and 45 (50%).

### 3.2. FINANCIAL SITUATION

'You cannot imagine the sacrifices that we make, we even sold our house to be able to pay for the assistive devices that were not reimbursed.'

(France, male, aged 55-64)

**1 of every 3 respondents said that they are having a hard time to make ends meet as a consequence of their caring role.** This is a very high number of people experiencing poverty, which can be explained by the fact that the proportion of economically inactive respondents is between 30% and 49% in each country. Employment situation obviously impacts someone's financial situation, as more than half of those, who do not have a paid job beside their caring role reported that they face poverty. Similarly, over

40% of those who have only a part-time job for less than 20 hours/week have problems with making ends meet.

Figure 18: **Experiencing poverty**

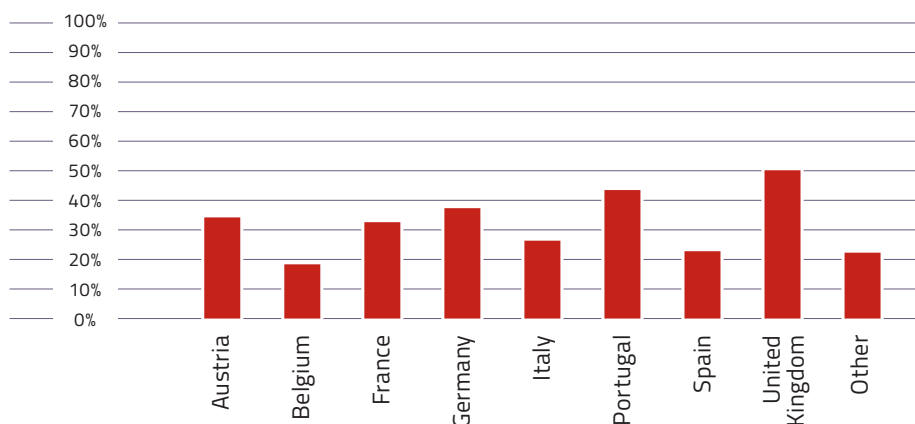
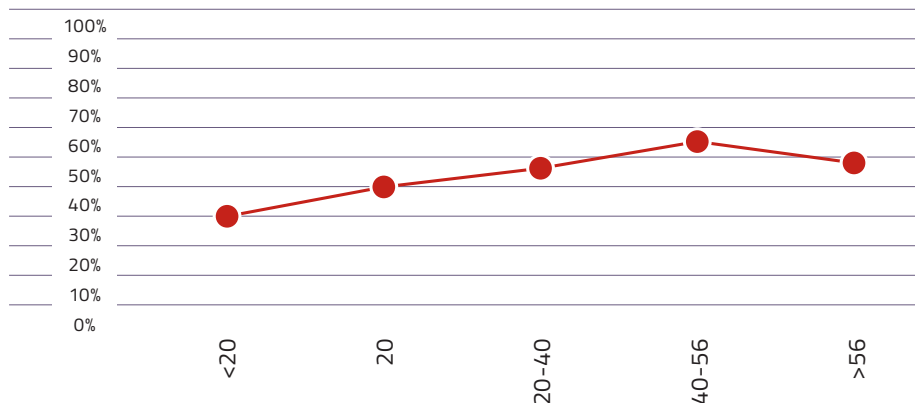


Figure 19: **Experiencing poverty by intensity of formal care**



The highest number of respondents who are facing poverty are in the UK, PT, DE and AT.

The intensity of care also has a negative impact on the financial situation of family carers: those who provide high intensity of care, are more likely experiencing poverty. The level of poverty rises particularly among carers who provide 40 hours, or more care per week.

Another factor in why making ends meet can be difficult for informal carers and their families is the increased costs relating to early childhood care and intervention, as well as different therapies. 43% of those who experience poverty provide care for their child with support needs. As one of them highlights:

'We have to pay for any activity and this is not fair. Over 60% of our salary goes into speech therapy, early care, educational support... it is really very difficult to make ends meet.'

(Spain, female, aged 35-44)

## 4- Main problems faced by family carers

In the qualitative part of the questionnaire, respondents were asked to specify the **three main problems they were facing in their everyday life as a family carer**. In total, 796 family carers (69% of all respondents) gave an answer to this question. Many different challenges were mentioned, which were clustered around the following six topics:

- impact on professional and personal life;
- access to community-based services;
- financial constraints;
- health issues;
- administrative problems;
- social recognition.

This section demonstrates the main problems that were brought up by family carers. Within each of the six topics, the problems are presented starting with the ones that were mentioned most frequently.

### 4.1. IMPACT ON PROFESSIONAL AND PERSONAL LIFE

'I am a carer almost 24 hours per day. I have very little time to go out, even if it is for shopping. I feel like a prisoner.'

(France, female, aged 55-64)

When describing the main challenges in their lives, the vast majority of family carers referred to the impact of their care responsibilities on their professional and personal life. They perceived various difficulties in reconciling care, work and personal life.

The lack of time was highlighted by a very high number of caregivers in all countries as one of their main challenges. Carers explained that much of their time was spent on caring and that it took over a big part of their life. Often, they had to provide permanent support, or supervision to the person with care needs, including duties at night. Hence, many carers felt exhausted and lacked enough sleep. Due to various responsibilities, there is a **lack of time for their own needs and a negative impact on their quality of life**. Moreover, some of them mentioned that they could not devote enough time to other family members. Some carers felt guilty that they were neglecting their partner and/or children, because care took over so much of their time. Therefore, **caring has often a strong impact not only on the carer's life, but also on other family members:**

'We are father, mother, doctor, nurse, chauffeur, counselor, administrative assistant, volunteer etc. simultaneously. But often we forget that we have a partner and friends, too.'

(France, female, aged 55-64)



**Reconciling care, professional and personal life** is a very difficult task for many family carers all over Europe. Respondents who are employed reported a lot of **stress due to the double burden of work and care**. Many had to give up their job due to their care responsibilities and were not able to work or find a job that was reconcilable with caring. Not only was it difficult to reconcile care with professional life, but caregivers also explained their difficulties organizing the household, or family activities in addition to work and care.

**Social isolation and loneliness** was another common problem. Family carers often suffered from social isolation and loneliness, and that care responsibilities affected negatively their social life. Respondents explained that they felt isolated from the rest of society, because they were not able to participate in social activities and had very limited contacts outside of their household. This problem was often highlighted by caregivers particularly from BE and FR.

**Other challenges at the workplace**, include for example the lack of flexible work arrangements, which caused problems for family carers. For example, carers considered it difficult to reconcile professional life with medical appointments, or a spontaneous leave for the person with support needs. Also, they mentioned the lack of understanding at the workplace, which made it even more difficult to leave work for the person with care, or support needs.

## 4.2. ACCESS TO COMMUNITY-BASED SERVICES

‘There is a lack of support in order to develop a normal life. Often you cannot perform daily tasks (shopping, cooking...) while you are accompanying the person.’  
(France, female, aged 55-64)

With regard to support services, family carers mentioned a range of challenges in their daily life. Overall, the answers gave a clear impression that the lack of adequate community-based services to support family carers is a crucial problem.

**The lack of support** was one of the biggest problems that family carers face. A very high number of respondents expressed **that they did not receive any support and had to undertake all care duties** related to the person with support needs. Therefore, carers often revealed that they felt completely left alone with their caring responsibilities. Many did not specify which kind of support service they lacked, but stated ‘no support’ or ‘overload’. The lack of support had an especially negative impact on the life of carers of persons with complex support needs.

**Lacking temporary and flexible support services** to relieve them from caring responsibilities were explicitly mentioned by many family carers. There is a **strong relation between the absence of support and the declining quality of life of caregivers** (e.g. increasing workload and stress). Therefore, respondents emphasized the need for support services, such as

respite care, (e.g. to be able to go on holidays or to have a free weekend), and short time care (e.g. in case the carer gets ill or has an increased workload at work). In particular family carers of children with disability were concerned about the lack of child care services, for example during school holidays, that prevents them from working in this period:

'My child does not have access to summer schools, daycare, or camps at the same price as other children. If you want your child to have a similar life to that of a normal child, the economic burden is multiplied by 10.'

(Spain, female, aged 35-44)

**Lacking affordable and high-quality services** were expressed as problematic by some respondents. This was mentioned in most countries, but most frequently among carers in ES and PT. Existing community-based services **were not always accessible, or affordable to them because they were either too expensive or not suitable for the support needs** of the person. Especially carers of persons with disabilities disapproved the high cost of treatments or therapies (e.g. logopaedics, surgeries), which are key to improve the quality of life of the person.

**Accessibility of buildings and services** was another problem mentioned by some family carers, especially in PT. Some criticised architectural barriers in buildings, like social services, the cinema or theatre which made it difficult for a person with reduced mobility to access. Consequently, caregivers described that it was **very complicated to participate in social activities with their relative in a wheelchair**. Some also stated they lacked accessible housing for themselves. Apart from architectural problems, mobility was also highlighted as a problem. Some family carers explained that they were not able to afford an adapted car to transport the person with support needs. Others pointed out the high cost of transport services for persons with reduced mobility.

'Another problem is the accessibility to public places, such as social security is on the 2nd floor without elevator.'

(Portugal, Female, aged 35-44)

**The lack of quality in-home services** presents a problem for some family carers. Family carers pointed out that they would need support in care activities, i.e. help with washing and dressing the person with care needs, but also support in daily tasks, such as cooking or cleaning. They often do **not receive any in-home service, or were unsatisfied with the quality** of existing services. Some also mentioned the lack of personal assistance to support the person with special needs.

**Other missing services**, were highlighted by caregivers, such as suitable housing. They could either not find accessible housing for their family, or it was difficult to find suitable housing for the person with support needs. Moreover, respondents expressed a need for psychological support to be able to cope with the psychological stress of their caring responsibilities. The high cost of psychological support was sometimes mentioned as well.

### 4.3. FINANCIAL CONSTRAINTS

'In the absence of work, the caregiver should be supported more. Not being able to work is already a financial constraint and additionally having the increased expenses with the person to care for, is the same as pushing people into misery.'

(Portugal, Female, aged 35-44)

Another considerable challenge for family carers were financial constraints. Respondents pointed out different problems with regard to their financial situation, which were related to special expenses, as well as to the lack of social insurance and legal recognition.

**Financial problems** were pointed out by a high number of caregivers from almost every country, as one of the main challenges have a significant impact on their daily life. Respondents generally lacked money, and some described difficulties in making ends meet, or being able to afford basic goods for living. Others further specified that they perceived a financial burden due to special expenses required by support needs of their relative. For instance, carers spent money for assistive devices (e.g. wheelchair, orthopedic devices), alterations for accessibility reasons, or medical expenses (e.g. therapies, medication). These expenses created an additional financial burden and often worsened a general tense financial situation within the family.

'I'm a single mother of four kids. I have to be a carer and I have to work at the same time. Nobody can take over my responsibilities. What if I stop working? Then, there is no income.'

(Belgium, female, aged 35-44)

**Lacking financial support** was a common challenge for many respondents. In some countries, carers received a form of remuneration (e.g. in FR or BE), but pointed out that the amount of support is not sufficient to make ends meet. Family carers of a person with complex support needs highlighted their daily workload and explained that caring can be considered their 'full-time job'; yet, they are not paid or do not receive enough financial support.

**Legal recognition and lack of social insurance** were other aspects that family carers were worried about. Mostly carers in FR expressed their wish to have an official status as family carer to recognise and value their work. Respondents also criticized the lack of social insurance for carers and they were mostly concerned about the lack of contributions to their future pension and feared facing poverty in old age due to low pensions.

## 4.4. HEALTH ISSUES

'Due to the double burden of caring and working, I become gradually sick myself (back, sleep disorder, exhaustion).'

(Germany, female, 45-54)

Family carers often support a person with health problems and special needs; however, carers also highlighted a negative impact of their responsibilities on their own mental and physical health.

**Mental or emotional stress** was experienced by many respondents from all countries. They perceived a high level of stress during their daily life, because they had to reconcile many different tasks and responsibilities. Respondents **were worried and uncertain** about what would happen when they for example could no longer provide care. In particular, parents of disabled children were very concerned about the future of their children after their own death. Others highlighted that they were afraid of a worsening condition of the person they cared for. This **mental stress sometimes even brought respondents close to burnout and depression**.

**Exhaustion** was another problem that was brought up frequently. A high number of respondents from all countries indicated that they felt exhausted due to the care responsibilities. They highlighted that it was tiring and hard to be a caregiver, especially when they were caring for a person with complex support needs. In particular, those who were economically active expressed a strong fatigue.

**Physical stress** of caregiving was pointed out by many family carers. Daily activities, such as washing, or carrying the person with support needs, caused back problems or were difficult to fulfil, because they did not have the physical strength. **Carers who suffered from an illness or realised their own ageing, said their condition was rapidly deteriorating**. Moreover, physical stress often goes hand in hand with mental stress.

## 4.5. ADMINISTRATIVE PROBLEMS

'The institutions which should improve my situation additionally complicate my life.'

(Germany, male, aged 55-64)

In order to access services, financial support or assistive devices, caregivers mostly need to go through administrative processes. In this context, respondents faced different challenges in contact with social services, the health care system or authorities.

The lack of information was a problem mentioned by many family carers in all countries. Many highlighted that they were not well informed about their rights or benefits, as family carers and lacked information about existing services and assistive devices. Some of them asked for a focal

point of information for carers. Respondents complained that it was time-consuming and complicated to find all information themselves. Sometimes, authorities and social services also provided different and conflicting information. Some carers (especially from PT) wished for more training and highlighted the lack of medical knowledge for their daily tasks.

'In recent years, everything has changed in health care. So much has happened that it is not clear to us. Rules come and are reversed or changed once again. As carers, we do not see the wood for the trees.'

(Netherlands, female, aged 45-54)

Bureaucracy was another problem, as many family carers in all countries mentioned the amount of paperwork in order to receive benefits, services or assistive devices and criticised the late responses from authorities. Often, it was necessary to give proof of e.g. disability or the entitlement to benefits several times. Family carers emphasised that it was stressful and exhausting to spend much time and energy on appointments and applications. Also, respondents in particular from PT highlighted the long waiting time to finally receive assistive devices (e.g. wheelchair, orthopedic devices). In some countries (e.g. BE), carers explained that many different authorities were responsible, which felt like an additional administrative burden.

Systematic problems in social services and health care were reported by some carers. They faced difficulties to contact social services, for example when they had to justify in the job center that they were not able to work while being a carer. Others pointed out that the access to allowances was restricted and despite needing financial support, they did not fulfill the criteria. Within health care, respondents criticised the lack of coordination between the different institutions, which made procedures slow and bureaucratic. These systematic problems were most often mentioned in FR and PT.

## 4.6. SOCIAL RECOGNITION

'We don't get enough involved or taken seriously. It is culturally considered a matter of course that especially women take over these duties.'

(Germany, female, aged 55-64)

**Low social recognition** for their work as caregivers, but also for the person with support needs was highlighted by many family carers. Respondents said that **society, medical professionals and authorities were often uncomprehending of their situation**. For example, carers felt there was a high expectation from other family members that they will fulfil care responsibilities, without understanding the difficulties, or sharing the duties. At the same time, some pointed out **prejudices in society against**

**both carers and persons with disabilities.** In particular, parents of children with disabilities felt that their children were discriminated and sometimes stared at in the street. It was also stated that medical professionals did not take carers seriously and did not involve carers in decision-making processes. Overall, caregivers in all countries, and especially in DE explained that society did not value the effort they made in their daily life.

#### 4.7. COUNTRY DIFFERENCES IN FAMILY CARERS' MAIN PROBLEMS

Apart from analysing family carers' main problems in detail, it is also interesting to look at the differences between carers from different countries. The following table shows one main problem from each of the six topics and how frequently it was mentioned in every country:

Table 8: **Main problems of family carers by country**<sup>54</sup>

Topic	Problem	AT	BE	FR	DE	IT	PT	ES	UK
Impact on professional and personal life	Lack of time	+++	+++	++	+++	+++	+++	+++	++
Access to community-based services	Lack of support	+++	+++	+++	+++	+++	+++	+++	+++
Financial constraints	Financial problems	+++	++	+	+++	+	+++	++	+++
Health issues	Mental stress	++	++	+	+	++	++	++	+++
Administrative problems	Lack of information	+	++	+	+	+	+	+	++
Social recognition	Low social recognition	++	+	+	++	+	+	+	++

The table shows that in all countries, the lack of time and support were mentioned very often. Financial problems were highlighted as very problematic in AT, DE, PT and the UK, which shows that both in Western and Southern Europe, family carers experience financial difficulties. Mental stress was a very common issue for carers in many countries across Europe, in particularly the UK, but also in AT, BE, IT, PT and ES. Some specific problems were most frequently highlighted in Western Europe, such as the lack of information (BE, UK) and social recognition (AT, DE, UK).

#### 4.8. INVOLVEMENT IN POLICY MAKING

'Ask us what help we need. Don't assume if you've met one carer, you've met us all: some of us hold down demanding jobs as well as being carers, but you seem to think the only kind of carer is a non-working mum with a disabled child.'

(Great Britain, female aged 45-54)

Furthermore, we asked family carers, if they had ever been involved in the development, implementation or evaluation of services or policies. Only

28% of those who answered this question, mentioned that they had any experience of being consulted on those matters. This shows that family carers are very often not involved in political decision making processes or in the development of services that are created to support them.

The most common form of engagement was through civil society organisations, where they tried to push for changes. Actual involvement in policy making, or in the evaluation of services was very low in most countries. Moreover, the experiences were not always positive; caregivers often expressed their disappointment with the outcome of consultations. They felt that their concerns were not a priority for policy makers and that they were not listened to:

'I have been very active in my attempts to influence and initiate changes in social policy. It is very difficult to achieve changes, though. The disabled person and their family comes very often second in the row.'

(Estonia, female, aged 55-64)

Respondents were mainly satisfied with the experience and the results of their involvement in BE, where they had achieved some positive changes and they were listened to by policy makers. Apart from being engaged in civil society organisations, Belgian caregivers were also sometimes involved in policy making processes and the preparation of studies, unlike in other countries.

In other countries, the opinions were more diverse: In FR, DE, PT and ES, some caregivers were satisfied with their experience, while some felt more disappointed. Respondents were mostly engaged through civil society organisations, where some described themselves as very active. However, only very few mentioned that policy makers, studies or services reached out for their opinion.

'Lawmakers have little interest in citizen involvement.'

(Austria, female, 65-74)

Caregivers from AT and the UK seemed to be very active in organisations as well, but they were mostly disappointed with the outcome. They described that policy makers did not take their claims into account and thus were not able to have real achievements.

Unlike in other countries, almost no respondents in IT had any experience with involvement. This could mean that they were neither members of organisations nor involved in other processes. Yet, it must also be noted that the number of respondents in IT was among the lowest, which could also explain why only so few describe a form of involvement.

## IV. RECOMMENDATIONS FROM FAMILY CARERS TO POLICY MAKERS AND GOOD PRACTICES<sup>55</sup>

In total, 736 persons (63% of all respondents) wrote recommendations to policy makers on how to improve the well-being and quality of life of family carers. These suggestions form a key part of this study, as family carers themselves highlight what they would need in order to improve their current situation. Family carers sometimes demonstrated a sense of disappointment and declining trust in policy makers, as some expressed that they felt completely forgotten and ignored by policy makers.

The recommendations were organised and clustered around the following six topics:

- provision of community-based services;
- financial support and social security;
- administrative changes;
- reconciliation measures;
- involvement, inclusion and awareness raising;
- health prevention.

Moreover, we asked family carers to describe positive examples of services in their country that provide adequate support. Despite the fact that many carers could not mention any good example in their country,<sup>56</sup> we were still able to collect some good practices. These will be included after the corresponding recommendation to give an idea how the recommendation could be implemented.

### 1- Provision of community-based services

'States should provide more benefits directly to persons with disabilities. If they were receiving a personal budget, they could live more independently and it would ease the life of their family members too.'

(Italy, female, aged 55-64)

With regards to community-based services, family carers gave many recommendations on how to improve their situation. Overall, respondents made recommendations to improve existing services, to provide temporary and flexible services, to provide in-home services, to provide daycare and suitable housing and to enhance accessibility.



Table 9: **Recommendations for the provision of community-based services**

<b>Recommendation</b>	<b>Example</b>	<b>Country</b>
Improve existing services	promote innovation in services	EE
	provide and train more staff for professional care	FR, DE, PT, ES, UK, GR
	train professionals on the rights of persons with disabilities	FR, ES
Provide temporary and flexible services	provide free/paid respite care for a number of days per year	AT, BE, FR, DE, PT, ES, UK
	offer social activities for persons with support needs, or the whole family	AT, BE, FR, DE, PT, NL
	provide flexible support services in emergency situations to replace the carer	BE, PT, ES, MT
	provide respite care during nights, weekends and holidays	FR, IT, ES
Provide in-home services	provide flexible and affordable services to support in-home care and household tasks	AT, BE, FR, DE, IT, ES, PT, EE, NL
	improve access to professional care	BE, FR, DE, PT, ES, UK, MT
	promote free short-time supervision for persons with special needs (visitor services for older persons/babysitter for children with special needs)	BE, FR, DE, IT, ES
	provide personal assistants	BE, FR, IT, UK
	let carers decide in which tasks they should be supported by services	IE
	provide in-home services at night and weekends	BE, DE, IT, PT
Provide daycare and suitable housing	increase the number of daycare centers for older persons, or persons with special needs	AT, BE, FR, DE, PT, ES, MT
	provide education and daycare for children with special needs	AT, BE, PT, ES, UK
	create more suitable housing	FR, ES
Enhance accessibility	reduce architectural barriers (in built environment, transport, buildings)	BE, FR, PT, ES
	provide financial support for adaptation of car, or housing	BE, FR, PT

## **1.1. GOOD PRACTICES REGARDING COMMUNITY BASED SERVICES**

### **Baluchon Alzheimer (BE)**

In BE, a special type of respite is offered to caregivers of persons with Alzheimer. During a limited period, a professional carer replaces the family carer in his or her home. Thus, the person with care needs stays in a known environment, without major changes while the caregiver is relieved for some days.

### **Seniors café (DE)**

In DE, municipalities organise meetings for older persons, so-called seniors cafés, for a few hours per week. During this time volunteers take care of

the elderly person, so that caregivers are relieved. At the same time, the person can meet and interact with others during the café.

### **Respite care (Many countries)**

In many countries, carers mentioned respite, as a very positive example. Yet, it is important to enable family carers from all economic backgrounds to access respite care, since many criticised that it is very expensive. Therefore, caregivers recommended the provision of free, or paid respite care which is not the case in any country.

### **Family assistance (BE)**

In BE, an in-home service exists provided by the social insurance, which supports the caregiver in daily tasks. The family assistance prepares for example meals, gives food to the person with care needs or does the shopping. Thus, the family carer is relieved in caring and household tasks.

### **Visitor services (DE)**

In DE, charities provide a visitor service to older persons or persons with disabilities. Volunteers undertake small activities with the person, such as going for a walk, reading the newspaper or just having a talk. In this way, the caregiver is relieved during a short period and the person with care needs has somebody to talk to.

## **2- Financial support and social security**

‘The immense work of carers should be recognised and they should be compensated for it. Working only at home is for many of us not an option, but an obligation.’

(Spain, female, aged 55-64)

Family carers from all countries in Europe made recommendations regarding financial support and social security for carers. As already highlighted earlier, financial constraints are one of the major problems which caregivers face. Carers recommended particularly to provide financial support, to provide coverage of social security and to make legal changes in relation to carers. The following table gives more detailed information about their suggestions.

Table 10: **Recommendations for financial support and social security**

Recommendation	Example	Country
Provide financial support	provide financial support/allowance to carers	AT, BE, FR, DE, IT, PT, ES, UK, GR, MT, NL, CH
	provide carers with the minimum wage	BE, FR, DE
	contribute financially to therapies and treatments (e.g. logopedics, physiotherapy etc.)	FR, PT, ES
	provide person with special needs with a personal budget	DE, IT, PT
	make carers' allowance tax free	FR, PT
	enable carers to choose for which services their budget should be used	EE
Provide coverage of social security	provide social security	AT, BE, FR, DE, IT, PT, ES, UK, NL, CH
	provide rights to pension	AT, BE, FR, DE, IT, PT, ES, NL, CH
	reduce retirement age for carers (without penalty)	FR, IT, PT
	provide social rights (e.g. to holidays)	BE, DE
	prevent poverty in old age	BE, DE
Make legal changes in relation to carers	recognise family carers legally, as a profession	AT, BE, FR, IT, PT, ES, GR
	adapt national legislation to demographic changes and current situation of carers	AT, PT, ES

## 2.1. GOOD PRACTICES REGARDING FINANCIAL SUPPORT AND SOCIAL SECURITY

### Direct Payments (UK)

In the UK, it is possible to get a direct payment by the local responsible authority. Instead of arranging the services for the person with care needs, the authority calculates how much these services would cost. The amount is then directly paid to the caregiver or the person with support needs. In this way, the person receiving the money has the choice on what service he or she wants to spend the money.

## 3- Administrative changes

'Simplify the administrative procedures, our children do not change! It is the rules that have been constantly changing for years.'

(Netherlands, female, aged 45-54)

With regard to administrative changes, family carers made several suggestions of how to improve their situation. As mentioned earlier, the lack of information and bureaucracy were major problems of respondents in all countries. Family carers recommended to improve the flow of information, to improve administrative procedures and to provide training and counselling to carers.

Table 11: **Recommendations for administrative changes**

Recommendation	Example	Country
Improve flow of information	provide information about existing support and assistive devices	AT, BE, FR, DE, IT, PT, ES, UK, FI, MT, NL
	provide information about rights of carers	BE, FR, DE, IT, PT, UK
	create a central contact point for information	AT, BE, FR, DE, PT, NL
	notify persons who are eligible for support	BE, FR, DE, ES
	communicate conditions for eligibility for support more clearly	AT, BE, FR, UK
	enhance exchange between carers (e.g. creation of self-help groups, meetings for carers, support of NGOs and associations)	BE, FR, DE, ES
Improve administrative procedures	reduce bureaucracy	AT, BE, FR, DE, IT, ES, PT, NL
	simplify administrative procedures (for support or assistive devices)	AT, BE, FR, DE, PT, ES, IE
	accelerate procedures (for support or assistive devices)	AT, BE, FR, PT, ES
	improve coordination between national and regional level and other responsible authorities (not having to prove conditions multiple times)	BE, ES, NL
	provide support in the administrative management of needed services (e.g. case manager)	BE, FR, DE
Provide training and counselling to carers	provide trainings for carers (on the local level)	AT, BE, FR, DE, IT, PT, ES, GR, MT
	offer free counselling	AT, IT, UK, FI

### 3.1. GOOD PRACTICES REGARDING ADMINISTRATIVE CHANGES

#### Civil society organisations, or charities (Many countries)

When asked for a positive example, many family carers mentioned voluntary sector organisations or charities, as very supportive. Many carers explain that these organisations provide home help, information, advice or organise meetings to exchange experiences and thus often fill the gap of support that the State does not cover. For example, a carer explains her experience with carers’ meetings of an organisation:

‘It is invaluable to speak with people who truly understand what you are going through.’  
 (Malta, female, aged 35-44)

## 4- Reconciliation measures

Family carers recommended several measures that would improve their reconciliation of work and care. Respondents suggested providing a

carer's leave to promote flexible arrangements at work and to promote the reintegration of carers on the labour market.

Table 12: **Recommendations for reconciliation measures**

Recommendation	Example	Country
Provide a carer's leave from work	provide additional days of leave for carers	BE, FR, IT, ES, PT, UK, MT
	provide the right to a longer leave without job loss (similar to maternity leave)	BE, FR, DE
Promote flexible arrangements at work	promote flexible working hours	BE, FR, DE, IT, PT, ES, GR
	provide possibility to telework	BE, FR, DE, IT, PT, ES
	provide reduction of working time (paid)	BE, FR, PT, ES
Promote reintegration of carers	enhance reintegration of carers in the labour market	DE, ES

## 4.1. GOOD PRACTICES REGARDING RECONCILIATION MEASURES

### Carer's leave for parents (FR)

In FR, there is a leave for parents to care for a child in need of care and constant supervision, for example due to disability, severe illness or an accident. The parent has the right to decide about the timing and length of the leave (not exceeding the maximum number of entitled days). During this period, the caregiver does not receive any salary, but can return to his or her job, after the leave is over.

## 5- Involvement, inclusion and awareness raising

'We need more awareness-raising. If people knew what caregiving entails, there would maybe be a little more understanding and respect for carers.'

(Belgium, female, aged 45-54)

As previously highlighted, family carers often felt that their work was not recognised or valued both in society, their workplace and in public authorities. Furthermore, carers found it problematic that the inclusion of persons with disabilities was not promoted. In many countries, carers highlighted that policy makers should promote involvement and inclusion as well as raise awareness for both carers and persons with special needs.

Table 13: **Recommendations for involvement, inclusion and awareness raising**

Recommendation	Example	Country
Promote involvement and inclusion	consult both carers and persons with special needs in political decision making	AT, BE, FR, DE, PT, ES, UK, MT, NL
	enhance inclusion of persons with disabilities	AT, BE, FR, PT, NL
Raise awareness about carers and persons with special needs	raise awareness about carers among authorities	AT, BE, FR, DE, IT, PT, ES, UK, NL
	raise awareness of both carers and persons with disability in society	AT, BE, FR, DE, IT, PT, ES, UK
	improve social recognition of carers	AT, BE, FR, DE, ES, CH
	raise awareness of carers among employers	BE, FR, DE, PT

## 6- Health prevention

Respondents also made recommendations regarding the improvement of their own mental and physical health. They suggested different measures to minimise the negative impact of their caring role on their state of health.

### 6.1. GOOD PRACTICES REGARDING HEALTH PREVENTION

Table 14: **Recommendations for health prevention**

Recommendation	Example	Country
Prevent mental and physical stress	provide access to psychological support	AT, BE, FR, DE, IT, PT, ES, FI, GR
	provide recreational activities for caregivers (e.g. relaxation, massages etc.)	AT, BE, FR, DE, PT
	promote regular health checks of caregivers (mental and physical)	BE, FR, UK
	provide telephone help for situations of mental stress	FR

#### Psychological support in day care centers (GR)

In GR (Athens), there are day care centers for persons with mental health problems, which provide psychological support, also to carers and family members. Through the participation in psycho-educational groups and support groups, the well-being of both persons with mental health problems and their family members improves.

#### Telephone help for Alzheimer's patients (IT)

In IT, there is a free telephone help for relatives or carers of a person with Alzheimer. The hotline provides support, information, data and advice for carers or helps to find a local association that can support the caregiver. Family carers can talk to experts or other carers through that number. Thus, they can share their experiences and easily get information and advice.

## V. CONCLUSIONS

'It's not 100% negative. I love my son to the ends of the earth. Yes, it's hard, but it's a privilege to be his mum, to watch him learn and grow. It might not be the life I chose, but I am blessed to have it.'

(UK, female, aged 45-54)

This report summarises the findings of a major data collection COFACE Families Europe carried out to take stock on the needs and challenges of family carers in Europe in 2017. With more than 1,000 answers from family carers from 16 European countries, the study provides a better understanding of the situation in Europe and offers policy recommendations to better meet their needs and tackle their social exclusion.

The study responds to some concerning trends we heard from our civil society members from the national level, to current social and demographic changes, and to the lack of comprehensive data on the challenges and needs and family carers. Our main goal is to channel directly the voice of family carers at the European and national level and to help policy makers better acknowledge the complex challenges faced by the thousands of family carers and their families in Europe.

### → Who are family carers?

As our results show, informal care work is mostly taken up by women (85%), aged between 35 and 64, who are often part of the 'sandwich generation' and provide care for multiple people (27%). There is a slightly increasing involvement of men, once they retire, or are close to retirement age. Policies and measures should also support the increasing number of young carers (6,64%) to avoid early school leaving, or other consequences on their social inclusion. In our sample, 73% of the respondents belong to the age group of 45 years and above, which corresponds to the OECD's data from 2011.<sup>57</sup> The three most common groups who received care are adults with disability (28,5%), older persons with support needs (22%), and children with disability (20%). Family carers most commonly support their own child, parent, or spouse/long-term partner.

In our study, 1 of every 3 carers provides very high intensity care of 56 hours per week, or more, which explains that 43% of the family carers are economically inactive. Those who provide 40 hours or more care per week are 4 times more likely to be unemployed than others. There is often no one who would help them in fulfilling this caring role (31%), and only 18% of them receive professional support from time to time from a nurse, or a social worker.

Some of our respondents have a paid full-time job (34%), or a paid part-time job (22%) besides caring for a family member. However, the rate of economically inactive people is 43%, of which 18% are unemployed and 19% are retired.

People do not plan to become family carers, but it happens to them when a family member - e.g. their newborn child, or older parent after an accident - suddenly needs extra care, or support. Becoming a carer is an emotionally difficult situation that brings significant changes in one's lifestyle and requires new skills and knowledge about medical support, or social protection. Yet, almost two third of the respondents never received any psychological support, nor were offered the opportunity to take part in training, or skill development.

## → **Financial and social recognition of the work of family carers**

### **Financial constraints highly affect the daily life of family carers in Europe.**

1 of every 3 respondents said that they are having a hard time to make ends meet, as a consequence of their caring role and many are unable to afford basic goods. It is especially concerning that 73% of the respondents do not receive any financial compensation for their work, as carers, and almost 2/3 of them don't have access to any kind of social benefits.

Nevertheless, there are some additional expenses, such as assistive devices, alterations to improve accessibility of housing, or medical expenses for persons with care, or support needs that create extra financial burden for families. Being out of the labour market, and living without adequate financial support to cover their expenses, consequently leads to financial deprivation of family carers, especially those providing intensive care.

**Across Europe, social recognition for family carers is very low.** Many carers explain that society, medical professionals and authorities do not value their work, and are uncomprehending of their situation. At the same time, prejudices in society against both carers and persons with disabilities are a reality. Overall, caregivers in all countries describe that society does not appreciate the effort they make in their daily life. This is especially concerning knowing that family carers provide the majority of care work in Europe and fill the gap in Member States' care system.

## → **Available services to family carers and to their relatives with care, or support needs in the community**

**Community-based services are not available for persons with care needs and their family members in Europe.** Families often do not receive any support and have to take overall care, or support themselves. There is a lack of flexible and temporary services, such as respite or short time care, to take a break from their responsibilities: Only 1 of every 6 respondents said they can access respite care where they live. It is also problematic that available community-based services are often too expensive, or not suitable for the person with support needs, thus the most vulnerable family carers providing intensive care cannot rely on them. Overall, the answers from carers gave a clear impression that the lack of accessible, high-quality



community-based services to support family carers and their relatives with support needs is a crucial problem.

**Family carers face significant challenges in administrative procedures across Europe** and they don't receive enough information about their rights, benefits or the existing services. Conflicting information, the lack of training and the complexity of bureaucracy create additional burdens in accessing benefits, services or assistive devices.

### → **Flexible time arrangements to support family carers in reconciling their care and work life**

A high proportion (30%) of carers reported that it is not possible for them to take time off from work, when they need to provide care for one or more of their relatives. In all countries, family carers are not satisfied with the available leave schemes. It is worrying that **the most common solutions family carers found was to either quit their job (21%),** or to reduce their working hours (21%). A significant proportion of the respondents do not even know if flexible time arrangements are available or not in their country (47%). Unfortunately, not everyone has a real choice about reducing working hours, or using flexible time arrangements to reconcile care with work, or personal life.

The low level of satisfaction and lack of knowledge of family carers about flexible time arrangements and leave schemes should incentivise policy makers to look more into the details and understand:

- what are the specific problems of family carers with the existing leave schemes (e.g. length, payment, administration, stigmatization etc.) and how the existing schemes could be improved;
- what is the take-up of available leave schemes by family carers and how they could be more aware of opportunities to use flexible time arrangements.

Flexible time arrangements can be a great way to better reconcile work, care and personal life, but COFACE Families Europe stands for laws, policies, or practices at the workplace that would encourage men to take up more leaves in order to rebalance the disparity and trigger positive change.

### → **The impact of providing care, or support on the quality of life of family carers**

**Most family carers struggle reconciling their professional and personal life.** Caregivers often provide intensive care, which means that they have less time for personal activities and for other family members. Providing informal care without having available support services has a strong impact on carers' quality of life, but also on their family members. Many family carers suffer from isolation and loneliness, because they are not able to participate in social activities and have limited contacts to people outside the household.

We found that **there is a strong impact of care on respondents' physical and mental health in all countries**. Caregivers are often exposed to strong mental or emotional stress that may lead to burnout, or depression. While mental health problems are more prevalent, many also experience physical stress in their daily activities. Yet, only 1.3 % of all respondents receive regular psychological support provided by the State, or local government to better cope with the situation. Considering the ageing of family carers, it is important to provide them with social insurance, access to health prevention and psychological support to prevent the rapid deterioration of their health.

### ➔ **Which countries do better in supporting family carers?**

Overall, we found that there are no countries that do significantly better than others, when it comes to supporting family carers. There are some national differences on specific issues, for instance AT and DE seem to provide better access to social benefits and insurance, as well as to respite care, or when it comes to providing financial resources directly to the person with care, or support needs. However, the general access rate to these services is still low (around 50%). Having said that, AT and DE are also among the countries where the highest proportion of respondents reported that they are facing poverty.

Likewise, **family carers face very similar and complex challenges all over Europe and reported about major challenges in their daily life**. The main problems that family carers face can be categorised around six topics:

- the impact on professional and personal life;
- access to community-based services;
- financial constraints;
- health issues;
- administrative problems;
- social recognition.

Table 15: **Main problems faced by family carers**

Impact on professional and personal life	Access to community-based services	Financial constraints	Health issues	Administrative problems	Social recognition
<ul style="list-style-type: none"> <li>■ Lack of time</li> </ul>	<ul style="list-style-type: none"> <li>■ Lack of support</li> </ul>	<ul style="list-style-type: none"> <li>■ Financial problems</li> </ul>	<ul style="list-style-type: none"> <li>■ Mental or emotional stress</li> </ul>	<ul style="list-style-type: none"> <li>■ Lack of information</li> </ul>	<ul style="list-style-type: none"> <li>■ Low social recognition</li> </ul>
<ul style="list-style-type: none"> <li>■ reconcile care with professional and personal life</li> </ul>	<ul style="list-style-type: none"> <li>■ Lack of temporary and flexible support services</li> </ul>	<ul style="list-style-type: none"> <li>■ Lacking financial support</li> </ul>	<ul style="list-style-type: none"> <li>■ Exhaustion</li> <li>■ Physical stress</li> </ul>	<ul style="list-style-type: none"> <li>■ Bureaucracy</li> </ul>	
<ul style="list-style-type: none"> <li>■ Social isolation and loneliness</li> </ul>	<ul style="list-style-type: none"> <li>■ Lack of affordable and high-quality services</li> </ul>				

## → What do family carers want?

We received a broad range of answers from family carers on how to improve their situation. Asking caregivers directly what they need to better cope with their caring role gives some first-hand recommendations that policymakers should take into account.

### 1. Provide access to community-based services:

Caregivers and family members of a person with support needs require support in daily activities (e.g. in-home services and personal assistants), and also need to take a break from their caring role by accessing respite care or daycare centers. It is very important that community-based services are affordable, so that the access is not only restricted to few. In this way, both carers and persons with support needs can choose the kind of support they want to give, or receive.

### 2. Financial support and social security:

Not being able to work or working part-time has financial consequences, which is why a form of financial contribution to the carer is indispensable. For a sustainable solution, it is furthermore very important to recognise caregivers legally, so that they are covered by social security and have access to an adequate pension.

### 3. Administrative changes:

When carers do not know about their rights or existing services, the uptake is very low. Thus, a central focal point, as many suggested, could

be a valuable solution to provide the necessary information. Trainings and counselling should further support carers. In terms of administrative procedures, fast and simplified structures need to be put in practice, so bureaucracy will not create an additional burden.

#### **4. Reconciliation measures:**

Providing reconciliation measures is essential for employed family carers to fulfill both professional and care responsibilities. 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.

#### **5. Involvement, inclusion and awareness raising:**

Respondents were rarely involved in policy making, or in the evaluation of services; Nevertheless, there was a strong request for such involvement of carers and persons with support needs. They felt that policy makers do not take them into account. Therefore, it is necessary to raise awareness of persons with disabilities and other support needs and their families to fight discrimination and isolation in society.

#### **6. Health prevention:**

Considering the impact of caregiving on family carers physical and mental health, it is crucial to apply preventive health measures. Caregivers especially demand access to psychological support, which can ease the mental stress that they are exposed to.

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## ANNEX:

# QUESTIONNAIRE FOR THE STOCKTAKING STUDY ON THE NEEDS OF FAMILY CARERS<sup>58</sup>

## I. GENERAL QUESTIONS

1. What is your gender?
2. How old are you?
3. Where do you live?
4. How many people do you care for, as a family carer?
5. How many hours of care do you provide per week?
6. What is your relationship to the cared-for person(s)? (Multiple choices allowed)
7. Who do you care for? (multiple choices allowed)
8. Do you receive help from someone to fulfil your role as a family carer?
9. If yes, who is helping you? (multiple choices allowed)
10. Do you live with the person who you care for?
11. What is your employment status at the moment, besides your caring role?
12. Do you have physical, or mental health problems that were developed due to your caring role?
13. Has the quality of your, or your family's life deteriorated due to the care responsibilities?  
(1=not at all, 10=very much)

## II. RESOURCES

1. Do you receive financial compensation for your work as a family carer?
2. Do you have access to social benefits as a family carer (social allowances, carer's benefit, pension etc.)?
3. Do you have access to social insurance as a family carer?
4. Does the person you care for receives financial support to cover his/her support needs? (e.g. personal budget, or care allowances)?
5. If the answer is 'yes' to the previous question: Where does this financial support come from?
6. Is your family experiencing poverty, or having a hard time to make ends meet as a consequence of your caring role?

## III. SERVICES

1. Did you receive information about your rights, as a family carer when you took up your caring role, or at a later stage?

2. Did you have access to training to improve your skills and knowledge on how to better provide care and support, as a carer?
3. Did you get psychological support, or counseling provided by the state, or local government, as a family carer?
4. Is respite care available where you live?<sup>59</sup> If yes, how many hours/month can you use it? Are there community-based services (early childhood care and education, in-home service, personal assistance, housing support services etc.) available where you live?
5. If the answer was 'yes' to the previous question, are these community-based services accessible for all people with support needs?
6. If the answer was 'yes' to question number 5, are you satisfied with the quality of these community-based services?

#### IV. TIME

1. Can you take time off from work/school to fulfill your caring role?
2. To fulfill your caring role, what is the solution you have found?
3. Are you satisfied with the available leave schemes (carers', maternity, paternity, and parental leave) in your country? (1=not at all, 10=very much)
4. If you took a leave period (carers', maternity, paternity, or parental): when you expressed your intention of taking the leave, did you feel harassed, or bullied by your colleagues, or your managers?
5. If you took a leave period (any): when you came back to work, did you feel harassed, or bullied by your colleagues or downgraded by your managers? (multiple choices possible)
6. Are flexible working/studying arrangements available for you (e.g. job sharing<sup>60</sup>, tele-work, smart work<sup>61</sup>, compressed working hours<sup>62</sup>, possibility to swap shifts among employees, or flexible exam period etc.)?
7. If you have to stop working to care/support a family member for a long period, do you know if there are instruments/public policies and agencies that would help you to get back in the labour market?

#### V. OPEN QUESTIONS

1. What are the 3 main problems you are facing in your everyday life, as a family carer?
2. What would you recommend to policy makers to improve the well-being and quality of life of family carers?
3. Can you describe a positive example of a service in your country that provides adequate support to family carers?
4. Have you ever been involved in the development/implementation/evaluation of services, or policies related to disability, long-term care, social, or health care? Could you tell us how this experience was?
5. Is there anything else you want to share with us in relation to the challenges you face, or the support you would need as a family carer to tackle these challenges?



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20. 'Institutional care' is understood as "any residential care, where residents are isolated from the broader community and/or compelled to live together; residents do not have sufficient control over their lives and over decisions which affect them, and the requirements of the organisation itself tend to take precedence over the resident's individualised needs." See EEG (2012): *Common European guidelines on the Transition from Institutional to Community-based Care*.
21. COFACE Disability (2017): *European Charter for Family Carers*.
22. COFACE Families Europe (2017): *Families on the Edge: Building a comprehensive European work-life balance reality*.
23. EEG (2012): *Common European guidelines on the Transition from Institutional to Community-based Care*.
24. COFACE (2015): *European Reconciliation Package*.
25. Ibid.
26. See questionnaire in Annex.
27. Beside English, the questionnaire was available in Dutch, French, German, Italian, Portuguese,

Slovenian and Spanish. Please note that we did not receive any answers in Slovenian.

28. Please find more information about the UN International Day of Families at: <http://www.un.org/en/events/familyday/>
29. The online platform we used was SurveyMonkey at <https://www.surveymonkey.net/>.
30. This happened mainly through COFACE's monthly newsletter, sharing on COFACE's Website, Twitter, Facebook and LinkedIn account and shared on the website, newsletter, or social media of our members.
31. Colombo et al. (2011): Help Wanted? Providing and Paying for Long-Term Care.
32. E.g. Eurofound (2015): Working and caring: Reconciliation measures in times of demographic change.
33. Colombo et al. (2011): Help Wanted? Providing and Paying for Long-Term Care.
34. Ibid.
35. Please note that this table refers to the care, or support needs of the person receiving care, but does not describe the relation between the carer and the cared person.
36. We counted everyone in this category, who said that they live at least 3 days, or more per week together with the person with care, or support needs. We chose to set this threshold, as there were some respondents who care for their older parents and share the caring with their siblings, which means that their parent lives with them, but not every day.
37. Colombo et al. (2011): Help Wanted? Providing and Paying for Long-Term Care.
38. The OECD considers 'intensive level of caring' more than 20 hours per week. See: Ibid.
39. This includes those who marked 'More than 56 hours/week (24/7)' in the questionnaire. It is important to note that we included '24/7' as an answer category in the questionnaire, following requests from a number of COFACE Disability members. They argued that carers often have to be available around the clock and wake up several times a night which is very exhausting and deserves visibility in the questionnaire.
40. Ibid.
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51. “Smart work as an approach to organising work through a combination of flexibility, autonomy and collaboration, which does not necessarily require the worker to be present in the workplace or in any pre-defined place and enables them to manage their own working hours, while nevertheless ensuring consistency with the maximum daily and weekly working hours laid down by law and collective agreements”, see in: European Parliament (2016): European Parliament resolution on creating labour market conditions favourable for work-life balance.
52. OECD (2016): Be Flexible! Background brief on how workplace flexibility can help European employees to balance work and family.
53. Eurofound (2012): Third European Quality of Life Survey.
54. +++ very often mentioned (among top 3 problems), ++ often mentioned (among top 6 problems), + mentioned
55. As part of this stocktaking study, respondents were also asked to make recommendations to policy makers on how to improve the well-being and quality of life of family carers. This chapter will therefore summarise these recommendations from family carers, but they don't necessarily reflect the views of the membership of COFACE Families Europe.
56. Especially in PT and ES, family carers were very critical about support provided by the State. They highlighted that the only positive examples were private and expensive.
57. Colombo et al. (2011): Help Wanted? Providing and Paying for Long-Term Care.
58. The questionnaire was published on SurveyMonkey between 15 May and 30 June 2017.
59. Respite care is a fundamental necessity to be met in terms of support, occasional and/or emergency assistance, substitution services and/or top-quality temporary care centres during various periods of time depending on needs (holiday, rest, health, etc.) (See : European Charter of Family Carers (2007), COFACE Disability)
60. Job sharing: Alternative work schedule in which two employees voluntarily share the responsibilities of one full time job, and receive salary and benefits on pro-rata basis. Job sharing creates regular part time (half days, alternative days, alternative weeks, etc.) where there was one full time position, and thus avoids a total loss of employment in a layoff. (See at: <http://www.businessdictionary.com/definition/job-sharing.html>).
61. Smart work: An approach to organising work through a combination of flexibility, autonomy and collaboration, which does not necessarily require the worker to be present in the workplace or in any pre-defined place and enables them to manage their own working hours, while nevertheless ensuring consistency with the maximum daily and weekly working hours laid down by law and collective agreements. (See at: <http://www.europarl.europa.eu/sides/getDoc.do?type=TA&reference=P8-TA-2016-0338&language=EN&ring=A8-2016-0253>).
62. Compressed working hours: Alternative work arrangement where a standard work week is reduced to fewer than five days, and employees make up the full number of hours per-week by working longer hours. (See at: <http://www.businessdictionary.com/definition/compressed-workweek.html>).



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