

COFACE THEMATIC NOTE

## TOO OLD TO CARE ?

# THEMATIC NOTE REFLECTING ON THE SPECIFICITIES OF THE AGEING FAMILY CARERS POPULATION IN THE EU

### DECEMBER 2023



### Too old to care?

#### Thematic note reflecting on the specificities of the ageing family carers<sup>1</sup> population in the EU.

#### BACKGROUND TO THE NOTE: THE EU POLICY CONTEXT AT A GLANCE

Principle 18 of the European Pillar of Social Rights stresses: the right to affordable longterm care services of good quality, in particular homecare and community-based services. For the first couple of years after its proclamation in 2017, little had been done to address care, and even less about the needs of the family carers, who provide 80% of the long-term care (LTC) in the European Union.<sup>2</sup>

The first noticeable change at the EU level came with the Work-Life Balance Directive in 2019 with the introduction of carers' leave: workers providing personal care or support to a relative are entitled to a minimum of five days of leave per year, however these days are unpaid.<sup>3</sup> Family care was as well mentioned in the 2021-2030 European Strategy for the **Rights of Persons with Disabilities**<sup>4</sup> as a driver of financial poverty for persons with disabilities and their families. In a similar way, the 2021 Ageing Green Paper<sup>5</sup> notes that "Relying on informal carers is no more sustainable, as help from family members is increasingly difficult to ensure, with families having fewer children, living further apart, and women participating more in the labour market."

It is only in 2022, with the European Care Strategy<sup>6</sup> and the Council Recommendation on Long-Term Care<sup>7</sup> that the EU took a more careful look at the situation of informal carers in Europe and put forward recommendations (in Article 9) on the need to establish clear procedures to identify and support informal carers notably by:

"(a) facilitating their cooperation with long-term care workers;

(b) supporting their access to the necessary training, including on occupational health and safety, counselling, healthcare, psychological support and respite care, as well as supporting them in balancing work and care responsibilities;

(c) providing them with access to social protection and/or to adequate financial support, while making sure that such support measures do not deter labour market participation."

Governments across the EU are called to present by June 2024 the measures they have taken to reform their LTC system to achieve the transition towards high quality, affordable and accessible care that will respect the rights and needs of the persons who draw on care and support services and of the carers, formal or family carers. In

<sup>&</sup>lt;sup>1</sup> The vast majority of the informal long-term care is provided by family members hence the use of the term "family carer" in this note. A family carer is 'a non-professional person, who provides primary assistance with activities in daily life, either in part or in whole, to a person with care, or support needs in his/her immediate circle. This regular care, or support, may be provided on a permanent or temporary basis and can take various forms, including nursing, care, assistance in education and social life, administrative formalities, travelling, coordination, vigilance, psychological support, communication, or domestic activities. According to <u>COFACE's European Charter for Family Carers</u>, 2019. <sup>2</sup> Council of the EU, <u>Recommendation on affordable high-quality long-term care</u>, 2022

<sup>&</sup>lt;sup>3</sup> European Commission, Directorate-General for Employment and Social Affairs, EU Work-life Balance Directive, 2019. <sup>4</sup> European Commission, Directorate-General for Employment and Social Affairs, Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030, 2021.

<sup>&</sup>lt;sup>5</sup> European Commission, Directorate-General for Employment and Social Affairs, <u>Green paper on ageing, 2022.</u>

<sup>&</sup>lt;sup>6</sup> European Commission, Directorate-General for Employment and Social Affairs, European Care Strategy for caregivers and care receivers, 2022. 7 Idem.

this context, it is the ambition of the COFACE Disability Platform to support the development of targeted measures to support family carers in the EU Members States plans or strategies.

As the LTC Recommendation suggests, the first step is to identify the family carers. In order to do so, it is crucial to realise that family carers are not a homogeneous block and consider that several factors need to be taken into account when proceeding to their identification, which then can influence what type of support is the most appropriate for their situation. In this thematic note, we will explore one of the dynamics that should be considered: the age of the family carers.

#### SETTING THE SCENE: WHO ARE THE FAMILY CARERS?

In the EU, an estimated 52 million people provide informal LTC, and informal LTC caregivers account for almost 80 % of long-term carers.<sup>8</sup> Identifying these family carers is one of the actions required from EU Member States in the implementation measures of the LTC Recommendation and it is arguably one of the most important. The reason is that to this day at the European Union level, **there has not been a survey that looked specifically at who are the family carers in the EU and what exactly are their needs and demands**.

A few years ago, the COFACE Disability Platform tried to remedy this situation by launching a Europe-wide survey to fill gaps in data. This resulted in the publication "Who Cares? Study on the challenges and needs of family carers in Europe". The findings of **the study show repetitive patterns in the nature of the challenges faced by family carers arising from the lack of recognition for their role: insufficient access to resources, time arrangements and services to support them**. It also highlighted that carers share some characteristics, notably the significant gender imbalance with around **80% of the informal carers being women.**<sup>9</sup> This mirrors the professional care sector where **90% of the workforce is female**<sup>10</sup>, hence the importance of mainstreaming gender in all initiatives concerning this sector.

However, even if gender is a central component to consider in any attempts to identify family carers and support them with appropriate and targeted measures, it should not be the only element to be taken into account. The European Care Strategy **presents a life course approach to care**, highlighting by this approach an important aspect of family care. Family care is not a static status that can be fully understood by looking at one point in time, it is a care and support relationship and as every relationship it is something dynamic that evolves over time and has a lasting incidence on one's life. As any relationship, the timing in which you enter it also matters, as matters what point of your life course and what is the nature of the relationship needs to be taken into account in the identification of family carers to understand the impact on the family carer and accordingly develop the appropriate support measures.

<sup>&</sup>lt;sup>8</sup> EIGE, <u>A Better Work–Life Balance: Bridging the gender care gap, 2023</u>

<sup>&</sup>lt;sup>9</sup> COFACE, Who cares ? Study on the challenges and needs of family carers in Europe, 2017

<sup>&</sup>lt;sup>10</sup> European Commission, Directorate-General for Employment and Social Affairs, Communication on the European care strategy, 2022.

In other words, if family carers are slowly entering the public discourse, their diversity is still little known. Currently, the European Union is at the beginning of its journey for the transformation of their care system toward the community based, high quality, affordable accessible, human right based and person-centred long-term care system that also cares for all the carers. In this thematic note, the COFACE Disability Platform looks at **age** as one of the important components of the identification of carers coupled with the challenges and needs identified in the study "Who cares?" to reflect on how they can affect differently carers in different age groups.

#### WHY IS AGE IMPORTANT TO SUPPORT FAMILY CARERS?

As the current system relies heavily on family carers, the measures put forward as implementation of the LTC Recommendation should not only focus on the transformation of the system and professional care services, as it would fail to address the current needs of family carers. Hence it should also aim to mitigate the effects that the current system has on the persons currently in an informal care relationship, who, as the rest of the population, are ageing. **Reforming care should not only be seen as a measure to support working carers into going back to the job market, but also as a way of enhancing and respecting the human rights of all. Therefore, LTC implementation measures should be inclusive of all persons providing care, both professional and informal. To simplify, family carers can be regrouped in 3 broad age categories that are defined by the set of rights and protection they should be able to benefit from.** 

**Young carers** are legally children under the age of 18 who provide care for a parent or relative in the community, usually within their own home. As children, they are entitled to rights and protection under the UN Convention on the Rights of the Child. However, for many of them, providing care hinders access to their most basic rights. They can be at risk of social exclusion with fewer possibilities to access play and leisure activities, may be at greater risk of not completing their formal education and are less able to enter into higher education and/or to the job market.<sup>11</sup>

**Working age carers** constitute the lion's share of the family carers, as most of the carers are of working age, under 54 years old (73 % of women and 75 % of men), which might impede their ability to maintain a healthy work–life balance.<sup>12</sup> They are the main focus of the public policies as it is estimated that the cost of family care is around 2.7% of EU GDP.<sup>13</sup> Juggling long-term care and work responsibilities is a challenging task impacting the carer's financial independence and access to essential financial services, thereby affecting their broader social inclusion, physical and mental health and wellbeing. As most of the carers are women, this gender care gap is also a major factor of the gender pay, and later the gender pension gap.

On the latter point about pensions, it is important to now concentrate on the third age group and the focus of this thematic note: **ageing carers**. It is estimated that every 10th LTC carer is retired (10 % of women and 11 % of men).<sup>14</sup> This is a non-homogeneous age group that

<sup>11</sup> Eurocarers <sup>12</sup> EIGE – idem

<sup>&</sup>lt;sup>13</sup> European Commission, Directorate-General for Employment, Social Affairs and Inclusion, <u>Study on exploring the incidence</u> and costs of informal long-term care in the EU, 2021

<sup>&</sup>lt;sup>14</sup> EIGE, Idem

can only be apprehended while looking at the global demographic trends. For instance, in this age group the gender imbalance in informal care provision tends to be slightly lower with the share of men carers rising, which can be explained by the fact that men tend to become family carers for their spouse<sup>15</sup> (or for their ageing parent to a lesser extent) while women take on the high-intensity long-term care activities such as the care and support of a child with disabilities (regardless of the age of the offspring).

Building on the common challenges identified in the COFACE study "Who Cares?", this thematic note reflects on the specific challenges that ageing carers face in relation to three keys area of family support: Resources, time and services. Additionally, it in this paper, the question of health, both physical and mental health has been streamlined as it is recognise that providing family care and support in the current conditions, often has harmful consequences on health<sup>16</sup>.

#### **RESOURCES: HOW INFORMAL CARE IMPACTS OLD AGE RESOURCES?**

In order to understand the impact of informal care in old age resources, the gender angle is central to the discussion. Indeed, the unequal distribution of informal care is one of the explanations of the gender pension gap. Career interruptions or the need to reduce paid working hours to take on care responsibilities have a proven effect on the level of the pension of family carers. Only 17 of the 27 EU Member States give pension credits and consider financial support measures for family carers, highlighting the need for a more unified EU approach to financial compensation for caregiving. Moreover, the conditions to access them are very specific and they do not always cover the complexity of informal caregiving situations which explains the relatively low income levels of ageing family carers.<sup>17</sup> Informal care has an incidence on the carer even when the caring relationship has ended since the years out of the labour market usually are an obstacle to employment, seen as a period of loss of skills. The skills acquired through stepping into a family carer role are not recognised and valued by society or employers, and there is still a stigma around informal care which can mean extra challenges resuming a career after having been an informal carer, leading to hindered career development or periods of unemployment that exceeds the duration of effective informal care provision.

The second aspect to take into account looking at the need to boost the resources and financial support to older carers, is that the poverty risks associated with caregiving are not only linked to the loss in pension but are felt well before. As seen above, family carers due to their responsibilities are at higher risk of poverty and social exclusion during their working years. Breaking out of financial hardship is complicated, especially because the nature of the challenge they face is not sufficiently recognised and supported. Hence, on top of the risk of a lower pension, family carers when ageing are likely to have to bear the consequences of a life of financial hardship and low savings and safety nets. In this regard, women are even more vulnerable, even when in a heterosexual long-term

<sup>&</sup>lt;sup>15</sup> World Health Organisation, Caregiving impacts on unpaid informal carers' health and well-being – a gender perspective,

<sup>2022</sup> <sup>16</sup> Pinquart M, Sörensen S. <u>Differences between caregivers and noncaregivers in psychological health and physical health: a</u> meta-analysis. Psychol Aging. 2003 <sup>17</sup> European Commission, Directorate-General for Employment, Social Affairs and Inclusion, <u>Study on exploring the incidence</u>

and costs of informal long-term care in the EU, 2021

relationship. As they are taking on the majority of the care responsibilities and that in European societies men tend to have higher wages (both realities contributing to higher pensions for men), **the death of a partner can push women in poverty years after they have retired**, as they cannot count on their partner pension any longer, even in the case of survivor pension it can be complicated.

The last point to take into consideration looking at the challenges around resources is when the situation of care remains active past the age of retirement. Some long-term care relations last for a lifetime notably in some cases for parents -mothers- of children with disabilities or the spouse of a person with disabilities. Looking at financial compensation for carers is a point in the LTC Recommendation with the precision that it should not hinder the participation in the labour market, which seems to indicate that the legislator had carers of a working age in mind when drafting the measure. The adequacy of pensions is questioned in multiple EU countries, notably in relation to the demographic changes. The question of care compensation and the interaction with pensions should be reflected upon not only from the point of view of an interrupted career but also from the perspective of coping with the extra costs of informal care and its impact on pension incomes. This should be considered on the basis that, to different extents, there are costs and benefits linked to the contribution of family carers who are past the retirement age yet who still deserve support including financial and social protection linked to their informal caring role. The repercussions on their own health and well-being shall be considered since, as seen earlier, the question of informal care should not only be seen as a hindering factor to access the labour market but for the societal value it has and hence be recognised and supported it all its forms. The repercussions of a care relationship on the health of ageing carers should be considered in order to mitigate the damaging physical, mental and financial effects that informal care can have on a person. The recent European Commission Communication on a Comprehensive Approach to Mental Health<sup>18</sup>, includes provisions to support carers and families alongside the supports for "patient" which can be seen as a step forward in recognizing and addressing the effects of informal care on mental health.

Another scenario to consider is a person who enters into a long-term care relationship while already at retirement age. Similarly, to the point made before, the idea of complementing the pension income to cover the costs of informal care should be considered. Furthermore, some findings suggest that for **persons becoming carers at an older age, so here in the vast majority for a spouse or for an ageing parent, the gender imbalance seemingly lowers and more male carers are in the picture** (even if the absolute number may still hide important questions such as the nature of the care tasks provided by different genders and their intensity). A recent study shows that male family carers tend to wait longer to ask for any type of help<sup>19</sup> - this is one reason more to not only **think about which type of financial help can be provided to older carers but also how to communicate it and provide it to ensure that there is a high take-up rate of support in the targeted population. It is important to note that the care situation sometimes "reverses" with adults with disabilities having to step into a carer role for their ageing parents.<sup>20</sup>** 

<sup>19</sup> <u>UNAF France</u>, publication forthcoming in 2024.

<sup>&</sup>lt;sup>18</sup> European Commission, Directorate-General for Health, Food and Safety, Communication: <u>A comprehensive approach to</u> <u>mental health, 2023.</u>

<sup>&</sup>lt;sup>20</sup> European Disability Forum, Inputs to the European Commission's consultation on the roadmap "<u>Demographic change in</u> Europe – green paper on ageing, 2020"

To summarise, in the implementation of the LTC Recommendation when it comes to financial support, it is important to consider the needs of the older carers whether they are still in an active care relationship or not; and to consider the different difficulties that can arise from different care situations and relationships. It is even more important given the current crisis in provision of adequate care services and staff shortages that have put family carers under increased pressure after the COVID-19 crisis. Actions must be taken to support all carers financially now and systems must be rethought in order for informal care to become less of a financial risk and associated to old age poverty and inadequate pensions.

#### TIME: HOW TO PROVIDE CARE-LIFE BALANCE FOR AGEING CARERS.

One of the ideas usually associated with retirement is **time**. Without the time constraints that come with paid work, it is a common vision associated with age that time is an abundant resource for ageing persons. However, **recognising that care is time-consuming should not be restricted to a vision centred around the working life and it is important when designing time measures for carers to look beyond paid employment** and include considerations for ageing carers.

Healthy and active ageing included in the community is one of the objectives of the European Care Strategy. Its life course approach makes it clear: policies and programmes should be put in place to allow persons to be active and included in society while ageing, the underlying idea being that there is more time to do so once freed of paid employment. For carers though, it has been estimated that the intensity of informal care provided increases after 64 years of age for women.<sup>21</sup> Here again, the gender angle must be underlined as it is pointed out in the 2021 European Commission Report on the Cost of informal Care which notes that in the EU "Women aged 65+ provide substantially more intense informal care, with up to 41 hours per week on average for Spanish women aged 65+. The high intensity of help that informal carers past the retirement age provide is likely driven both by the dependency of family members (such as partner) on care and by time availability of the informal carer." Hence, here in the specific case of Spain the average care provided by Spanish women past retirement age is equivalent to the average time spent in full-time employment which does contradict the idea of pensioners with care responsibilities being able to enjoy retirement as they see fit. The prevalence of the gender imbalance here is also striking, as it seems to show that there is no retirement from care responsibilities for women. Therefore, policies that address the question of time balance around the question of informal care should not only look at work-life balance measures but seek to address this care time penalty that affect women family carers more than men. Informal care should remain a choice, with a certain control over the intensity of the care provided, and having time free from paid employment should not be a reason enough to push older women into that role.

The second point in relation to ageing carers **is the incidence that this caring time has on the overall quality of life during the older years**. Focus groups were conducted in the UK

<sup>&</sup>lt;sup>21</sup> European Commission, Directorate-General for Employment, Social Affairs and Inclusion, <u>Study on exploring the incidence</u> and costs of informal long-term care in the EU, 2021

on ageing carers<sup>22</sup> and most reported exhaustion due to the care activities which had influence on their care-free time. Most also, as seen earlier, are reticent to call for help – when such a support service even exists - which can increase the intensity of the help needed. The same study also shows that for the carers who enter the caring relationship at a later stage, when they do reach out for help, **one of the most time-consuming aspects is figuring out how to coordinate the care with the formal care services** and different supports available, since they may not have previous knowledge of the care system or they are not sufficiently informed of the potential system changes.

Numerous studies have also highlighted the **detrimental consequences that informal care has on physical and mental health and wellbeing, and these consequences can be felt years after the informal care relationship has ended,** indicating also that providing informal personal care was significantly associated with poor mental health and poor physical health over a follow-up period of eight years.<sup>23</sup> Elder carers are therefore more likely to suffer from poor physical and mental health, which can increase further social exclusion and hinder their participation in society even years after their care relationship has ended. Isolation in old age can have dramatic effects on people, and older carers also should have a right to access a break from care, through appropriate support services – such as carers holidays, day care, adapted family holidays - that will take over their caring and support responsibilities temporarily to allow them to engage in activities that support their inclusion in society and support their mental, physical and emotional wellbeing.

A recent study that looked at parents of children with disabilities in France highlighted the prevalence (95%) of deep states of anxiety among family carers concerning the future of their relative when they will no longer be able to provide this informal care and about what will happen after them<sup>24</sup>. This is a pressing issue linked to the current overreliance on family carers in a context of an ageing society. Ageing family carers are themselves in a position of being in need of care and support services. One of the fears that most share regarding the future of the persons they provide care and support for is the financial resources management: what will happen to them without their family's financial support and will they be allowed to have choice and control over their finances, or will that be taken over without any supported decision-making scheme put in place? Or on a more worrying level. there is a high risk of forced institutionalisation or re-institutionalisation for the persons cared for because of the end of provision of informal care and because the necessary professional support services are not available. This is in total opposition to what COFACE Disability stands for as explained in the 2019 Guide for the meaningful inclusion of persons with disabilities, their families: S.H.I.F.T.<sup>25</sup> and this risk should be properly addressed in the implementation measures of the European Care Strategy. Some legislation supports carers and the persons they care for to choose in advance appropriate and community-based living arrangements that will ensure that the person will get the appropriate support, such as the "Dopo di Noi" (After Us) legislation in Italy<sup>26</sup> with the specific

<sup>&</sup>lt;sup>22</sup> Carers Trust, <u>Retirement on Hold Supporting Older Carers, 2016</u>

 <sup>&</sup>lt;sup>23</sup> European Commission, Directorate-General for Employment, Social Affairs and Inclusion, <u>Study on exploring the incidence</u> and costs of informal long-term care in the EU, 2021
<sup>24</sup> UNAPEI, <u>La voix des parents, 2023.</u>

<sup>&</sup>lt;sup>25</sup> COFACE, <u>S.H.I.F.T. GUIDE, 2019</u>

<sup>&</sup>lt;sup>26</sup> Multisite of the Itelian ministra for

<sup>&</sup>lt;sup>26</sup> Website of the Italian ministry for employment and social affairs

objective to improve autonomy and independent living after the death of the family carer for persons with severe and multiple disabilities. The "Dopo di Noi" (After Us Law) 112/2016 helps parents guarantee that their children with disabilities will be taken care of once they are gone. With the newly introduced formal contract of "Affidamento fiduciario" (trusteeship), parents are in a position to set up a trust, fully effective and enforceable under Italian law, to make provisions for the protection, care and assistance of their children with disabilities, during the parents' lifetime and after their death. Therefore, when looking at the time aspects of support to family carers, especially ageing carers, it is important to look at how to support the balancing of the time but also giving the appropriate support, including through policies, to ensure that the informal care relationship is forward looking and centred on a logic of inclusion in the community, so it can carry on even if one of the family carer cannot.

#### SERVICES: INCLUSIVE SERVICES TO SUPPORT ALL CARERS.

The LTC Recommendation, while calling out the unsustainability of the current overreliance on family carers, does recognise that they will always remain part of the LTC equation. In that sense, the measures that are suggested to support them include aspects that will make the collaboration with the professional carers smoother and more efficient, while in parallel, **developing the community based, high quality, accessible and affordable LTC services that will allow persons who draw on care and support and their family the opportunity to make real choices when deciding how to handle the care relationship**. These services should be fully accessible to all persons who draw on care and support and to their family carers.

As mentioned earlier, older carers tend to be in a particularly difficult situation when it comes to access to support services, and this low take-up should be taken seriously in the implementation measures of the LTC Recommendation, since service effectiveness and quality is also measured by the diversity of its reach and its accessibility. Looking at the different barriers, the first one is on the identification and outreach to older carers who might sometimes have become invisible to public authorities/policy-makers. To do so, there is a need for outreach professionals in the care and health sector to be more informed and trained about informal care, about its importance and its consequences, in order to identify and advise the family carers. In France for instance, the strategy to support family carers put forward the idea of a "carer check" for health professionals to develop a procedure to recognised them and to learn about the "Carer syndrome" and support family carer better.<sup>27</sup> Awareness raising and information campaigns on what is informal care, should be put in place with specific measures to target the family carers in the most excluded and vulnerable situations, such as ageing carers, carers from the Roma community or other families in marginalised situations. Formal care workers should also have the possibility to attend trainings on how to collaborate with family carers of different backgrounds and sensitivities.

Information needs to reach ageing family carers so that they can make informed decisions and be fully updated about the different opportunities for training for instance. **Techniques** 

<sup>&</sup>lt;sup>27</sup> Vidal, <u>Le syndrome de l'aidant : les signes qui doivent alerter, 2023.</u>

and technologies evolve constantly and some of the new assistive technologies can seem very technical and hard to handle for carers. They need to be able to access proper training and advice on the possibilities to make care tasks easier. It is even more important to consider this taking into account the physical and cognitive changes that arise with ageing. Even with all the prevention and rehabilitation measures, ageing comes with physical changes that can make some of the tasks relating to caregiving more complicated or dangerous for ageing carers to perform. Ageing persons often face discriminations in accessing disability support schemes, as their impairment is often not identified as a disability but as age-related. As a result they are not always eligible for the services and assistive technologies that they need.<sup>28</sup> Where the support is adequately provided, such technological changes should not mean that the informal care relationship ends, but that it will undergo a shift towards a model of care supported by new types of services or technologies. Without this flexibility in service provision, there is a risk that persons who do want to continue to be in this informal care relationship are not able to carry on. The same goes with the possibility of adapting to the cognitive changes that may happen with old age. In other words, these physical and cognitive changes can mean that the family carer will also need care and support in some way, without necessarily wanting to end the care relation. For instance, it is often one of the spouses who takes care of the administrative tasks in a household - if these persons become in need of care and support and can no longer fulfil these tasks, there is no certainty that the other spouse, now the family carer, will be able to do so without support. Therefore, services should be flexible and consider care provision as a continuum where the intensity between formal and informal can vary without threatening the quality of care and ensuring the respect of the rights and dignity of all parties involved.

In order to make sure that the specificities of service provision for ageing family carers are taken into account, they should also be represented in co-creation procedures and programmes around the building of the support services because as we have seen, although the challenges faced pertain to the same broad categories, there are differences that can influence the way carers are able to cope with them. One of the solutions that is often put forward is to centralise the information and the file through the creation of integrated care and support services that will coordinate the services and allow the persons and their carers to go through one single point of contact. This solution is also very relevant when looking at ageing carers for whom coordination of the different services can be an extra challenge. It can also help to cope with the issue that can be encountered regarding the inaccessibility of the transport to access the services which are often situated in populated/ urban areas, knowing that older people are in the EU more likely to live outside of urban areas<sup>29</sup>, creating a geographical divide.

The other divide to take into account when talking about inclusive provision of support services to older carers is the digital divide. With the rapid digitalisation of some services, it is important to ensure that it does not come with leaving behind a part of the service users who are not accustomed to the digital tools, what they can offer and the danger they can pose. The LTC recommendation insists on the necessity to support family carers through trainings - these should be continuous making sure that they can

<sup>&</sup>lt;sup>28</sup> European Disability Forum, Inputs to the European Commission's consultation on the roadmap "Demographic change in Europe – green paper on ageing, 2020" <sup>29</sup> Eurostat, Ageing Europe - statistics on population developments, 2023

acquire through them the skills necessary for their care and support tasks, including financial literacy training<sup>30</sup>, to ensure they can manage and access financial services effectively alongside their care and support tasks. But also as suggested in the Strategy, ensuring that there can be training on the other aspects that surround informal care including on the digitalisation of services.

In conclusion, when it comes to service provision and delivery, taking into account the need of older family carers calls for a better attention provided to the adaptability of the services, the need to prevent low take-up and the need for trainings on all aspects of care and support.

#### CONCLUSION

The rolling out of the LTC Recommendation through national implementation measures by the 27 Member States is an important step towards the care system of the future. Care is not a problem at the margins of society, it is central as everyone will be at some point in the situation of providing or receiving long-term care and support. Hence, it is important that the reform of the care system leaves no one behind and considers care and support for their true value to society. It is crucial that all family carers, regardless of their age, get access to social recognition, to support and to a set of rights, defined by the COFACE Disability Platform in the European Charter for Family Carers.<sup>31</sup>

With the necessary emphasis put on the shortage of care services and care staff and its effect on all society<sup>32</sup>, the implementation of the LTC Recommendation should ensure that the questions of the diversity of family carers is also addressed in the measures put forward to train professional carers on how to handle best relations with families of the persons who draw on care and support services.

The life course approach to care that is central to the European Care Strategy must continue to inform the implementation measures that the EU Member States will put forward by June 2024 as it is a tool to grasp the complexity of the situations of family carers. It also centres the debate around the people drawing on care and support and those who provide it formally or informally and does not present care reform solely as a way to improve participation in the labour market.

Supporting ageing carers is not a problem of tomorrow but should be addressed now, as the current system is failing them and since not enough measures are in place, the consequences will be felt even stronger in the years to come. Hence the strategies put in place by Members States should also have for aim to mitigate the effects on the current carers.

To do so, there is an urgent need for the European Union to conduct a general benchmarking survey on the reality of family carers, in order to provide a clearer picture of

<sup>&</sup>lt;sup>30</sup> Pinciple VII, Towards an Economy which Cares, COFACE Families Europe, 2021.

 <sup>&</sup>lt;sup>31</sup> COFACE Disability, <u>European Charter for Family Carers, 2011</u>
<sup>32</sup> Joint statement by 17 European Organisations, <u>Building up European care capital – sustainable investments, not</u> burdensome costs, 2023

who are the carers in the EU, taking into account factors such as the gender, the age, the nature of the relationship and the intensity of the care and support provided. Such European actions on data collection and monitoring should also be complemented by the allocation of adequate EU funding for similar (sub-)national initiatives and actions aiming for similar results to shed light on the situation of family carers in different countries.

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