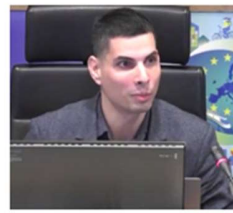
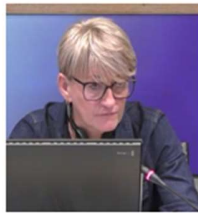


Family carers in Europe today: State of play

European Round Table



Key reflections and findings
October 2024



Background

In the run-up to the [UN international day of care and support](#) on 29th October, COFACE and the European Committee of the Regions organised a European Round Table on family carers. This Round table fostered debate on the realities and support needs of family carers in Europe today. It shed light on the role of European policies and legal frameworks to support families with disabilities and/or in need of care through robust community-based intervention models at the local and regional levels.

During this round table, the COFACE Disability platform for the rights of persons with disabilities and their families (founded in 1998) outlined the needs of family carers today based on its European Charter for Family Carers.

This Charter was created in 2005 by COFACE Disability (and reviewed in 2024) in accordance with the provisions of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and other significant international conventions and documents developed under the auspices of the United Nations, the Council of Europe, the European Union, and the European Disability Forum, concerning the life, dignity, rights, and full citizenship of persons with disabilities and their families.

The Charter highlights the needs of family carers in their diversity, regardless of the cause of the individual's support need (disability, age, illness, accident).

It is designed as a tool for national decision makers, EU institutions, care services providers, organisations representing persons in need of care and their families within the European Union, as well as local and regional authorities responsible for service provision and community-based support.

It was discussed together at the round table on 24th October 2024 by 50+ participants, members of COFACE Disability, key Brussels-based EU stakeholders from the European institutions, including officials from the European Commission and the European Social and Economic Committee, as well as major EU civil society organisations and local and regional representations.

Programme

Moderator: Elizabeth Gosme, Director, COFACE Families Europe

9.30-9.40 **Welcome words**

Antonia Torrens, President, COFACE Families Europe

9.40-10.20 **Key concerns and recommendations of family carers**

Sylvie Hirtz, Co-chair of the COFACE Disability Platform.

Sebastian Gonzalez, Policy and Advocacy Officer, COFACE Families Europe

10.20-11.30 **Reactions and debate**

Dovilė Juodkaitė, Member of the EESC and co-creator of the EESC opinion on Caregivers.

Haydn Hammersley, Social Policy Coordinator, European Disability Forum.

Mathilde Prilleux, Programme Assistant, European Social Fund + Community of Practice on Social inclusion, DG EMPL, European Commission

Katarina Ivanković Knežević, Director for social rights and Inclusion, DG EMPL, European Commission. (video message)

11:30-12:00 **Concluding remarks and recommendations for next steps**

All speaker presentations are available [here](#).

Welcome

Antonia Torrens, President of COFACE Families Europe

Antonia welcomed participants in the European Committee of the Regions. As the newly elected President of COFACE Families Europe -and as a professional herself who has dedicated a great part of the last 20 years to the sector of psychosocial rehabilitation of people with mental health challenges – she thanked COFACE Disability, the whole COFACE team, and the European Committee of the Regions for organising this European Round Table.



Just days before the International Day of Care and Support on 29th October 2024, she reminded participants of the urgent need to address the growing care challenges that affect so many families across Europe and beyond. The establishment of this day by the UN General Assembly highlights the importance of care in our societies and the pressing need for reforms in our care systems—reforms grounded in human rights, dignity, and social protection for both carers and those they care for.

COFACE Families Europe, through its Disability Platform, has long been committed to advocating for the rights of persons with disabilities and their families. And as we all know, family carers—who provide much of the care—are often overlooked or undervalued. She emphasised that the Round Table was an opportunity to discuss how we can continue to push for systemic changes to ensure they receive the recognition and support they deserve.

The European Union is also at a pivotal moment. With a new college of Commissioners taking shape, new policies and priorities will soon be set. This is a critical time to ensure that long-term care, especially family care, remains a top priority on the European agenda. The adoption of the European Care Strategy in 2022 was a major step forward, and we must work collectively to maintain this momentum. The monitoring process for the implementation of the Council's Recommendation on long-term care is beginning, and it is crucial that family carers are a key focus in this effort. Their contributions need to be fully recognised, and their rights protected.

We also find ourselves facing broader societal changes that demand from us to rethink the future of long-term care. Europe's demographic shifts, coupled with the growing strain on social protection systems, mean that families are often asked to fill the gaps left by underfunded and inaccessible care services. This puts an unjust burden on families—especially women, who are disproportionately impacted by the demands of caregiving. If we do not address these issues now, the global care crisis will only worsen, leading to further inequality, exclusion, and stress for families.

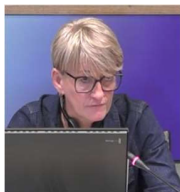
She stated that this European round table is a chance to reaffirm our commitment to supporting carers and creating sustainable, human rights-based care systems across Europe. We have seen promising progress in recent years with initiatives like the European Child Guarantee, the EU Work-Life Balance Directive, and the EU's Disability and Gender Equality Strategies. At the same time, Member States are taking steps to support family carers, whether through financial support, healthcare access, or training programmes.

These efforts are important, but we must ensure they are ambitious enough to bring about real change. We need long-term care systems that are accessible, affordable, and of high-quality. Systems that promote independent living for all, particularly persons with disabilities and older adults. Systems that respect the dignity of carers, whether they are family members or professionals.

On that note, she announced that COFACE Disability is launching a revised version of the European Charter for Family Carers—a document first developed in 2005. This revised Charter reflects our continued commitment to advocating for the rights and well-being of family carers across Europe.

Key concerns and recommendations of family carers

Sylvie Hirtz, Co-chair of the COFACE Disability Platform



Sylvie opened the session by reading out the speech of Chantal Bruno, COFACE Disability co-chair, who could not be present at the Round Table.

“Thank you to Sylvie, co-chair of the COFACE Disability platform, for lending me her voice. Welcome to you all. I'm very sorry I cannot be with you. I have had to take temporary leave of absence. I hope you have a wonderful meeting and fruitful discussions.

In 2005, COFACE Disability began to look in depth at those family members known as ‘natural carers’ or ‘informal carers’ who come to the aid of a relative who needs care due to illness, old age or disability. We began by carrying out a study, the results of which showed that, overall, family carers had no specific rights or recognition. They received little or no support, except in Luxembourg, the UK and Sweden, where legislation on the subject was already well advanced.

First of all, we had to agree on a definition of a carer. Nearly 20 years ago, the term ‘carer’ did not exist everywhere, sometimes not at all, and when it did, it was associated with ‘natural’ or ‘informal’, terms that carried a lot of meaning. Mothers who looked after their disabled child were simply, like spouses and children helping a parent: family members who were simply doing their duty! *Why give rights to people who don't work?*” said a trade unionist in France...

So, for several months, each partner in our COFACE Disability working group consulted the families they represented to find and then refine a ‘European’ definition of the person we have chosen to call ‘family carer’. The aim was also to gather the opinions and expectations of these families. The exercise culminated in the COFACE Disability European Charter for Family Carers.

The objectives of the Charter in 2005 and of this updated version in 2024 are the same:

- To make carers visible by naming them and making them exist outside the private sphere;
- Raising awareness on the invaluable role of these economic players, highlighting the consequences and the resulting needs;
- Make public authorities face up to their duty of solidarity and respect for the fundamental rights of families, carers and those being cared for.

If COFACE Disability has chosen to present the Charter again at the European Round Table, it is to highlight the persistence and increasing situations of extreme vulnerability for many families, and more particularly for women carers.

COFACE Disability's ambition was, and still is, to create public policy responses for those people we now call ‘family carers’ or ‘informal carers’. This ambition has remained the same for almost 20 years, because although significant progress has been made, there is still a lot to be done, as you will have realised.”

Sebastian Gonzalez, Policy and Advocacy Officer, COFACE Families Europe

Sebastian presented COFACE Disability's [European Charter for Family Carers](#) (available in English and French, and in Easy-to-read English).



As highlighted in the introductory remarks of the COFACE Disability co-chair, Sylvie Hirtz, the drafting process of the Charter began in 2005.

At that time, the specific needs of family carers had not yet been addressed in a structured manner by the European Union, although some significant advancements had already been made regarding the non-discrimination of persons with disabilities, which, in certain cases, also provided protection for family carers. On the other hand, at the level of Member States, policy responses targeting family carers were at a very early stage of development, and such measures remain absent in many cases.

The lack of policies tailored to address the needs and challenges faced by family carers was—and remains—a pressing issue, given the crucial role they play in providing long-term care across the

European Union. Estimates suggest that as much as 80% of long-term care is provided by non-professional carers, most of whom are family members.

In this context, COFACE Disability's efforts to provide a structured set of recommendations and objectives, encapsulated in a Charter consisting of ten points, was a milestone at the EU level. The Charter's aim was to promote the development of a wide range of policy responses to support family carers. It was the result of a collective effort by COFACE Disability members, who drew upon their own local and often personal experiences to create this valuable tool.

In light of recent policy developments at the EU, national, and sub-national levels regarding family carers—such as the EU Work-Life Balance Directive, the European Care Strategy, and the EU Disability Rights Strategy - COFACE Disability deemed it appropriate to revise the Charter.

It is this revised version of the Charter that Sebastian presented. He explained that the Charter is based on principles. It does not seek to address every specific challenge that family carers face. Rather, it highlights key principles that can guide the design of appropriate responses for all family carers, and that can be applied in a wide range of circumstances. Furthermore, these principles can be beneficial to all stakeholders involved. Indeed, under the title "About the Charter", the document is described as "a reference tool" that can be useful not only to policymakers at all levels of governance, but also to service providers, as well as the organisations that represent persons in need of care and their families.

It is also under this title that there is the **first principle** of the Charter. That is, that the Charter is founded on human rights. This underscores an approach based on the equality of rights to dignity, autonomy, non-discrimination, and inclusion in society. The Charter is aligned with EU and international frameworks promoting human rights, such as the UN CRPD, and others that are referenced within the document.

In the Foreword is the **second principle**: that providing care is the responsibility of national public authorities, as it is an essential good for society as a whole. Therefore, family care should only be undertaken as a personal choice by both the family carer and the person in need of care, and it must be supported by social protection and rights.

Family care should never result from necessity due to a lack of accessible, affordable, high-quality public support and care services. Promoting the provision of accessible and appropriate community-based services, as well as the formal recognition of the role of family carers and their rights—are among the overarching goals of the Charter.

The third principle is that the Charter applies to all family carers, regardless of the reason for the care needs, whether due to disability, age, or illness. Differences in care needs should not justify differences in, or a lack of, protection for family carers.

Sebastian briefly outlined the ten points of the Charter.

The infographic consists of ten numbered points, each with a title and a brief description. The points are:

- 1 DEFINITION OF FAMILY CARER**: A family carer is a non-professional person who provides primary assistance with activities in daily life, either in part or in whole, to a person with care or support needs (due to disability, age or illness) in their immediate circle. This regular support may be provided to persons in need of care at any age and can take various forms, including nursing, assistance in education and social life, in administrative formalities, in travelling, vigilance, coordination, psychological support, assistance in communication, or in domestic activities.
- 2 CHOICE OF FAMILY CARER**: Persons with care needs should always, and at any age, have the choice of receiving support from a family or a professional carer. If a person has limited verbal capacity, all efforts should be made to ensure their will is respected. Similarly, family carers should also have the opportunity to decide whether to fulfil caring duties on a full-time or part-time, and to reconcile it with their work and personal life. Such choices for both the caregivers and care receivers must be free, informed, and open to reassessment. As concerns children or young people, whether with care needs or providing care, their views should be fully acknowledged.
- 3 FAMILY AND PUBLIC SOLIDARITY**: The family environment is the primary socialisation area for children and the natural environment for the growth and well-being of all its members. Solidarity within families should be underpinned and complemented by public solidarity. The fact that persons with care needs may choose a non-professional carer and benefit from the effective solidarity within the family, in no way releases the national and local public authorities from their obligations towards those receiving and those providing care. Furthermore, such national solidarity in care provision should be tailored to the needs of those being cared for and entail full social recognition and access of family carers to social rights and all kinds of social support. There should also be a legal provision ensuring that care work is financially compensated, should the family carer choose this.
- 4 THE INCLUSION OF THE FAMILY CARER WITHIN THE HEALTHCARE SYSTEM**: The role of family carers should be recognised and their needs taken into consideration in the development of health and social protection policies. Family carers must receive adequate support, including physical and mental health care.
- 5 RECOGNITION OF THE SOCIETAL ROLE OF THE FAMILY CARER**: Family carers should benefit from resources, social rights and financial benefits when they provide support to persons with care needs due to disability, age or illness. Their role of family carer should be taken into account in terms of access to:
 - the labour market and employment: working time arrangements, holidays, leaves, return to work support;
 - health and social protection schemes;
 - retirement benefits, through their formal recognition as carers;
 - the recognition, in the open labour market, of the experience and skills learned through caring and supporting;
 - transport, housing, culture, built environment and communication when supporting the person in need of care.
- 6 AGE DIMENSION OF CARE**: Since caring can occur at any point in a lifetime, it is also crucial to consider the age dimension of care, distinguishing between the challenges faced by younger and older carers. For young carers, the challenges include the impact on education, training, social life, mental health, and the lack of knowledge of their rights. In addition to youth-friendly social protection rights, they should have access to flexible school policies, tutoring, counselling, mental health services, time for leisure and social interactions. For older carers, the challenges include poor or deteriorating health conditions, social isolation, financial difficulties, and lack of capacity to manage administrative burdens. Social protection rights should be tailored to these realities, through accompanying measures aimed at preventing the escalation of needs.
- 7 QUALITY OF LIFE**: The quality of life of the person receiving care and the family carer are interdependent. It is therefore necessary to develop preventive measures to avoid exhaustion, psychosocial risks, illness, burnout, or any abuse. Community-based services and facilities play a key role in contributing to the well-being of persons with care and/or support needs, their carers, and their family members.
- 8 RESPIRE BREAK**: Respite is a break from caring, while the person cared for is looked after by someone else. Respite is a fundamental necessity that requires the development of regular support solutions that can take various forms, including occasional and/or emergency assistance, substitution services and/or high-quality temporary care centres during varying periods of time depending on the needs (holiday, sick, health). Providing family carers with respite breaks is extremely important to prevent the deterioration of their physical or mental health.
- 9 INFORMATION/AWARENESS/TRAINING**: Family carers should be informed about their rights. They should have access to all the information that will help them in their role as carers. They should also have access to social awareness-raising and training programmes aimed at improving their capacity to provide care. A training system should be set up by public authorities in full consultation with family organisations, which play a fundamental role in supporting family carers. In this sense, information, training and support programmes, as well as peer programmes run by family organisations should be supported and funded. Furthermore, professional carers should be trained and be aware of the needs and challenges of families, and awareness-raising/training involving peer carers should be prioritised.
- 10 ASSESSMENT AND MONITORING**: Public authorities should, with the involvement of persons in need of care, family carers, and family organisations, continuously assess and monitor:
 - the needs of both the person in need of care and their family carers;
 - the implementation of measures;
 - the quality, affordability and accessibility of community-based services (social and health) for persons with care needs and their family members;
 - the continuous improvement of services based on the assessments carried out;
 - the implementation and effectiveness of social rights.Persons receiving care, family carers and family organisations are the best placed to determine the needs for support and how to answer them. Therefore, they should be closely involved and fully participate (or be represented by a person of their choice) in the assessment process of their support needs, in the development of community-based services, and in the evaluation of the measures developed.

The first point addresses the definition of "family carer". Albert Camus famously said, "To misname things is to add to the misfortune of the world." Defining the term "family carer" is a crucial first step towards securing rights. However, even choosing the appropriate term is often challenging. Different Member States and international bodies use various terms to refer to similar categories of carers, each with its merits and drawbacks. As a

family organisation, COFACE Disability chose the term "family carer" because, in the vast majority of cases—often over 80 or 90%, depending on the Member state—a family member assumes this role. Nonetheless, our definition is **inclusive and intentionally encompassing**, covering all forms of non-professional care provided **within the immediate circle**, with no restrictions based on the degree of familial relationship or specific status, such as that of a spouse. It also covers a wide range of activities, including nursing, psychological support, and domestic tasks.

The second point of the Charter underscores a key principle mentioned previously: family care should be a choice. Therefore, it should not arise from necessity; it should be possible to balance caregiving with paid work, and the intensity of care provided should be at the discretion of the carer, with the option to reassess this decision over time.

The third point reiterates the duty of governments to provide for society's care needs. The existence of family solidarity does not absolve public authorities of their responsibilities. As mentioned by COFACE President Antonia Torrents, family carers constitute the majority of long-term care providers in Europe, but this is unsustainable. The ageing population in Europe is leading to increased needs for long-term care, while also reducing the number family carers, who themselves are growing older. This is one of the reasons we urgently need a rethinking of long-term care in Europe.

The fourth point of the Charter calls for better integration of family carers within the healthcare system. Family carers can play a more positive role, and we can collectively avoid adverse consequences when they are meaningfully involved in the care process and have access to healthcare services themselves.

Point five outlines the social role of family carers, detailing the areas in which they should receive rights, protection, and support. To give a few examples, they should have rights related to working time arrangements, or to pension benefits for their care work; they should have protection against discrimination or adverse health effects, and they should be supported via financial benefits, specific services like respite care, or trainings. Several of these dimensions are developed in other points, of the Charter.

Point six focuses on the age dimension of care. It seeks to shed light on specific categories of carers who are often invisible and particularly vulnerable. These include both young carers and older carers.

In the EU, the number of carers under the age of 18, constitutes between 4% and 10% of this age group across different Member States. Conversely, at the other end of the spectrum, 16% of carers in the EU are over the age of 65. Both of these groups encounter unique challenges that require targeted interventions, such as difficulties in accessing essential information, limitations in their capacity to provide care, and more. Young carers, for instance, may need respite that is tailored to their circumstances, along with flexibility in managing their studies.

Point seven of the Charter emphasises the interconnectedness of the wellbeing of carers and those they care for. Services should be designed to ensure the wellbeing of both. Including the notion of wellbeing has deeper implications than it may seem. It affirms a broader and more profound role for our welfare systems, a role that goes well beyond the provision of minimal assistance.

Point eight highlights the importance of respite, which is an essential requirement for family carers. This point underlines that appropriate respite demands the creation of regular and diverse support solutions tailored to the wide range of life circumstances family carers face. For example, respite care can vary in duration, being either temporary or longer-term, and may be provided in the home, within the community, during holidays, or in both standard and specialised settings.

Point nine of the Charter takes a deeper look at the need for information and training. Without access to the necessary information and knowledge, family carers will be unable to fulfil their role effectively, which can lead to significant negative consequences for both the carer and the person in need of care. For example, when a family member is diagnosed with a disability or illness, the family should receive the information and support needed to understand what actions to take, what to avoid, and how to adapt to specific circumstances.

Point 10, the final point of the Charter, addresses the critical issues of assessment and monitoring. It highlights the importance of involving those in need of care, alongside their families or representative organisations, in the assessment of needs and the evaluation of policy responses to those needs. This involvement is essential, as no policy measure can be truly effective if it fails to reflect the specific needs that arise in the wide variety of care situations. As COFACE Disability calls for policies to be carefully targeted, thoroughly implemented, and open to regular

reassessment with the participation of all relevant stakeholders, the aim is to encourage the development of a broad range of diversified, tailored measures that a single document, such as the Charter, could not possibly address in its entirety.

Key discussion points

After bilateral discussions, participants made a few points for the plenary, which can be summed up as follows:

- The burden of care is even greater for family carers given the current crisis in the professional care sector, with greater risks for care receivers.
- It can be challenging to achieve equal partnerships between professional care services and parents/relatives, with few services taking into account the family environment of the person supported or cared for.
- In practice, in some cases, home support workers start by giving some time to family members, and then to the person cared for, in order to avoid a situation where no time is left to talk to relatives.

Reactions and debate

Dovilė Juodkaitė, Member of the EESC and co-creator of the EESC opinion on Caregivers.



Dovilė highlighted the work of the European Economic and Social Committee on caregivers, including the recommendations of its latest July 2024 opinion (as member of the study group working on this opinion). She is EESC member and works for the Lithuanian Disability Forum, an umbrella organisation in Lithuania advocating for the human rights of people with disabilities. A forum which also focuses on raising awareness and supporting caregivers, to alleviate the considerable burden they often carry. Finally she highlighted that she serves as a board member of the European Disability Forum.

She highlighted the key recommendations of the EESC based on the recent opinion on caregivers. This opinion raises the long-standing issue of family caregivers who often sacrifice their professional lives, income, and security to care for their relatives.

The COVID-19 pandemic has intensified these challenges, and restrictions imposed by countries made caregiving more complex and visible. Since 2022, the EESC has issued two opinions on this matter, with the most recent led by Pietro Vittorio Barbieri, an active advocate for disability rights. Barbieri, himself a wheelchair user, brings deep personal insight into both disability rights and the importance of social services for people with disabilities.

In preparing this opinion, they held hearings with representatives from various Member States and welfare systems. The findings revealed a dire situation. Even countries like Germany, with some of the highest welfare spending globally, still rely on secondary, often ineffective policies for caregivers. Here are the EESC opinion's main recommendations and statements:

- **Legal Framework:** The opinion examines the EU's legal framework on caregiving, referencing the 2021 Long-Term Care Report on the adverse impacts of informal care on income and pensions. The 2019 EU Work-Life Balance Directive offers flexible leave days and working arrangements for caregivers but does not support those who have left employment to provide care.
- **European Care Strategy:** The strategy outlines goals for improved care regarding accessibility, quality, sustainability, innovation, and social inclusion. It advocates for support for informal caregivers—through counseling, psychological support, respite care, and financial assistance—without discouraging labour participation.
- **Gender and Economic Impact:** Caregiving often leads to gender-based discrimination, impacting women's health and financial stability. Caregivers, primarily women, face tangible and intangible impoverishment due to inadequate social support systems.
- **Statistical Gaps:** There is a lack of comprehensive data on informal caregiving. Without accurate data, the scope of beneficiaries remains unclear, making the issue largely invisible at the political level.
- **Data and Research:** The majority of caregivers are women, and qualitative research shows they often experience identity loss and physical and mental health decline. Reliable data is essential to address these issues effectively.

In summary, the opinion calls for a platform for best practices exchange, policies that support caregivers' self-determination, high-quality community-based services, and emergency respite services. It highlights the need for flexible working conditions and re-entry support for caregivers who leave the workforce. Further, the opinion recommends economic transfers and social protections to prevent caregivers' impoverishment, along with expanded data collection on their actual living conditions.

She referred to a [survey](#) recently conducted by the Lithuanian Disability Forum in collaboration with academic institutions on family caregivers of relatives with disabilities. The [results](#) show that caregivers spend an average of 13 hours daily on care, with 30% leaving the workforce altogether. More than half receive no state support, and 60% report long-term stress, driven by concerns for their relatives' futures. Support services, inclusive education, day centres, flexible home care, and personal assistance were identified as essential to reduce isolation and alleviate caregiver burdens. She was glad to be able to share these findings and experiences from Lithuania, which reflect a broader need for structured support for caregivers across Europe.

Read the EESC opinion on Caregivers in all official EU languages at: [Caregivers | EESC](#)

Haydn Hammersley, Social Policy Coordinator, European Disability Forum.



Haydn explained that we find ourselves at a pivotal moment in the implementation of the European Union Strategy on the Rights of Persons with Disabilities, which is now halfway through its timeline. This ambitious strategy, launched in 2021, is a cornerstone of the EU's commitment to upholding the rights of persons with disabilities, in line with its obligations as a party to the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). As we look back at the progress made, we must also look forward to what more can be achieved between now and 2030.

One of the flagship initiatives in the first half of this strategy will soon be realised: the forthcoming EU guidance on independent living and inclusion in the community for persons with disabilities. This guidance, which has been developed with

contributions from the European Disability Forum, COFACE Families Europe and other stakeholders, promises to be a major step forward in ensuring that persons with disabilities across the EU have the support they need to live independently and fully participate in their communities. This guidance will offer crucial direction to EU Member States on how to create frameworks that enable persons with disabilities to make meaningful choices about their lives, and be active participants in society, rather than being segregated or sidelined.

A key element of this guidance will be its focus on informal carers. Informal carers—family members, friends, and neighbours who provide essential care to persons with disabilities—are often the unsung heroes of our communities. They play a vital role in ensuring that persons with disabilities can live in their own homes and stay connected to their communities. However, we know that informal carers face significant challenges, both in terms of the emotional and physical toll of their caregiving responsibilities and the financial hardships they often endure.

The new EU guidance acknowledges this and suggests a number of key actions to better support informal carers. Importantly, it highlights the need to support informal carers of children with disabilities. By providing in-home support, guidance, and respite care, we can reduce the pressure on families and prevent the placement of children with disabilities in institutions. This is crucial because, as we know, institutionalisation can lead to a range of negative outcomes for children with disabilities, from social isolation to limited opportunities for personal development.

Moreover, the guidance recognises that for adults with disabilities, if they choose to receive support from a family member, that informal carer should be financially supported for the work they do. This is not just a matter of fairness but a matter of ensuring that informal carers are not left financially destitute as a result of their caregiving duties. EDF believes this will send a strong message to national governments across the EU about the importance of supporting informal carers and making it easier for them to continue providing the care their loved ones need.

As we celebrate the successes of the first half of the EU Strategy on the Rights of Persons with Disabilities, Haydn invited participants to also consider how to build on this foundation in the coming years. One of the key areas to focus on is expanding support for informal carers. While the

forthcoming EU guidance will offer strong recommendations, the second half of the EU Strategy must go further. There is a need concrete proposals and actions to ensure that informal carers are fully supported across Europe.

First and foremost, EDF would like to see more EU funding directed towards support services for informal carers. This should include not only services that provide direct support to carers, such as respite care and counselling, but also compensation for the work they do. Informal carers often sacrifice their own careers and financial security to care for a loved one, and it is only right to recognise and compensate them for their invaluable contributions.

In addition to financial support, it is important to ensure that informal carers have access to the training they need to effectively care for their loved ones, particularly when those loved ones have complex needs. Providing access to training will not only benefit the person receiving care but will also reduce the burden on carers and give them the skills and confidence they need to continue providing high-quality care.

Another area where action is needed is in supporting children who act as informal carers. Across the EU, there are children who care for parents, grandparents, or siblings with disabilities. These young carers face unique challenges, and social services should be equipped to support them. This includes offering counselling, respite care, and other services that can help alleviate the emotional and physical burden these children face.

He emphasised the need to recognise that women are more likely to act as informal carers, and this has significant implications for gender equality. Women who provide informal care often have to reduce their working hours or leave the workforce altogether, which can impact their financial independence and future pension entitlements. The EU must take steps to support these women, not only through financial assistance but also by ensuring that they have access to pensions later in life. Caring for a loved one should not mean sacrificing one's financial security in the long term.

Finally, Haydn emphasised the importance of supporting independent living for persons with disabilities. While family care can be an important source of support, it should not be the only option. Persons with disabilities should have access to personal assistance budgets that allow them to choose professional personal assistance if they

prefer. This will give both persons with disabilities and informal carers greater flexibility and ensure that institutionalisation is not seen as the default option.

As part of the EU Strategy on the Rights of Persons with Disabilities, EDF are also calling on the EU to begin work on a new strategy on deinstitutionalisation. This strategy should include a strong focus on supporting informal carers, as they are often at the forefront of efforts to keep persons with disabilities out of institutions. By supporting carers, we can ensure that persons with disabilities are able to live independently and participate fully in their communities, as is their right under the UNCRPD.

In conclusion, the European Strategy on the Rights of Persons with Disabilities has already achieved significant progress, but there is much more that can and must be done. Informal carers are a crucial part of this equation, and it is time we give them the recognition, support, and resources they need to continue their vital work. Together, we can ensure that persons with disabilities across Europe are empowered to live full, independent lives—and that those who care for them are not left behind.

Mathilde Prilleux, Programme Assistant, European Social Fund + Community of Practice on Social inclusion. DG EMPL, European Commission



Mathilde started with an overview of the European Social Fund Plus (ESF+). This fund is part of the EU's cohesion policy framework, intended to promote balanced development across all European regions. Running from 2021 to 2027, the ESF+ has a budget of €95 billion, allocated across Member States and supplemented by national or regional budgets. While the European Commission does not decide exactly how the funds are used locally, it does provide guidance within the framework of ESF+ regulations.

The ESF+ focuses on three main areas: (1) training and skills development, which receives one-third of the investment; (2) access to employment and labour market activation, which takes another third; and (3) social inclusion, supporting marginalised communities, integrating migrants, alleviating child and family poverty, and more. This broad scope allows Member States flexibility to address their

unique needs. For instance, the ESF+ can support people with disabilities and their caregivers—whether formal or informal—when these priorities are reflected in a Member State’s agenda.

Additionally, there is an “enabling condition” within a horizontal law (called the [Common Provisions Regulation](#)) which applies not only to the ESF+ but also to the European Regional Development Fund (ERDF). This requires national and regional authorities to fulfil specific criteria to access ESF+ funds, including respecting the UN Convention on the Rights of Persons with Disabilities. One of the key stipulations is to avoid funding institutions that reinforce traditional institutional care, focusing instead on community and independent living supports.

So far, there have been three main themes in disability-related investments, totalling around €5 billion. These funds, while not yet fully implemented, will focus on: (1) supporting inclusive education, especially for children with disabilities; (2) facilitating the transition from institutional to independent living; and (3) promoting social inclusion and poverty alleviation for individuals and families.

Activities to be supported by ESF+



Regarding support for family and informal caregivers, the ESF+ offers funding for training and skill validation, especially to support reintegration into the labour market. For instance, last year’s European Year of Skills highlighted the importance of recognising everyday skills and making them count for future employment, which applies significantly to informal carers.

The Commission also facilitates knowledge-sharing among Member States through ESF+ [Communities of Practice](#). These are networks where ESF+ Managing Authorities and beneficiaries can exchange best practices and learn from one another. For example, in September 2024, they organised a visit of an ESF+ funded project in Prague, called Bona, which provides independent living opportunities for individuals with intellectual disabilities. Projects like these, highlight how to

combine ESF+ and other EU funds to create effective, integrated support systems.

Looking ahead, Mathilde mentioned that they are working on a toolkit on EU funding for independent living and caregiver training, expected to be published soon. Additionally, they will host an online workshop on 4th December to exchange practices around independent living initiatives.

One more initiative she mentioned is the [Social Services Helpdesk](#), which offers resources and training on how to access ESF+ funding, particularly in the social services and care sectors.

In early 2025, they plan to launch a new ESF+ transnational funding call focusing on social innovation, and specifically on the Disability Employment Package. While this primarily supports the employability of persons with disabilities, it may also offer value to COFACE members active in this field.

Mathilde finished with reflections on the future of European cohesion policy, and the importance of enhancing local-level relevance of ESF+. Expert groups have voiced strong support for cohesion policy’s role, especially regarding social inclusion, and a new regulatory draft is expected for the second semester of next year. Hence, early 2025 will be a crucial time for stakeholders to share feedbacks. Organisations like the European Disability Forum are actively contributing to these discussions.

Katarina Ivanković Knežević, Director for social rights and Inclusion, DG EMPL, European Commission. (video message).



Katarina was unable to join the round table in person, and thought it would be important to send her contribution, in particular to emphasise the contribution that the Commission is striving to make in the in the area of disability. This includes actions to support the families of persons with disabilities through the EU Strategy for the rights of the persons with disabilities 2021-2030, as well as through the European Care Strategy.

She reminded participants about the current transition between different Commission colleges, highlighting that the last five years 2019-2024 have probably been the most productive ones in the Commission’s history as regards delivering policies in the area of the disability.

For the first time in history, the Commission has had a Commissioner for Equality (Helen Dalli) and this has certainly been a great support in framing disability policies within the human rights based approach which is enshrined in the United Nations Convention on the Rights of the Persons with Disabilities.

The Commission also adopted the Strategy for the Rights of Persons with Disabilities and since March 2021 when the Strategy was adopted, huge efforts were made to deliver on a number of flagship initiatives. First, they set up the Disability Platform in which COFACE takes part. They proposed the [European Disability Card](#) which was rapidly approved by the co-legislators. They launched the [Accessible EU Resource Centre](#) (which also contains a section with country reports), and also presented the [Disability Employment package](#), which is in its implementation phase.

Last, but not least, they are now close to the finalisation of two remaining important flagships in the area of independent living and also in the area of social services. She believed these two were particularly relevant for the round table topic and for the audience of COFACE members and partners striving to promote the well-being, health and security of families. She highlighted that COFACE is part of the Disability platform subgroups working on the two flagships.

Katarina then proceeded to explain the initiatives taken under the European Care Strategy. This strategy was adopted by the Commission in September 2022 and serves as a comprehensive framework aiming at enhancing access to quality care services across the EU and improving the situation for both care receivers and the people caring for them professionally or informally.

This strategy also aims to tackle, inter alia, the challenge of an ageing population leading to growing demand for quality long term care services. In addition, it addresses gender equality concerns. It promotes work-life balance for informal carers, in recognition that caregiving responsibilities often fall disproportionately on women; and the strategy also calls for a better gender balance in the care sector. Among the various overarching objectives of the Care strategy, she highlighted the following:

- Improving access to high quality care services for children and long-term care for older adults and persons with disabilities.

- Supporting formal and informal carers, including family carers through better working conditions and recognition.
- Ensuring adequate investment in the care sector to address staff shortages and improve working conditions.
- Promoting gender equality by reducing the gender care gap and fostering better work-life balance policies for carers.
- Improving evidence-based approaches and progress monitoring based on sound and timely indicators.

In order to achieve these objectives, the Care Strategy includes a series of EU level commitments, some of which have been already translated into reality. For example, a large-scale partnership for skills in the long-term care sector and sectoral social dialogue for social services were launched. In collaboration with the World Health Organisation, the Commission is developing a training toolkit that will be available in Spring 2025, and this toolkit will provide informal carers with access to essential information and support.

The Council Recommendation on Long-term care, adopted in December 2022 as part of the broader European Care Strategy, underscores the importance of supporting informal carers. For instance, by recognising them as a fundamental part of the care system and ensuring they receive adequate financial support, access to respite services and to information and training. Encouraging the Member States to invest in training and upscaling opportunities for informal carers. Another important element is ensuring work-life balance measures such as flexible working arrangements and caregiver leave. Lastly, promoting psychological and emotional support for informal carers who are often at risk of burnout.

The successful implementation of this recommendation relies heavily on the leadership of Member States, but also of the active involvement of all relevant stakeholders namely social partners and civil society organisations, which are a driving force in this respect.

Civil society can help by advocating for better implementation at the national, at the regional and the local levels by engaging with the policy makers and raising awareness of the importance of support systems for carers. They can also facilitate peer-to-peer learning and capacity building initiatives to empower informal carers and connect them with key resources. Civil society can also monitor and

evaluate the implementation process. They can also provide feedback and hold governments accountable to their commitments under the European Care Strategy. All Member States have submitted their reports on the foreseen implementation measures of the Council recommendation on long-term care, and also more than half have proposed measures concerning informal carers such as France, Latvia and Portugal.

In conclusion, the Care Strategy and the Strategy for the Rights of the Persons with Disabilities have clear links and, to some extent shared objectives. They address targets groups which partially overlap. In the transition towards deinstitutionalisation, it is important that we ensure the availability of community-based care and support services for persons with disabilities and that we work towards full accessibility of mainstream services, using the full potential of assistive technologies. This would not only allow persons with disabilities to live as independently as possible and to decide for themselves in line with a person-centred and human rights based approach. This would also allow families and informal carers to feel supported and valued, to be able to participate into the labour market despite their care responsibilities and thus to avoid falling into the trap of poverty and social exclusion.

Katarina finished by wishing participants a productive and inspiring meeting, and looked forward to continued exchanges with all during upcoming events. Namely the stock-taking conference dedicated to the European Care Strategy planned on 12th November 2024, and the European Day of Persons with Disabilities event to take place on 28th and 29th November 2024.

Key discussion points

Bureaucracy was highlighted as one key barrier for family carers to access the support they need. Is there a potential role for Europe to address this? Namely through guidelines to ensure better access to information on the rights of family carers, or ESF+ funding to improve coordination of local support services. The European Child guarantee is trying to improve the coordination of different interventions, which could partially contribute to reducing bureaucratic barriers for family carers of children with care needs.

The DG REFORM technical support instrument could also be useful to reduce bureaucratic burden for beneficiaries – they launch annual calls to

Member States to support reform in different areas, including social protection systems. Finally, EU funds could be used to strengthen the capacity of local authorities, NGOs and social partners in delivery services more effectively.

The relation between deinstitutionalisation and family carers was also discussed. Namely the risks of rapid deinstitutionalisation shifting the burden on families. The ESF+ can finance activities such as training of family carers, also through streams focusing on public employment services and inclusion in the labour market after long periods of unemployment due to caring responsibilities.

However, some participants asked if there are any quality criteria to be used, to ensure that the approach is not only to professionalise family carers; rather than to empower them to make choices. Another point made was that even if ESF+ funding is available for informal/family carers, sometimes the overarching goal of the programme related to labour market inclusion (e.g. for ESF+ Belgium), which can be challenging for family carers.

Concluding remarks

Elizabeth Gosme, Director, COFACE Families Europe



Elizabeth gave her own key take-aways based on the Round Table presentations and discussions. She noted that there were many frameworks (policy, legal, funding) available to support family carers, but we need to take care not to shift towards professionalisation of family carers in the absence of professional care. She highlighted recommendations made throughout the round table, linking them to EU frameworks:

- Half of the long-term care country reports submitted to the Commission in 2024 focus on family/informal carers. ALL countries should target informal carers with strong measures, to ensure consistent implementation of the European Care Strategy.
- The 2024 EESC opinion on caregivers contains useful recommendations, including setting up a platform to monitor informal care.

- We are in a crucial phase for defining future priorities and flagships of the EU Strategy on the Rights of Persons with Disabilities. It is time to strengthen the family dimension of the strategy.
- The European Child Guarantee emphasis on children with disabilities can help remove barriers in access to education, and support inclusive education and early childhood intervention.
- The European Charter for Family Carers can be used as a reference tool to understand the needs and adequate responses for family carers, and used as a basis to include family carers as an explicit target group of the European Social Fund Plus.
- One area that needs to be improved is research and data collection on family carers, starting with a European benchmarking study to understand who are the family carers in Europe today.
- The work-life balance rights of carers were also discussed, with calls to re-open the recent 2019 directive to ensure decent carers leave and minimum standards for adequate payment of these leaves.
- The risks of poverty linked to the role of family care were highlighted by different speakers and participants. The upcoming EU Anti-Poverty Strategy promised by the von der Leyen II Commission should be a useful framework for discussion on the links between care and poverty, and for developing measures as appropriate.
- The von der Leyen II Commission is also planning a new EU Gender Equality Strategy, with care as a central point in relation to women's rights and to fight care stereotypes. It will be important to find complementarity between different strategies covering the reality of family carers.

Key resources

[Toolkit: Using the European Social Fund Plus for Staff Training in Independent Living Support \(Commission, 2024\)](#)

[European Charter for family carers \(COFACE Disability, 2024\) available in EN/FR and in Easy-to-read version](#)

[EESC Opinion on caregivers \(EESC, 2024\) available in all EU languages](#)

[European Care Strategy \(Commission, 2022\)](#)

[Recommendation on access to high quality long-term care \(Council, 2022\) available in all EU languages](#)

[Recommendation on quality early childhood education and care \(Council, 2022\) available in all EU languages](#)

[Long-term care: The family dimension \(COFACE, 2018\)](#)

[EU Strategy for the Rights of Persons with Disabilities \(2021-2030\)](#)

[Recommendation establishing a European Child Guarantee \(Council, 2021\)](#)

[EU Gender Equality Strategy](#)

[European Social Fund+](#)

[ESF+ Communities of practice](#)



Co-funded by
the European Union

Co-funded by the EaSI strand of the ESF+ programme. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Commission. Neither the European Union nor the granting authority can be held responsible for them.