



**EURO
CARERS**

European Association Working for Carers

Eurocarers' Position Paper

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Towards a positive¹ EU obligation to support informal carers?

Is the EU on the path of creating an identity for informal carers as well as a positive obligation for EU Governments to respect and protect carers' rights and meet their needs?

Introduction

Demographic ageing in Europe gives rise to a growing incidence of age-related conditions, an increasing demand for care and a serious sustainability test for our social and health-care systems. According to research, informal carers provide over 80% of all care in Europe, with women providing approximately two-thirds of care mainly as daughters (in law) and wives/partners. Estimates suggest that the economic value of unpaid informal care in the EU - as a percentage of the overall cost of formal Long-Term Care provision - ranges from 50 to 90 %. Informal carers are thus vital, both to the care of people with long-term conditions and disabilities in the community and to the economy of EU countries. Yet for decades, their needs have largely gone unmet due to the use of narrow-focused definitions of informal care or the absence of such definitions in the legislation.

Since 2006, Eurocarers have been calling on decision makers to develop comprehensive responses to the needs expressed by informal carers and to urgently recognize their invaluable role in the health care and social systems across the EU. **Today the recognition of the role of informal carers seems a reality:** the EU Care Strategy² unequivocally emphasises the invaluable contribution of informal carers and acknowledges their need for support. The introductory sentences in this new EU programming document setting an agenda to improve long-term care in the Union contain a powerful statement:

“Care concerns us all. It creates the fabric that holds our societies together and brings our generations together. Throughout our lives, we and our loved ones will either need or provide care.”

The Strategy also expresses a strong ambition to make the care sector more resilient and gender balanced, to improve the working conditions of the care workforce, to ensure a better balance between work and care responsibilities, to invest in care, etc.

The Strategy is accompanied by two Commission's proposals for Council Recommendations, one of which concerns notably the access to affordable high-quality long-term care.³

The EU Care Strategy is not the only EU programmatic document that demonstrates EU policy makers' political will to expand the EU social rulebook to cover in particular the carers rights. There are also:⁴

- 📄 European Economic and Social Committee (EESC) Opinion SOC/535- EESC-2016 of 21 September 2012 entitled “The rights of live-in care workers”;
- 📄 European Economic and Social Committee (EESC) Own-initiative opinion “The role of family members caring for people with disabilities and older persons: the explosion of the phenomenon during the pandemic”;
- 📄 Commission's Communication of 26 April 2017 entitled “An initiative to support work-life balance for working parents and carers”;⁵
- 📄 2021 Long-term care report prepared by the Social Protection Committee and the European Commission (DG EMPL) on “Trends, challenges and opportunities in an ageing society”;
- 📄 European Economic and Social Committee (EESC) Opinion SOC/687-EESC-2021 of 19 January 2022 entitled “Towards a New Care Model for the Elderly: learning from the Covid-19 pandemic”;
- 📄 European Parliament resolution of 15 November 2018 on care services in the EU for improved gender equality (2018/2077(INI));
- 📄 European Parliament resolution of 5 July 2022 towards a common European action on care (2021/2253(INI)).

And of course, there is the Work-life balance Directive obligating the EU Member States to ensure that as a minimum, each worker has the right to carers' leave of five working days per year.⁶

As the list of policy and legal acts addressing carers' rights and needs is growing, questions arise:

- 🔍 **What practical implication will they have on the daily life of carers?**
- 🔍 **Are they legally binding on the Member states governments?**
- 🔍 **Are those instruments justiciable?**

In other words, is the EU on the path of creating an identity for informal carers as well as a positive obligation for EU Governments to respect and protect carers' rights and meet their needs?

Identification of carers

Until recently, a 'carer' or 'caregiver' was a nebulous concept, defined differently by different social actors depending on their goals and agendas. This has recently changed as informal carers, who according to some studies represent more than 50 million people or 12% of the EU population⁷, have received formal identification in the EU legislation. A legal definition had already been introduced for the first time at EU level in the Work-Life Balance Directive, whereby a 'carer' is defined as 'a worker providing personal care or support to a relative, or to a person who lives in the same household as the worker, and who is in need of significant care or support for a serious medical reason, as defined by each Member State.'

The Directive recognises in its Preamble that '[i]n light of the challenges that arise from demographic change, together with the resultant pressure on public expenditure in some Member States, the need for informal care is expected to increase.'⁸ The Directive lays down carers' right to additional leave of five working days per year. Thus, the definition of a carer is forged in the realm of EU employment law and serves the purpose of this one Directive; it does not cover carers who are not employed or who have been forced to give up their work to handle caring duties or retired people. Nonetheless, the definition has a greater and more symbolic import as it formally recognises the existence of a specific group of people characterised by certain commonalities, acknowledges the presence of their needs and grants them individual rights.

The formal identification of carers at EU level is a long-awaited development that rewards decades of advocacy work. It represents a wide political consensus, based on countless

evidence that carers experience adverse social, economic, health and political consequences as a result of their caring role and that there is a salient gender disparity among informal carers.⁹

It could also be argued that the identification of carers is a logical by-product of the legally-entrenched duty to provide care (or financial support as a substitute of care) to family members in need of care that is still prevalent in many EU Member States and even in countries with no enforceable legal obligation to care, societal attitudes tend to place a duty of care on family members. It should also be mentioned that research studies have identified the existence of corresponding positive actions taken by the states to address the needs of carers in different European countries.¹⁰

The definition of a carer in the Work-Life Balance Directive was followed by a definition of 'informal care' in the Proposal for a Council Recommendation on access to affordable high-quality long-term care accompanying the EU Care Strategy. According to the proposal, 'informal care' is 'long-term care provided by someone in the social environment of the person in need of care, including a partner, child, parent or other relative, who is not hired as a long-term care professional'.

While the wording of the two definitions differs, the essential elements remain the same. Both definitions delineate and (regrettably) limit the scope of care recipients to family members, however broadly the word 'family' may be defined, thereby excluding situations where informal care may be provided by members of the community not connected by family ties.

The definitions contain as a second element the non-professional context of the caregiving activity: the Council recommendation clearly states that the carer is not hired as a long-term care professional while the non-professional nature of the care activity could be inferred from the definition of the Work-Life Balance Directive.

Other parts of the definitions include terms like 'significant care or support', 'long-term care' and 'serious medical reason', which are not clarified and it remains to be seen how they will be transposed and interpreted by Member States.

The introduction of a formal definition of an informal carer in Union Acts is encouraging as it indicates that the EU is progressively creating an identity for informal carers by defining their role and situation. This will form the necessary basis to develop policies and support services targeted at carers across the continent.

The binding force of the Union's commitment to support carers

A strict legal interpretation of the EU policy measures listed above shows that only the **Work-Life Balance Directive** is **obligatory to the EU Member States**. In accordance with the EU legislation Directives are binding on the Member States as regards the objective to be achieved but leaves it to the national authorities to decide on how the agreed Union objective is to be reached and incorporated into their domestic legal systems.

As a legal measure, **Recommendations** mostly have political and moral significance but have no binding force. However, Recommendations can have an **indirect legal effect** where the issuing institution has committed itself, thus generating legitimate expectations that must be met. This will be the case once the EU Care Strategy and, more specifically, the Commission's Proposal for a Council recommendation on access to affordable high-quality long-term care is adopted by the Council and the EU Member States pledge to fulfil its political commitments.

As for **Strategies**, they are coordination instruments used by the Commission, along with the other main EU institutions to identify political priorities and goals and **sets the political direction** of the EU.

From a wider perspective though, the EU Care Strategy and the Council Recommendation on access to affordable high-quality long-term care should be seen and analysed as part of the broader EU social rulebook established by the European Pillar of Social Rights. The European Care Strategy explicitly states that it supports the implementation of the principles enshrined in the EU Pillar of Social Rights and sets an agenda to improve the

situation for both carers and care receivers. The proposal for a Council Recommendation on access to affordable high-quality long-term care refers specially to Principle 18 on long-term care, Principle 9 on the right to work-life balance for people with care responsibilities and Principle 17 on the right of people with disabilities. Both documents express a firm commitment to identify, support and finance informal carers thus giving binding instructions to EU governments in pursuing their policies.

The EU Pillar of Social Rights, although conceived as a soft law instrument due to the limits of EU competences in the areas of employment and social affairs, is a high-profile political commitment towards a broad set of social rights and principles solemnly proclaimed in Gothenburg on 17 November 2017 by the European Commission, Parliament and Council. This commitment has been reaffirmed at the 2021 Porto Social Summit by EU leaders, social partners and civil society organisations. In March 2021, the Commission presented the European Pillar of Social Rights Action Plan. The EU governments have endorsed the EU 2030 social targets included in the Pillar Action Plan and presented their national contributions to reaching these targets. To date, a large majority of the measures set out in the plan have already either been adopted or launched by the Commission.

Thus, the Pillar comprises not only its core set of 20 social rights and principles but also a wide range of legislative and non-legislative acts that implement the Pillar in the Member States, including henceforth the EU Care Strategy and related Council recommendations. The Pillar is reinforced by a well-established framework for integrated surveillance and coordination that is the European Semester with the Social Scoreboard as a central tool to monitor progress on the employment and social situation across the EU. Further, the Commission has at its disposal the leverage mechanism of EU funding available to the Member States to implement the Pillar, notably under the European Social Fund Plus (ESF+) as well as other Cohesion policy funds, the Recovery and Resilience Facility and InvestEU.

Since the EU Pillar of Social Rights has been proclaimed, voices have been continuously raised in favour of turning the Pillar from a political document into a legally binding Union's catalogue of social rights.¹¹ While such calls may look like a long shot to some, the Pillar's legal value as a **source of interpretation of EU law is undeniable**. Besides, we should not overlook that most of the rights and principles it contains are legally binding on the EU and/or the Member States by virtue of other measures, such as the EU Charter of Fundamental Rights, the European Social Charter of the Council of Europe and various Conventions of the International Labour Organization. In practice though, it is often the maturity and preparedness of the judicial systems that determine whether protected rights may be litigated.

The associated rights of the carers – the case law

In parallel with the EU creating an identity for informal carers and committing to supporting and financing services targeted at them, rulings by the Court of Justice of the European Union (CJEU) and UN bodies seem to suggest that some of the recognised fundamental human rights could be construed as conjoint or binary rights. These are the rights of the persons who, by reason of age, medical or mental condition, are dependent on the care provided by their carers.

Thus, in 2008, the CJEU forged the notion of discrimination by association through a landmark decision concerning the *Coleman v. Attridge Law* case¹², where the court was asked to interpret the Equality Framework Directive¹³, a major part of EU labour law which aims to combat discrimination on grounds of disability, sexual orientation, religion or belief and age in the workplace. The applicant, a woman providing informal care to her disabled son, claimed that she was dismissed from her employment after seeking time off work to care for her son, a decision – she argued – rooted in “discrimination by association”. The CJEU ruled in her favour and concluded that the prohibition of direct discrimination is not limited only to people who are themselves disabled but also **applies to the carer of the child** as long as ‘...it is established that the less favourable treatment of that employee is based on the disability of his child...’

More recently even, the Committee on the Rights of Persons with Disabilities (CRPD), the UN body that monitors compliance with the Convention on the Rights of Persons with Disabilities came up with a View on an individual complaint from an Italian citizen who is an informal carer to both her husband and her adult daughter. The claimant argues that

the Italian legal system does not provide for any legal status and protection for ‘family caregivers’, in violation of several articles of the Convention. The claimant also maintains that due to this lack of legal recognition she is a victim of impoverishment. In its consideration on the merits of the case, on 20 October 2022 the Committee stated that:

- 🗣️ The failure to provide adequate support services to family carers so they can in turn support their relatives to live independently in the community, including by providing respite care services, other supportive services, financial support, social support, counselling services, and other adequate support options amounts to a violation of the author’s daughter’s and partner’s rights under article 19 (Living independently and being included in the community) of the Convention;
- 🗣️ The legal vacuum characterizing the Italian legal system leaves family caregivers vulnerable and exposed to discrimination due to association in violation of article 5 (Equality and non-discrimination) of the Convention;
- 🗣️ The Committee recalls its General comment No. 6 (2018) on equality and non-discrimination in which it stated that the obligations to prohibit all discrimination on the basis of disability includes persons with disabilities and their associates, e.g. parents of children with disabilities. Discrimination “on the basis of disability” can therefore also be made against persons who are associated with a person with a disability, known as ‘discrimination by association’;
- 🗣️ The lack of social protection, assistance with disability related expenses, adequate training, counselling, financial assistance and respite care provided by the State party authorities amounts to a violation of the author’s and her family’s rights under article 28 (Adequate standard of living and social protection), read in conjunction with article 5 of the Convention.

Consequently, the Committee requires that Italy amend its domestic legislation to stop the violation of the Convention on the Rights of Persons with Disabilities and submit to the Committee, within six months, a written response, including information on any action taken.

From this Committee’s View it could be inferred that by virtue of Article 19 of the Convention states have a positive obligation to provide informal carers with adequate support services. Further, under Article 28 of the Convention States have a positive obligation to guarantee social protection and provide assistance with disability related expenses, adequate training, counselling, financial assistance and respite care to family carers.

This line of reasoning is not new in human rights theory and is derived from the reciprocal nature of dependency¹⁴ - that without a positive obligation on states to enable carers to carry out the caregiving activities (inform, train, assist, counsel, guarantee respite and financially compensate them), the care recipients ‘will continue to remain disenfranchised’ and their carers ‘will continue to share varying degrees of the dependents disenfranchisement.’¹⁵

The current case law establishes the dual nature of the rights of disabled and prohibits discrimination by association on the basis of disability but it is not difficult to see the same reasoning applied to other protected rights as the right of the child¹⁶, the right of the elderly¹⁷ or the right to health¹⁸ since it is common sense that the right of a person in need of care depend entirely on the capacity of the carer to provide care.



Conclusion – from recognition to rights

It is evident that the EU has committed ‘...to care about care’¹⁹ and has sealed this promise with a number of high-profile political documents, some of which are binding on the EU governments. While this already could be considered a success, the momentum should not be lost and political commitments should be better articulated and entrenched in the EU legislation and if need be, enforced by the national courts.

This can be achieved: the EU could build on the example set by the Community Charter of the Fundamental Social Rights of Workers, a political declaration signed in 1989 by (then) all the EU Member States except the UK. Many rights listed in the Community Charter and the ensuing Social Charter Action Programme were implemented by enacting secondary legislation, such as on occupational health and safety, written statement, posted workers, working time, pregnant workers and younger workers.

Legislation ensuring informal carers’ right to financial support, health and social protection, respite care and other supportive services is the best move to take action in care and other relevant policies with tangible results; it is an insurance policy against political enthusiasm fading away and good intentions being threatened by political and socio-economic ebb and flows.

It is, from Eurocarers’ perspective, the only possible way towards a proper Care Deal for Europe that genuinely tackles democratic deficits while mitigating social and gender inequalities.



End notes

1. In the human rights vocabulary this is the obligation of the states to respect, protect, and fulfill fundamental social rights.
2. COM(2022)440 final.
3. Proposal for a Council Recommendation on access to affordable high-quality long-term care, 2022/0264 (NLE).
4. The list of political documents is indicative and non-exhaustive. It only serves to illustrate the opinions expressed in this position paper.
5. COM(2017)0252.
6. Directive (EU) 2019/1158 of the European Parliament and of the Council of 20 June 2019 on work-life balance for parents and carers and repealing Council Directive 2010/18/EU, OJ L 188, 12.7.2019, p. 79–93.
7. EPEMPL- Study on policies for long-term carers (2022), [http://www.europarl.europa.eu/RegData/etudes/STUD/2021/695476/IPOL_STU\(2021\)695476_EN.pdf](http://www.europarl.europa.eu/RegData/etudes/STUD/2021/695476/IPOL_STU(2021)695476_EN.pdf)
8. Recital 7.
9. See Opinion of the European Economic and Social Committee on 'Gender Equality Strategy' (COM(2020) 152 final) at OJ C 364, 28.10.2020, p. 77
10. See Luke Clements 'Does Your Carer Take Sugar? Carers and Human Rights: the Parallel Struggles of Disabled People and Carers', 19 Wash. & Lee J. CIVIL RTS. & SOC. JUST. 397 (2013), see OECD 'Help wanted? Providing and Paying for Long-Term Care' (2011), https://read.oecd-ilibrary.org/social-issues-migration-health/help-wanted_9789264097759-en#page3
11. See for example <http://global-workplace-law-and-policy.kluwerlawonline.com/2020/11/17/what-if-we-make-the-european-pillar-of-social-rights-legally-binding-overcoming-the-paradoxes-of-european-labour-law/>
12. Judgement of 17 July 2008, Coleman, C-303/06, EU:C:2008:415.
13. Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation, OJ L 303, 2.12.2000, p. 16–22.
14. See Clements, supra note 10.
15. See Clements, supra note 10.
16. Charter of the Fundamental Rights of the European Union, Art. 24.
17. Ibid, Art. 25
18. Ibid, Art. 35.
19. Vice-President for Democracy and Demography, Dubravka Šuica, see https://ec.europa.eu/commission/presscorner/detail/en/ip_22_5169



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