***UNHR’s Call for inputs for an expert workshop and a comprehensive thematic study on the human rights dimension of care and support***

**Eurocarers: the human rights dimension of informal caregiving in Europe**

# **1. Recognition of the human rights of informal carers in Europe**

## **Definition of informal carers**

Eurocarers defines an ‘informal carer’[[1]](#footnote-1) as any person who provides care - usually unpaid - to someone with a chronic illness, a disability or any Long-Term Care (LTC)[[2]](#footnote-2) need, outside a professional or formal framework. The carers’ movement advocates that everyone should be protected from any form of discrimination and disadvantage resulting from their caregiving activities (in line with Art. 7 of the UN Universal Declaration of Human Rights), and should benefit from equal opportunities to realise their full potential through social inclusion (UDHR Art. 22), education (UDHR Art. 26) and work (UDHR Art. 23). The human rights argument is at the core of this vision.

## **The role of informal carers in society and the economy**

Eurofound estimates that at least 44 million people above the age of 18 years in the EU provide informal care more than twice a week.[[3]](#footnote-3) That is 12% of the adult population: 10% of men and 14% of women. When using full-time equivalents, informal carers account for close to 80% of care providers at EU level.[[4]](#footnote-4) In monetary terms, the value of informal care is estimated between €320 and €368 bn/year which corresponds to 2.5% of the EU GDP. By contrast, the average share of GDP devoted to professional LTC services is 1,7% of the EU GDP. A shift from informal to formal care would require an increase of 109% in the share of GDP devoted to LTC.[[5]](#footnote-5)

## **Erosion of the rights of informal carers**

It is currently not possible to meet the care demand in Europe solely through professional (paid) LTC services, and informal carers play a crucial role in ensuring accessibility, affordability and quality LTC for all those in need. At the moment, however, informal carers bear the brunt of the unpaid labour they provide, without adequate support (i.e., investments, training, services, allowances) from governments and institutions. When not adequately supported, informal care can jeopardise the rights of carers, as outlined in the UN Universal Declaration of Human Rights (UDHR). In practical terms, the physical and mental well-being of many informal carers can be compromised (violation of UDHR Art. 25), their educational and employment opportunities limited (UDHR Art. 26 and 25), their social inclusion and economic stability impeded (UDHR Art. 22). This is expanded further in section 3 of this paper.

## **Recognition and legal protection of informal carers**

Informal carers’ contribution to society and the economy is still not uniformly acknowledged. The level of recognition, legal protection and support they receive in Europe varies largely from country to country. Overarching policy guidelines are provided by the EU, but decision-making competence remains with Member States.

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| ***Example: The legal framework for informal carers in Belgium***  In 2014 the Belgian government adopted a new Act for the legal recognition of ‘informal carers’ (‘*mantelzorgers’* in Flemish*, ‘aidants proches’* in French). Key elements of the definition are that informal carers provide help in a non-professional way and in cooperation with at least one care professional, and that the time spent providing informal care must amount to at least 20 hours per week.  In 2019 two royal decrees integrated the 2014 Act, and the following provisions were introduced:   * A person providing care to someone with impaired independence is to request an official recognition as ‘informal carer’ by submitting a declaration of honour to the compulsory health insurance (‘*mutuelle’*). If the request is successful, this will grant access to a number of social rights, including paid carer leave, and flexible working conditions. * For recognised informal carers, the full-time leave scheme for medical assistance is extended from 12 to 18 months. * Measures are put in place to alleviate the administrative burden faced by informal carers. * Civil servants and employees of public authorities have access to a carer’ leave.   *Source:* [*https://eurocarers.org/country-profiles/belgium/*](https://eurocarers.org/country-profiles/belgium/) |

## **Reforms to advance the rights of informal carers**

A crucial principle that the carers’ movement wants recognised is the integration of informal carers on an equal footing as other (paid) care professionals, centring principles of mutual respect and exchange of information. To promote a rights-based approach, then, care should be a free choice: everyone should have the right to choose voluntarily whether they want to be a carer, and to what extent they want to be involved in caring. Similarly, people needing care should have the right to choose who they wish their carers to be. When these decisions are dictated by circumstances, lack of resources and support, they come at the detriment of the quality of life of both caregivers and care recipients.

A comprehensive approach is needed to address all the needs and vulnerabilities associated with informal care. Carers need to be supported to take care of themselves (self-care), for example through: emotional and psychological support; physical health promotion and protection; respite care; information and training to acquire any specific skills they might need in their daily caregiving[[6]](#footnote-6). Informal carers also need protection from socio-eco vulnerability, through measures like: income support; access to social protection; flexible work arrangements and carers’ leaves; awareness raising to combat stigmatisation and loneliness. Finally, carers and care recipients need their voice heard in the political arena, to be able to contribute to the design of policies that have an impact on their lives.

# **2. Policy measures to promote the rights of informal carers in Europe**

Policy developments were accelerated by the impact of COVID-19 on the LTC sector, and by the demographic challenge posed by an ageing population across Europe. Recent ones worth noting are:

**2017 EU Pillar of Social Rights:** This initiative launched by the European Commission, although not legally binding, is a clear political reaffirmation of social rights in and for the EU. It serves as a compass to achieve better working and living conditions in the EU, and consists of 20 principles to support fair and well-functioning labour markets and welfare systems. Informal carers are directly concerned by:

* **Pillar 9 on Work-Life Balance**, stating that “*Parents and people with caring responsibilities have the right to suitable leave, flexible working arrangements and access to care services. Women and men shall have equal access to special leaves of absence in order to fulfil their caring responsibilities and be encouraged to use them in a balanced way*”.
* **Pillar 18 on Long-Term care**, stating that“*Everyone has the right to affordable long -term care services of good quality, in particular home-care and community-based services”.*

**2019 EU Work-Life Balance Directive:** With this piece of legislation, the EU introduced new rights for informal carers and families. Member States retain significant room of manoeuvre in

implementing these rights. Informal carers are directly concerned by:

* **The right to a carer’s leave**: the Directive establishes a right to a minimum of 5 days of leave

per year per worker for caring purposes. Member States get to decide whether this leave should be paid or not;

* **The right to request flexible working arrangements**: the Directive mandates the possibility for workers to adjust their working patterns, including through the use of remote working arrangements, flexible working schedules, or a reduction in working hours;
* **Protection of workers**: Member states should take the necessary measures to protect working carers against discrimination or dismissal happening on the grounds of exercising these new rights; and
* **The promotion of a dialogue aimed at fostering the reconciliation of work and private life**.

**2020 EPSCO Council Conclusions on “Tackling the Gender Pay Gap: Valuation and Distribution of Paid Work and Unpaid Care Work”:** these Council Conclusions were adopted to guide the implementation of the **2020 Gender Equality Strategy**, and highlight the need to promote an equal sharing of care responsibilities. Informal carers are directly concerned by the EU ministers of employment and social policy stressing *“how indispensable paid and unpaid care work is for economic stability as well as for the continued functioning and well-being of our societies”*and agreeing on the need to enhance the status of care work *“whether paid or unpaid”.* The Conclusions formalised the ministers’ willingness to address the gender care gap, duly identified as “*an underlying cause behind women’s lower participation in the labour market”*, including through improving the availability, accessibility, affordability and quality of Long-Term Care services.

**2020 EU Child Guarantee:** This initiative is one of the flagship measures of the **2021** **EU Strategy on the Rights of the Child**, and aims to prevent poverty and social exclusion by guaranteeing access of children in need to a set of key services, including free healthcare. The Guarantee calls for specific attention to the obstacles faced by Young Carers[[7]](#footnote-7), and implicitly recognizes them as a vulnerable group. One of the categories of children identified as requiring particular attention is 'children in precarious family situations', that is children exposed to risk factors that could lead to poverty or to social exclusion. This includes: “*(...) living with a parent with disabilities; living in a household where there are mental health problems or long-term illness; (...)”*.

**2022 EU Care Strategy and Council Recommendation on access to affordable high-quality LTC:** These constitute a framework for national-level policy reforms focusing on working conditions in the LTC sector, and identification and support of informal carers. The Strategy remains a ‘soft policy’ measure, as legal competency on this matter sits with Member States. Informal carers are directly concerned by the identification of need for: better interface between informal carers and LTC workers; training; counselling; healthcare; psychological support and respite care; adequate financial support for carers. In practice, these measures aim to achieve impact through:

* + **Exchange of plans** and dialogue among Member States;
  + Building of relevant and **comparable data and statistics** (i.e., common indicators for LTC);
  + **Funding** for LTC: Cohesions funds, Recovery and Resilience Fund, Research and innovation programmes (Horizon Europe, Erasmus+, EaSI, CERV);
  + Recommendations on **governance** and **quality** principles.

**3. Challenges to the creation of care systems that ensure the respect of human rights**

Informal carers are confronted with several obstacles that prevent the respect of their human rights. Some of the most notable challenges include:

## **Labour and economic rights**

The work of informal carers is, for the most part, unpaid. Many carers of working age, mainly women, are forced to reduce or give up paid employment in order to keep up with their caring responsibilities. When they stay in employment, they often struggle to realise their full potential at work. This reality keeps them from accessing social protection and constitutes a violation of their human rights (UDHR Art. 22). It also contributes to locking informal carers, especially women, in poverty and social exclusion. Carers often face financial precarity due to income loss, cuts in social provision, and direct costs associated with care (e.g. medication, heating, special diet, medical devices, home adaptations). According to Eurofound, 45% of non-working carers are in the lowest income quartile (compared to 25% of non-carers), while 54% of non-working carers have difficulty making ends meet (compared to 38% for non-carers).[[8]](#footnote-8)

## **Work-Life Balance**

A large share of informal carers experience time poverty and lack of privacy, as they attempt to juggle unpaid care work, paid employment, other family commitments, and self-care. This is especially true for ‘sandwich carers’ who have to care for both children and elders at the same time. This is in contrast with UDHR Art. 12 that establishes the right to privacy, UDHR Art. 24 on the right to rest and leisure, and UDHR Art.27 on the right to participation in the life of the community.

In nearly all EU countries, more than 50% of carers under 65 combine unpaid care with paid employment.[[9]](#footnote-9) Many workers, however, still do not have access to flexible work arrangements, and have to give up on work altogether - with dire consequences for their income and pension. Re-entering the labour market after some time spent as a full-time carer can also prove difficult, as care work is still perceived as an unproductive ‘career break’. This set of circumstances is a violation of UDHR Art. 23, that established the right to work for all people.

## **The right to health and wellbeing**

While caring for a loved one can bring a lot of joy and personal satisfaction, the task is often taken up without any preliminary preparation and professional support, in the context of a crisis, by a relative who may already have other family or employment obligations. In this scenario, the physical and emotional strain of care can have heavy repercussions on the health and wellbeing of caregivers. Research shows that, for these reasons, informal carers tend to experience poorer physical and mental health outcomes than non-carers, and are at greater risk of becoming in need of LTC themselves. There is also evidence that the burden of caring is most acute among marginalised groups, for example those who are socially isolated, of lower socioeconomic status, or with a migratory background. Being in a vulnerable economic situation makes it disproportionately harder to overcome the difficulties and sustain the pressure deriving from informal care. This is in contrast with UDHR Art. 25, that establishes every person’s right to health and wellbeing.

## **Gender-based inequalities**

The majority of informal carers in Europe (59%) are women.[[10]](#footnote-10) The gender imbalance is greatest at ages 50–64 years, when caregiving prevalence is highest. It is also worth noting that more than 80% of workers in the formal long-term care sector are women, and women are more prone to needing Long-Term Care.[[11]](#footnote-11) There are also considerable differences in the way men and women provide care: while male caregivers mostly provide care for spouses and carry out household management tasks, female caregivers deliver more personal care, and frequent and high-intensity care. Overall, the gender dimension is very prominent across the whole spectrum of care work and care service utilisation. For this reason, the financial impact of care on carers’ socio-economic status and social isolation is a major gender equality issue. Resistance to the recognition of the economic value of informal care is still rooted in cultural norms and perceptions that care is a ‘feminine’ task that is ‘naturally’ provided within the home, not ‘work’ that consumes resources. Redressing this imbalance is mandated by Art. 2 of UDHR, that establishes the principle of non-discrimination on the grounds of sex and gender (among other factors).

## **Access to education and training**

Informal carers gain a wealth of skills and experience while performing their caregiving tasks. These competences are generally overlooked, even though they could be an important instrument to improve the caregiving experience. Recognising and developing informal carers’ skills, highlighting transferability to the labour market, is a sound investment for society as a whole. It works in favour of welfare systems, as it helps secure carers’ crucial contribution in LTC provision. At the same time, valuing and strengthening informal carers’ skills may prove a promising tool to counter their social isolation and poverty, alleviate their burden, improve their social participation and re-enter the labour market. Providing informal carers with tailored education and training is in line with UDHR Art. 26 that mandates the protection of everyone’s right to education. It equips them to better preserve their physical and mental wellbeing, improves the quality of care, and therefore the wellbeing of care recipients.

## **Young Carers and child rights**

Young Carers are children and young people under the age of 18 who provide care for a parent or a relative in the community, usually within their own home. In many cases this comes at great personal expense – they are deprived of their childhood, many miss out on educational opportunities, few have established friendships or other support networks. Young Carers are at greater risk of not completing their formal education and are less able to access higher-education, increasing their chances of social exclusion later in life.

Very often caregiving is seen as an ‘extension of family or personal relations’ rather than as work. Children and young people themselves might not perceive their role as caregivers, and do not have the tools and knowledge to demand their rights are respected. The carers’ movement therefore urges policy makers to introduce specific positive actions to ensure that Young Carers’ right to education (UDHR Art. 26) and employment (UDHR Art. 23), to the highest attainable standard of physical and mental health (UDHR Art. 25.1), to participation (UDHR Art. 27), to an adequate standard of living and family life (UDHR Art. 25.2) be respected.

## **Access to quality care and ‘care poverty’**

Care is a basic human need, a necessary component of wellbeing and human dignity, as stated in UDHR Art. 25.1. The term ‘Care poverty’ describes those situations where people in need of care do not receive sufficient assistance from either informal or formal sources. This concept was developed by Prof. Teppo Kröger to emphasise how this inadequate coverage is not just an individual issue, but a phenomenon linked to systemic inequalities in society and the economy.

For example, there are distinctive health inequalities arising from intersecting forms of structural discrimination – i.e., poverty, disability, low socio-economic status, marginalised genders, racialised groups – all resulting in specific LTC needs. Similarly, while care resources depend on individual factors like family relations, access to care is also determined by societal structures and social policies. These include public funding for the provision of professional LTC services, the ability to retain LTC workforce (with adequate working conditions), and informal caregivers having the support and skills to provide quality care in informal settings. Using a ‘care poverty’ lens urges us to take all these aspects into consideration for the protection of the human rights of informal carers, and care recipients alike.

The current case law establishes the dual nature[[12]](#footnote-12) of the rights of disabled people, and prohibits discrimination by association (of the carer) on the basis of disability. The same reasoning could be applied to the rights of children (Charter of the Fundamental Rights of the European Union, Art. 24), the rights of the elderly (CFREU Art. 25) and the right to health (CFREU Art.35), since the rights of a person in need of care depend largely on the capacity of the carer to provide care and have their own rights respected.

1. Also known as a ‘family carer’ or an ‘unpaid carer’ in some contexts. [↑](#footnote-ref-1)
2. Long-Term Care includes a broad range of personal, social, and medical services and support that ensure people with, or at risk of, a significant loss of intrinsic capacity (due to mental or physical illness and disability) can maintain a level of functional ability consistent with their basic rights and human dignity. (WHO). [↑](#footnote-ref-2)
3. Eurofound (2020), Long-term care workforce: Employment and working conditions. Publications Office of the European Union, Luxembourg. [↑](#footnote-ref-3)
4. Hoffmann, F., & Rodrigues, R. (2010). Informal carers: who takes care of them?. European Centre for Social Welfare Policy and Research, Vienna [↑](#footnote-ref-4)
5. European Commission (2021). The 2021 Ageing Report: Economic and Budgetary Projections for the EU Member States (2019-2070). Publications Office of the European Union, Luxembourg. [↑](#footnote-ref-5)
6. For example: Disease-specific knowledge; Skills required to maintain the health status of the patient; Skills dealing with the management of symptoms; Skills related to support of daily life activities (i.e., bathing and dressing, feeding); Management of emergency situations; Ability to manage stress and protect one’s own health. [↑](#footnote-ref-6)
7. Young Carers are children and young people under the age of 18 who provide care for a parent or relative in the community, usually within their own home. [↑](#footnote-ref-7)
8. European Commission (2018). Informal care in Europe: Exploring Formalisation, Availability and Quality. Publications Office of the European Union, Luxembourg. [↑](#footnote-ref-8)
9. Eurofound (2015). Working and caring: Reconciliation measures in times of demographic change. Publications Office of the European Union, Luxembourg. [↑](#footnote-ref-9)
10. Eurostat, Health variables of EU-SILC, 2018. [↑](#footnote-ref-10)
11. Eurostat, Health variables of EU-SILC, 2018. [↑](#footnote-ref-11)
12. Recent rulings by the Court of Justice of the European Union (CJEU) and UN bodies have highlighted that certain fundamental human rights could be seen as interrelated or dual rights. These encompass the rights of individuals who, due to age, medical, or mental condition, rely on the care provided by their carers. [↑](#footnote-ref-12)