

Informal care, poverty and social exclusion

Supporting informal carers must be a key component of policies aimed at strengthening social cohesion, for the benefit of the whole society.

It is hard to think of a human right that is not potentially affected in some way by the unequal distribution and difficulty of unpaid care work. **Unpaid care negatively impacts on carers' ability to enjoy economic, social and cultural rights as well as the right to participation.** Excessive burdens of unpaid care work may also threaten the enjoyment of other human rights by carers, such as freedoms of speech, association and assembly. [...]

UN Special Rapporteur on extreme poverty and human rights: Report of 68th Session (2013)



**EURO
CARERS**

European Association **Working for Carers**

INTRODUCTION

Persisting poverty and social exclusion in the EU: the impact of informal care.

The European social model is often considered to be the best in the world. Still, the risk of poverty and social exclusion, which pre-existed the economic crisis in 2008 and was exacerbated by it, is currently affecting one out of four people in the EU, i.e. 118 million Europeans in 2016. In 2010, in an attempt to deliver more sustainable and inclusive growth, EU heads of government adopted the Europe 2020 Strategy which aimed, among its five headline targets, **to lift at least 20 million people out of the risk of poverty or social exclusion by 2020. As we draft this briefing, it is not only clear that this objective will not be achieved but that the situation has actually gotten worse across Europe.** This casts doubt on the efficiency of our social model and it is therefore crucial to identify the mechanisms by which millions of people slip through the social protection safety net, fall and remain in poverty and social exclusion, in order to adapt our social protection model accordingly and foster social cohesion.

Providing care to a relative who is dependent because of age, disability or chronic disease, is well identified as one of the life circumstances that contribute to poverty and social exclusion by informal carers¹, and those who work to support them. A wide range of issues impacts on carers' level of income. Carers can experience significant financial hardship as a consequence of their caring role. They are often faced with additional costs, as a result of the illness or disability of the person they care for, and their caring responsibilities can act as a barrier to entering paid employment. Many carers do not claim the full range of benefits to which they may be entitled. The majority of informal carers being women, this is a **major gender equality issue. However, the negative impact of informal care on carers' socio-economic status is generally overlooked.**

Although informal carers provide a huge contribution to our societies [which has been estimated to range from 40% to 90% of the overall costs of long-term care (Triantafyllou, J. et al., 2011)], **informal carers often have difficulties to make ends meet.**

While evidence shows that informal carers are disproportionately affected by poverty and social exclusion, policies aimed at supporting informal carers remain insufficient in the EU. While informal carers provide 80% of all care

Who are the carers?

As identified in the last European Quality of Life Survey 2016, "for many societies in Europe, there is a growing gap between the need for long-term care and the availability of formal care provision", and people may fulfil care responsibilities across the life cycle.

12% of the survey's respondents said that they were involved in caring at least weekly for someone aged 75 or over (10% of men and 14% of women).

Involvement in care is also frequent in people of working age: 73% of men caring for someone who is disabled or infirm are in employment, compared to 58% of women.

Women still provide most of the care, whether for their own children, grandchildren or for relatives, friends and neighbours with a disability or infirmity. When it comes to providing care on a daily basis, twice as many women as men do so (Eurofund, 2017.)

is in Europe, they often bear the cost attached to their contribution, **which makes them particularly vulnerable to poverty and social exclusion**. Their role is seldom acknowledged and its impact on their socio-economic status rarely considered.

The state plays an important role in supporting low-income carers – indirectly through care benefits targeted at patients and directly through carer benefits as well as local authority support packages. Improving these services should be the primary concern for reducing carer poverty. Alongside this, there is a role for employment support that helps carers reskill and return to work after a period of caring and to support carers with the capacity to work to access opportunities. Since 2006, Eurocarers has been calling on decision makers to invest in qualitative long-term care services including home-based services, as well as to develop comprehensive responses to the specific needs expressed by informal carers, including financial support, social protection and equal opportunities, access to supporting services (counselling, training, respite care), and work-life balance measures. **Everyone should have the possibility to choose between caring informally for his/her loved one -with adequate support- or have the person cared for by adequate long-term care services.**

Today, while the situation of informal carers has been further weakened by cuts in benefits and services as part of austerity policies, and against the backdrop of a quickly evolving labour market, the need for policies protecting carers against the risk of poverty and social exclusion is all the more pressing.

The present document aims to give an overview of the mechanisms at stake and to list the policy solutions that must be explored in order to prevent demographic ageing from generating even more fragmented societies.

1. Eurocarers defines a carer as a person who provides - usually - unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework.

Informal caring is a determinant of poverty and social exclusion

Evidence shows the economic vulnerability of informal carers.

A study by the OECD concludes that high-intensity caregiving is associated with a higher risk of poverty (OECD, 2011).

Non-working carers are disproportionately affected by poverty. In 2016, 45% of non-working carers are in the lowest income quartile (compared to 25% of non-carers), 54% of non-working carers have difficulty making ends meet (compared to 38% of non-carers) (Eurofund, 2017).

In 2011, 44 % of citizens aged 55 or more identified financial remuneration to carers as one of the most useful things that governments could do to help informal caregivers, as part of a Eurobarometer survey (TNS Opinion & Social, 2012). Indeed, providing care, especially intensive care, to a relative, **often entails a substantial economic sacrifice**: informal carers may be forced to cut down their working time or leave paid employment, which in return reduces their pensions rights, causing poverty when they reach pension age. In the case of young people, caring responsibilities can have a negative impact on their education and social life, hindering their inclusion in employment and future life prospects.

In addition to devoting their time and energy, informal carers tend to contribute to the costs associated with the chronic condition of the person for whom they care. They indeed **often chip in the out-of-pocket expenditure** attached to the care required by their 'caree'. Recent policies aimed at controlling public health spending have resulted in an increase of these costs for the patients and their relatives. In addition to the unavoidable costs of medicines and treatments prescribed, infor-

mal carers very often contribute to the **costs of additional treatments and materials** which are not - or not totally - covered by health protection systems, but which are key to the well-being of the person for whom they care (i.e. incontinence aid, physiotherapy....). Moreover, **housing adaptation**, which allow care to be delivered at home rather than in an institution meet the preference of most of the dependent people, and contribute to avoid unnecessary hospitalisations, can entail a significant cost for those who provide informal care

A study from the Rowntree Foundation showed that, among 5.3 million carers in the UK, 1.2 million are in poverty. The poverty rate among working-age carers increases with the number of hours they care for, particularly after 20 hours per week (Rowntree Foundation, 2016).

A survey in France showed that informal carers in this country spend an average of 2 049 € annually to support their loved one (LA CARAC Opinionway, 2017).

A study conducted in Italy showed the negative impact of a chronic disease on the income of patients. Financial difficulties are associated with relevant cancer patients' outcomes like quality of life and survival. Researchers define as 'financial toxicity' the negative impact of the disease on the financial situation of the patient in the long term (Perrone F., 2016).

Informal carers are more exposed to social exclusion and health related difficulties.

Informal carers, whether they care for an older person in need of care, a person with a disability or a chronic disease have in common to be disproportionately exposed to the risk of social exclusion, understood in a wide sense as the **difficulty to participate fully in the society and being able to benefit from equal opportunities**. Lack of time to participate in social activities and isolation are the common lot of carers. Stigmatisation attached to the specific condition of their loved one may also impact the carer.

17% of carers who are not working and 14% of working carers FELT LONELY more than half of the time in previous two weeks, against 10 % for people who are not caring. Being a regular unpaid carer for an elderly person is one among twelve IMPORTANT DRIVERS OF PERCEIVED SOCIAL EXCLUSION (Eurofund, 2017).

Taking care of a relative in need of care, while bringing some personal satisfaction, can have a **negative impact on own's physical and mental health**, especially as informal care is more and more provided by older people, some of them having a health condition.

15% of non-working carers between 18 and 64 have a bad perception of their own health and well-being (compared to 4% of working carers and 6% of non-carers) (Eurofund, 2013).

Many of the informal carers who provided intensive caring were themselves older people or had a limiting disability or health condition. Among informal carers who themselves had a limiting disability or health condition, 28% reported undertaking caring activities for 20 hours a week or more (Eurofund, 2017).

Informal care is often associated with a **significant level of stress**. Indeed, carers tend to provide more and more intense care for longer periods, and take part in the delivery of complex treatments, without adequate training. Besides, a growing number of them struggle to conciliate work and family duties.

The prevalence of mental health problems among informal carers is 20% higher than among non-carers, and particularly high for people who provide very intensive care (more than 20 hours per week). Depressive disorders, anxiety, anger and hostility are frequently associated with heavier caring duties. (OECD, 2011)

41% of non-working carers, and 27 % of working carers consider their health as fair or bad compared to 22% of non-carers (Eurofund, 2017).

Being in a vulnerable economic situation makes it even more difficult to overcome the difficulties attached to informal care. On the contrary, employed carers with higher education, those with fewer difficulties making ends meet have higher levels of satisfaction with life (Hlebec & de Oliveira, 2016).

Being a carer is major obstacle to social inclusion through employment through the life cycle

One of the core mechanisms whereby informal care generates more poverty and social exclusion is the obstacle it constitutes with regard to employment. This negative impact is observed **at various stages in the life cycle**.

- Providing care to a relative on a regular basis during youth can be a **significant impediment to completing education and training**, as well as to enjoying a normal social life. This has in return a detrimental impact of the opportunities the carer would be in a position to seize on the labour market.
- Informal caring, even with a low intensity, constitutes an important organisational constraint, which makes it **impossible for an informal carer to apply for jobs requiring availability and flexibility according to the needs of the employer**. Though, such requirements tend to be more and more a prerequisite in news forms of employment.
- Working carers struggle to conciliate their responsibilities at work with their caring duties, which often lead them to **reduce their working time or even to quit their job**, to the detriment of their income security.
- On the work place, being an informal carer is **an obstacle to professional development, career progression and promotion**. Indeed, informal care are less likely to participate in training, and to obtain more responsibilities (Ligue des droits de l'homme, 2016).
- At school, university or on the workplace, informal carers are subjected to **isolation and stigmatisation**, reflecting a society where the value of informal caring is not recognised (Employers for carers, UK, 2015).
- All the limitations in relation to training and employment have a very negative impact on the level of income informal carers will benefit from at the age of **retirement**.

- Given their overrepresentation among informal carers, women are the most impacted by the obstacles listed above. Informal caring is a key determinant of the **gender pay gap** as well as the **gender pension gap**.

The economic case

Poverty and social exclusion of both informal carers and their carees represent a major economic issue. Indeed, from a macro-economic point of view, missing out on the contribution of informal carers who would prefer to be active on the labour market but remain outside of it, paying no taxes or social contributions, as a result of their caregiving activities means a **huge opportunity cost** for our societies and a waste of human capital. The fact that informal carers are more vulnerable than other groups to poverty and social exclusion contributes to a less equal society, which in turn tends to perform less efficiently.

From a micro-economic point of view, losing trained and experienced workers, who may decide to quit their job or reduce their working time because they are not able to balance work and care anymore, means a **huge cost for an employer**. To such an extent that many companies are now developing innovative support measures and HR policies in order to retain those among their employees who are also informal carers (Carers UK, 2016).

The economic value of the contribution brought by informal carers should also be better evaluated. Without their benevolent contribution, our long-term social and health protection system would simply not be sustainable. It would also have an impact on the poverty level in our societies: indeed, because they provide care freely and often share costs associated with dependency, **carers contribute to buffer the risk of poverty in old age**. The capacity to rely on informal care is considered as an element of the social capital of a person (Myck, 2017).

This is why, in order to ensure that our social, health and long-term care systems can still count with the vital contribution of informal carers in the future, more investment should be devoted to supporting people who are willing to care, through tailor-made services and income support.

What should be done?

Change public policies reinforcing the negative impact of informal caring

The lack of acknowledgment of carers' contribution and the specific difficulties they face has led to the implementation of policies with a detrimental and aggravating impact on their situation.

- Against the backdrop of public deficit containment, **activation policies** have recently been developed in a series of countries, often accompanied by more severe conditionality criteria for unemployment benefits. The unemployed are invited to take up jobs under increasingly low acceptability criteria (flexible hours, distance from home...) with little regard to people's complex personal situations (European Anti-Poverty Network, 2016). Where strict conditionality is implemented, the specific situation of informal carers who can only take up a job that is compatible with their caregiving responsibilities, may not be considered. Informal carers may then lose their unemployment benefits, and be pushed outside of the labour market. As a result, although spending time and energy providing care for their loved one, informal carers are often labelled as "inactive", and so benefit from reduced support and counselling with regards to employment.
- In the context of **austerity policies** following the recent financial and budgetary crisis, informal carers have been excessively hit by budget cuts affecting the provision of social, health and long-term care services.

Yet, access to affordable and quality services is key to support informal carers in providing quality care.

- The **work-life balance of the carer** – typically a woman of working age – is a problematic issue which is rarely recognised as such in the policy making agenda. Only a few countries – namely those with universal and comprehensive long-term care systems – make the necessary arrangements to enable carers to remain in employment and preserve their work-life balance (Eurofound, 2015), (European Commission, 2016).
- The **lack of accessible long-term care services of relevant quality in some countries or regions** is likely to reinforce the social exclusion of carers. People from a low socio-economic background often have no choice but to assume caregiving responsibilities toward a relative, because of the lack of affordable alternatives. Hence, they end up trapped in a vicious circle, as their caring duties draw them away from new opportunities. In some countries, the trend to move away from residential care

has not always been coupled with the provision of adequate community-based services (Spasova, S. et al., 2018). This implies a growing level of responsibilities for families, friends and neighbours.

- In some countries, an **income support** is provided to informal carers, either directly or to the dependent person who can use it to compensate the services provided by a carer. Financial support provisions vary greatly in terms of amount and eligibility across countries, and may be assorted of burdensome administrative procedures for dependency assessment. In most cases, they clearly fail to prevent informal carers from being exposed to poverty. Support services, likely to break the isolation affecting informal carers are also lacking.

“We need to make sure that our legislation and our policies are still fit for purpose for the reality of today and tomorrow”.

**Marianne Thyssen, European Commissioner for Employment, Social Affairs, Skills and Labour
Mobility 2014-2019**

Build policies on a better understanding of how the distribution of caring responsibilities impacts on key challenges: social cohesion, gender equality, and quality of long-term care.

Although the negative impact of carer duties on one's socio-economic status has been regularly underscored both by researchers and informal carers themselves, the amount and distribution of the caregiving responsibilities across income groups and gender are rarely among the indicators selected to inform and assess public policies against their capacity to strengthen social cohesion. **More detailed comparative data should be collected and analysed across the EU**, and more qualitative research should be undertaken so as to better understand the mechanisms at play at national or regional level.

The impact that poverty and social exclusion can have on the **quality of the care provided** should also be better analysed. Indeed, less affluent informal carers tend to **use less services**, and the difficulties they face are likely to impact on the quality of life of the person they care for (European Commission, 2014).

In the absence of adequate financial compensation, people in vulnerable situation who would be willing to give precedence to their caregiving responsibilities over their participation in the labour market are discouraged to do so due to the negative impact such a decision would have on their financial situation. This leads to negative consequences for the quality of the care received by the dependent person, who might see his or her **needs unmet and/or be institutionalised against his/her preferences**.

More precise comparative data should be gathered, and relevant indicators should be set up to inform public policies. Comprehensive strategies should be put in place at all levels likely to buffer the negative impact of caring duties throughout the lifecycle, **allowing those who want to provide care to a relative to do so with the recognition and support they need and deserve and without being economically punished for their choice**.

Progress can be driven at the level of the European Union (EU)

The design of employment and social policies, including the organisation of welfare systems, remains a competence of the Member States. In these matters though, the EU role is to complement and coordinate EU governments' initiatives, in accordance with Article 3 of the Treaty on the European Union. Consequently, a series of policies and instruments managed by EU Institutions are relevant to the economic situation of informal carers across Europe, and can be used as leverages to foster change at national or regional level. These include notably:

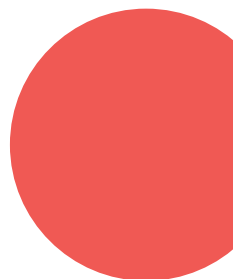
- The extensive range of **comparative data and studies** regularly published by the European Union as well as the EU research supported through Horizon 2020 and other funding programmes. While the existing EU data already provides enlightening elements of comparisons and analysis, these instruments should include a stronger focus on the impact of informal care on the socio-economic status of carers.
- Stressing the need to foster employment, in particular for women, the EU has been promoting the **reconciliation between work and private life**. Though initiatives have been primarily focusing on parents, the situation of informal carers is also considered. In April 2017, the European Commission encouraged member states to recognise 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” and to allow parents as well as carers to a compensated leave of 5 days per year and the right to request flexible working arrangements (European Commission, 2017).

- The **EU active inclusion strategy**, adopted in 2008, aims at including people excluded from the labour through three interrelated policies: adequate income support, access to quality services, and inclusive labour markets. This strategy should guide policies targeting informal carers in a situation of poverty and social exclusion (European Commission, 2016).
- The EU has been stressing the **need to invest in fully-fleshed and accessible health and long-term care services** as well as credit care duties in pension systems as a necessity to address the challenges of our ageing societies and ensure the sustainability of our social protection systems. These recommendations are followed-up annually with the member states in the **European Semester process**.
- **The development of innovative ICT-based solutions in the area of health and long-term care** is supported at the EU level in the framework of European Innovation Partnership on Active and Healthy Ageing. Such innovative solutions, provided they remain accessible to all, can be very instrumental in facilitating the combination of work and care. ICT-based tools can also be used to reach out to informal carers, offer them online information and training, and help them break their isolation and find a space where they are able to connect and exchange with peers.
- The development of relevant training pathways specifically aimed at informal carers can deliver positive results in terms of empowerment of informal

carers, and help them valorise their skills on the labour market. Indeed, informal carers develop medical, communication as well as transversal skills through their caring experience, which are not formally recognised, though likely to be valued on the labour market. In this domain, innovative projects are supported within the **European Erasmus + programme** which aims to modernise education, training and youth work across Europe.

- **European Funding instruments** (European Social Investment Funds, Cohesion Fund...) can be used to boost investment in the health and long-term care sector, including in human capital. European programmes can support transnational innovative projects to the benefit of informal carers.



CONCLUSION

Informal care is a complex issue which is having an increasing multidimensional impact on our ageing societies. Policy choices made today to recognise and value informal care adequately, or not, will have **tremendous impact not only on the future of our health and long-term care systems, but also on the level of cohesion and poverty in our societies.** Along with ensuring access to all to qualitative long-term care services (European Commission, 2017), policies at the EU and national levels should ensure that those willing to provide care to their relatives are not pushed to the margins of society and away from opportunities on the labour market.

Eurocarers will continuously advocate at the EU level to ensure that the impact of informal caring on poverty and social exclusion is considered in relevant policies, and will continue to support carers' organisations active at national and European levels in their endeavours to translate EU incentives into concrete improvements in the life of informal carers.

References

- Carers UK. (2016). *Who cares wins: The social and business benefits of supporting working carers*.
- Employers for carers, UK. (2015). *Caring and isolation in the workplace*.
- ETUC. (2014). *Who cares? Experiences and possibilities to reconcile work and care responsibilities for dependent family members*.
- Eurofound. (2015). *Working and caring: Reconciliation measures in times of demographic change*.
- Eurofound. (2017). *European Quality of Life Survey 2016: Quality of life, quality of public services, and quality of society*. Luxembourg: Publications Office of the European Union.
- Eurofund. (2013). *Third European Quality of Life Survey – Quality of life in Europe: Social inequalities*. Luxembourg: Publications Office.
- European Anti-Poverty Network. (2016). *EAPN Position on Active Labour Market*.
- European Commission. (2014). *Analysing equity in the use of long-term care in Europe*.
- European Commission. (2008). *Commission Recommendation on the active inclusion of people excluded from the labour market*.
- European Commission. (2016). *Work-life balance measures for persons of working age with dependent relatives in Europe, a study of national policies*.
- European Commission. (2017). *Commission recommendation on the European Pillar of Social Rights C(2017) 2600 final*.
- European Commission. (2017). *Proposal for a Directive of the European Parliament and of the Council on work-life balance for parents and carers*.
- Hlebec, V.; de Oliveira, D.C. (2016). *Predictors of satisfaction with life in family carers: evidence from the third European Quality of Life Survey*.
- LA CARAC Opinionway. (2017). *Baromètre « Argent et entraide familiale : où en sont les Français ? CARAC*.
- Ligue des droits de l'homme. (2016). *Speaking out against the gender pay gap, taking into account the case of an informal caregiver*. Paris.
- Myck, M. O.-W.-K.-F. (2017). *Economic aspects of old age exclusion: a scoping report*. ROSEnet Economic Working Group.
- OECD. (2011). *Help Wanted? Providing and Paying for Long-Term Care*. OECD.
- Perrone F., J. C. (2016). *The association of financial difficulties with clinical outcomes in cancer patients: secondary analysis of 16 academic prospective clinical trials conducted in Italy*.
- Rowntree Foundation. (2016). *Informal carers, poverty and work in the UK*.
- Schmidt, A. (2016). *Juggling family and work – Leaves from work to care informally for frail or sick family members, an international perspective*.
- Spasova, S. et al. (2018). *Challenges in long-term care in Europe. A study of national policies European Social Policy Network (ESPN)*. Brussels: European Commission.
- TNS Opinion & Social. (2012). *Special Barometer 378 Active Ageing*. European Commission.
- Triantafyllou, Judy et al. (2011). *Informal care in the long term care system – A European overview*. Interlinks.
- World Health Organisation. (2011). *European report on preventing elder maltreatment*.