

Eurocarers' Position Paper

July 2020

Eurocarers' analysis
of the **EUROPEAN SEMESTER:**
Informal carers,
left aside again?

Introduction

Informal carers play a central role in the provision of long-term care in Europe. According to some estimates, 80% of all care is indeed provided by families, friends and neighbours. At a time when Europe's overall increase in life expectancy and ageing demographic generate a growing incidence of age-related conditions and a growing demand for care in all age groups, carers' contribution to the sustainability of our care system and to the well-being of people in need of care is simply vital. Yet, despite the heavy price they often pay in their own health and economic status, they remain in the blind spot of policy analyses. The outburst of the COVID-19 pandemic has dramatically exacerbated the challenges they face and many had to manage complex care situations in a context of restricted health and social care services, acute isolation and constant worry for the health of their relative as well as their own. Still, they only received very limited attention or targeted support during the crisis.

Beyond informal carers' situation, the pandemic has shed light on the shortcomings of our health, social and LTC systems, of which informal care is a key component. Our systems are at a crossroads; transformative positive change can only be achieved if member states commit to implement long-awaited reforms, building on a dialogue with all stakeholders, including informal carers. In order to ensure the sustainability of our care systems, achieve gender equality and respect for the human rights of vulnerable people, our approach to care needs a rethinking. The pressing need to adjust the way we value and organise care – and informal care in particular - in Europe has served as a red thread in our analysis of the Semester.

To begin with, we looked at the visibility of informal carers in the process. Since addressing the needs and preference of carers depends on the interaction between a broad set of policies in the social, health and employment fields, our analysis¹ focused on the main policy areas which have an impact on care and caring – i.e. health, long-term care, gender equality and social inclusion. So, is the EU Semester guiding member states towards more care(r)-friendly societies, building on the lessons learned from the COVID-19 crisis? As it stands, the approach does not seem to take stock of the stakes at play as regards care and caring. We therefore make some suggestions as to how this process could further inspire and lead member states on the way to resilient health, social and LTC systems, taking into account the perspective of carers.

Where are informal carers?

Decreasing attention

In the last few years, Eurocarers was pleased to see informal carers, and more generally, care and caring issues, benefiting from increased attention via the Semester (Eurocarers, 2019). We cannot help but note that this trend is refuted this year. While informal care was explicitly mentioned in 17 countries in 2019, it is only mentioned for 12 countries this year. In 2020, informal care to a dependent relative is clearly identified in 8 countries² against 12 in 2019, while caring responsibilities towards a child is mentioned in 4

¹ Our analysis builds on a systematic review of the content of the Country Reports and Country Specific Recommendations, as well as on contributions from Eurocarers' members from 7 countries (BE, DK, EE, FI, IT, PT, SP).

² AU, CZ, FI, LV, MT, PL, SK, PT.

countries³. Issues related to care and caring have been clearly identified at EU level for several years, notably through the EQLS Survey, and the toll and impact of caring responsibilities during the COVID-19 have visibly intensified: the Semester should provide a systematic review of the situation and action taken in each country in these areas.

Heterogenous terminology

We also note that, while the wording 'informal carer' has now been adopted by EU institutions to designate people *"such as relatives, spouses, friends and others" "providing care typically on an unpaid basis and in the home of the care recipient"*, the terminology is not homogeneously applied in the Semester. For example, the Country report concerning the Czech Republic refers to "informal family carers" while for Spain, the phrase "informal carers" seems to designate care workers employed informally (thus not a next of kin or unpaid carer)⁴. The lack of a unified and unambiguous terminology contributes to obfuscate the understanding of what informal care is, at the expense of a vulnerable group in urgent need of recognition. Moreover, this generates barriers to the much-needed dialogue regarding the role of informal carers in our society. We call for a clearer and more consistent designation of informal carers across the Semester.

The lack of any reference to carers is all the more striking since they provide the bulk of care and support to COVID patients, be it during the acute phase or in the long run. (Aidant Proches Wallonie, Belgium)

Uneven attention paid to policies aimed at supporting informal carers

On a positive note, we observe that, for some countries, the emergence -or lack- of policies aimed at supporting informal carers is captured in the assessment. This is the case for example for Portugal (*"An older population will also require more long-term care, so the recently-approved legal status for informal carers is welcome"*), Poland (*"A comprehensive strategic approach based on the analysis of needs of persons requiring long-term care and their carers as well as the definition of financing sources would be a first step in addressing current and future demographic challenges"*), Slovakia (the Country report underlines the negative impact of the *"practically non-existence of respite care services for informal carers of persons with severe disabilities"*).

However, the number of countries for which the Semester refers to policies targeted at informal carers is far too limited, given that the need for such policies is an issue shared by most countries across Europe, who face similar demographics trends. Recent reports published by the European Commission emphasised the key importance of informal carers as well as the fact that only a limited number of countries have well-developed services tailored to informal carers (Zigante, 2018; Spasova, 2018). While the EU encouragement of positive initiatives aimed at carers is very welcome, a more proactive approach is required, such as inviting member states to resolutely explore care and caring issues. This would contribute to secure and scale-up the progress that is being achieved in some countries and regions.

³ EE, EL, UK, RO.

⁴ In the sentence: *"As of April 2019, exemption from social security contributions boosted the affiliation of informal carers, 89% of whom are women, to the system (from 6,700 in March 2019 to 55,100 in December)."*

Such strategic approaches should also foster the recognition and support of organisations representing informal carers, as they often deliver direct services to informal carers, understand their needs, play an essential role as carers' advocates and possess the know-how to constructively contribute to better and more balanced policies in the area of long-term care. These civil society organisations are not at all mentioned. Many of Eurocarers' members point out the risk that the looming economic crisis entail for their sustainability as organisations (for example in Finland). The recognition and support of carers' organisations, who can provide essential knowledge and help co-design sustainable long-term care and caring policies, should be encouraged by the EU institutions.

Health

The long-term challenges facing health care systems, which had been identified in Country reports back in February (in particular their financial sustainability), have now been aggravated as a result of the COVID-19 pandemic. On a positive note, the EU is currently devolving large-scale financial means⁵ in order to strengthen the resilience of healthcare systems. While we welcome EU commitments for health, we urge that these funds be used to accelerate the transition towards integrated care designed around users' needs, in addition to the essential response required to meet the urgent equipment needs.

Support and recognition of informal carers are needed to build the resilience of health systems

Health and long-term care costs are considered a threat to the sustainability of public finances in most member states in the context of ageing societies. At the same time, underspending in health is highlighted as problematic in a series of countries⁶. In the light of this public health crisis, all Country Specific Recommendations have prioritised the resilience of health care systems, and thus mentioned various weaknesses in member states. In this context, where the costs of various solutions will be evaluated against their expected adequacy and efficiency, support for carers should be considered as a meaningful and cost-effective investment. Firstly, because taking deliberate pre-emptive actions that protect and support the wellbeing of this vulnerable group also allows to prevent economic and societal costs in the long run. Secondly because carers contribute greatly to the efficiency and adherence to treatments and to the wellbeing of patients, provided that they have access to adequate support. Therefore, investing in personalised support to carers – including via innovative measures co-developed with carers themselves - should be promoted by the EU not as cost but as an investment.

Besides dedicated support, improving the situation of informal carers also implies addressing the current shortfalls that are clearly identified in the Semester documents, including staff shortages, equal access, quality and efficiency of care services, as well as eHealth development. While doing so, specific attention should be paid to informal carers, the impact of their caregiving and their needs should be assessed, and the carers' identification role of resilient health systems should be better defined.

⁵ EU4Health, and health-in-all-policies approach developed through the ESF+, ERDF, Horizon Europe, Digital Europe and Connecting Europe Facility.

⁶ Notably in Baltics countries such as Latvia and Lithuania, and Eastern countries such as Romania, Poland, Slovakia.

Measures seeking to address staff shortages must truly recognise the value of care

The lack of healthcare professionals is a widespread issue across the EU. It is highlighted in 14 countries⁷, and foreseen as a future problem in two additional countries⁸. Addressing this shortage will certainly need a change of perspective on care in our societies, at a time when the value of care is being undermined and the contribution and commitment provided by carers, be they professional or informal, are taken for granted. A better recognition of the 'real' value of care should address various dimensions, including remunerations and working conditions. Alongside measures concerning formal care staff, the conditions under which informal carers carry out their activities, in particular those performing intense care tasks (e.g. care transitions and hospital discharge to home care, home-based care to complex, multi-morbid and chronic diseases, palliative care at home, etc.) need urgent attention. Health promotion and preventative measures (e.g. counselling, peer support, access to social services etc.) as well as adequate financial compensation should be put in place to support carers.

Additionally, life-long learning opportunities should be offered to informal carers who wish to (re)enter the labour market and need a supportive pathway towards professionalisation via a formal recognition of the expertise and skills gained through their caring role. A number of informal carers indeed develop essential knowledge and competences throughout their caring experiences which are worth identifying and nurturing. This would foster a better inclusion of informal carers, who often face isolation, negative mental health outcomes and exclusion in our societies.

A missed opportunity to refer to informal carers among other health workers. (Care Respite, Spain)

Equal access, quality, efficiency: the need for structural reforms for integrated care systems

Unequal access to health services is an issue for 15 countries⁹, either due to regional disparities, or other obstacles such as excessive out-of-pocket payments. The need to develop access to primary care is identified in 7 countries¹⁰. Ensuring equal access to health is particularly important for carers, who are already facing various obstacles in using health services for themselves, notably their lack of availability which, combined with the prioritisation of the needs of their 'caree' over their own needs, may jeopardise their health status. Effective prevention measures should proactively target informal carers, as a group at risk.

A number of Country Specific Reports usefully underline issues regarding the quality of health services (10 countries¹¹) and their efficiency (also 10 countries¹²). On a positive note, the need to undertake reforms towards a more integrated provision of care appears as a red thread across a number of Country Reports. The focus is put on a more seamless continuum between prevention and care (Germany, Romania), on

⁷ BE, BG, HR, CY, FI, DE, HU, IT, LV, MT, NL, SW, UK, RO

⁸ LT, LU

⁹ BE, BG, EL, FI, HR, HU, IE, IT, LV, LT, PL, PT, RO, SP, UK.

¹⁰ IE, LV, NL, PL, UK, SK, RO

¹¹ CY, CZ, FI, DE, EL, HU, LV, LT, SK, SP.

¹² CY, CZ, FR, DE, EL, HU, LV, IT, RO, SK.

integrated care (Slovakia, Netherlands), on patient-centred care (Italy), on improved coordination between social and health services (Poland, Slovakia, Spain), including better cooperation between different levels of governments. Given their positioning at the interface between health, social, and long-term care services, informal carers are all the more impacted by the lack of coordination between services. Some carers even report that caregiving is not the source of their stress and exhaustion, the constant battle for services is.

We believe that the EU should promote a more ambitious definition of integrated people-centred care, ensuring a continuum of services from prevention to long-term care, centred around people's needs, and as recommended by the WHO. Within this approach, informal carers - who often play a decisive role in the treatment and (secondary) prevention of a patient, should be identified as partners in care, should they wish to be involved in caring. Consequently, the necessary support to carers through information, training, respite care and home-base services should be fully integrated in the delivery of qualitative and efficient health services. Such reforms require determined action and investment, they should not be set aside due to the expected decrease in public resources or projected economic recession. On the contrary, they should be supported by EU financial instruments.

The pandemic calls for member states to find fiscal measures to alleviate the pressure on the economy and on social and health care sectors, with a strong impact on public spending. Prioritisation will be important and informal carers may end up drawing the shorter straw. (Ivar Paimre, Estonia)

eHealth

Importantly, the development of eHealth is strongly promoted as a means to build the resilience of health systems. It appears in the Country Specific Recommendations addressed to six countries¹³. The deployment of eHealth solutions should also take into account the needs of informal carers who face difficulties in accessing face-to-face services. In this respect, ICT-based solutions have proven useful to facilitate carers' access to information, training, counselling, mutual support and care coordination between carers and health and social care professionals. Nevertheless, ICT-based solutions for care should not be the only kind of support offered, but be used as a supplement to support face-to-face services. Besides, large-scale action aimed at tackling the digital divide is still required. While this aspect is identified for 10 countries¹⁴, action is needed in more countries, especially towards informal carers as an exposed group.

Portugal still has a large digital gap: it would be important to promote an EU digital transition strategy the carers (Cuidadores Portugal)

¹³ CR, CZ, DE, FR, NL, PL.

¹⁴ CY, CZ, FR, EL, IE, IT, LV, RO, SK, SP.

Long-term care

A series of acute challenges are duly identified...

In a dramatic way, the outburst of the pandemic has revealed the weaknesses of our long-term care (LTC) systems. Not only have people living in residential care not been properly protected against the virus, but services providing LTC at home have been interrupted, leaving informal carers with the overwhelming responsibilities of providing care, in addition to other work and family responsibilities, in a context of fear and isolation.

The shortcomings of our LTC systems had clearly been identified before the crisis, through Country reports. Notably, the need to reinforce accessibility of LTC services was highlighted for 19 countries¹⁵, while the quality or efficiency was considered at stake in 11 countries¹⁶. The EU Semester highlights the lack of skilled LTC workforce or the fact that the number of skilled professionals in 11 countries¹⁷ is lower than the EU average.

Organisational issues are also underlined, such as the fragmented governance in Slovakia, the need to enhance integration between the social and the health sector in Czech Republic, Estonia and Latvia. The necessary transition to community-based care is still an issue in five countries¹⁸. Regional disparities are particular acute in some countries, such as Spain. For 9 countries, the documents call for a strategic framework at national level¹⁹, and LTC is mentioned as a priority for investment in 5 countries.²⁰ At the same time, the expected increase in the needs for LTC is considered as a threat to the sustainability of public finances in at least 16 countries²¹.

...but are still not properly prioritised.

While the weaknesses of the current system are detailed in Country Reports, it is disappointing to see that they are not really prioritised in the Country Specific Recommendations. Indeed, LTC is mentioned in the recitals in only 11 countries²², and in only one recommendation. While Portugal is invited to “*ensure equal access to quality health and long-term care*”, EU services limit their recommendations to health only for all other countries. This is a missed opportunity to urge member states to undertake comprehensive reforms concerning their LTC challenges.

The difficulty to issue recommendations in the area of LTC may be explained by the lack of relevant indicators allowing to compare member states’ respective achievements. Indeed, even though access to adequate LTC contributes to the achievement of the Sustainable Development Goal 3 (Ensure healthy lives and promote well-being for all at all ages), there is no indicators on LTC in the annex D, assessing countries’ short-term progress towards the SDGs. More data is now available, drawing particularly from recent OECD’

¹⁵ BG, CY, CZ, DE, EE, EL, FI, HU, HR, IE, IT, LV, MT, PL, PT, RO, SK, SP, UK.

¹⁶ BG, CZ, DE, EE, EL, HU, IE, NL, PL, PT, SK.

¹⁷ CZ, DK, DE, DK, HR, HU, MT, PL, PT, RO, SK.

¹⁸ EL, HU, IE, LV, SK.

¹⁹ AU, BE, CY, EE, FI, HU, PL, RO, SP.

²⁰ BG, CY, IE, PT, SK.

²¹ AU, BE, CZ, EE, FI, EL, HU, IE, LU, MT, NL, PL, UK, PT, SP, SW.

²² BE, BG, CY, CZ, EE, EL, IE, IT, LT, PL, SK.

research. Yet, without commonly agreed indicators on the availability, affordability and quality of LTC, the Semester will remain ill-equipped to support progress in this essential policy domain.

Support to informal carers is a central element in resilient long-term care systems

Informal carers are an essential component of our long-term care systems. Facilitating dialogue and collaboration between formal and informal carers is essential to deliver integrated long-term care services that respond to people's needs and situation. Considering their role, it is also important to empower carers and strengthen their resilience. This implies better support and compensation of informal carers (OECD Health Policy, 2020). Informal care should be considered for what they are – i.e. one of the options that people in need of care and their relatives can opt for – rather than as a default solution or an arrangement belonging entirely to the private sphere. As such, they should be associated with relevant support services for both care recipients and carers themselves. Adequate support to informal care is already being developed in a series of countries, and explored as a way forward in policy research (Leichsenring, 2019) (ICF, 2019). The extent to which countries consider supporting informal carers as part of the reinforcement of the LTC system should be more systematically reviewed in the Semester, while paying due consideration to the different national starting points.

Social Aspects

Gender Equality

The unequal sharing of unpaid care responsibilities has been identified as a factor of gender inequalities across Europe (EIGE, 2019), including the Gender Pay Gap (Council of the European Union, 2020). The Semester documents underline a correlation between the lack of care facilities - be it for children or people in need of LTC- and the situation of women on the labour market in 13 countries²³. It would have been relevant to explore further the extent to which the lack of available LTC services perpetuates gender inequalities in a range of other countries²⁴, for example in those countries for which the indicator 'Gender Pay Gap in inactive population due to caring responsibilities' (SDG 5) is above the EU average (27,1 %), such as Italy (32%) Spain (36,9 %) or Hungary (28,9 %).

Interestingly, informal carers are considered as a group at risk of being excluded from the labour market in Finland, hence specific incentives are geared to them. In Poland, the risk of exclusion faced by carers of people with disability is given attention. The reality is that informal carers from all EU countries are struggling to remain at work or re-enter the labour market after a career break devoted to caring for a relative. Member states should be incentivised to develop specific policies targeting this vulnerable group. The Work Life Balance directive, adopted one year ago, recognised the specific needs of informal carers in terms of work-care balance. The recent crisis, which intensified working carers' difficulties, has also made the need to support them even more critical.

²³ AU, CZ, EE, EL, FI, HR, IT, LV, MT, PL, RO, SK, UK

²⁴ RO, SK.

The process accurately underlines how measures to promote equal opportunities and work-life balance policies, as well as the supply of affordable early childhood education and care and long-term care services, remain weak and poorly integrated. (ANS, Italy)

While the lack of progress is underscored for some countries (such as Italy), it is disappointing to see little reference made to Work-Life Balance for the vast majority of member states. The progress achieved in the implementation of the Directive and in moving towards a carer-friendly employment market, is not reviewed systematically and, when Work-Life Balance is mentioned, it is often with regards to parents mainly. Worryingly, we see that a focus is put on the need to develop “flexibility” of employment in order to restrain the impact of the crisis. While flexible work is one key component of the reconciliation between work and care, it is not the only one. Furthermore, in the current context, the risk is to see this used to preserve the interest of employers at the expense of carers’ health and well-being.

*We are still waiting to see how the Danish government will implement the work-life directive - there has been much discussion here about earmarked paternity leave, but nobody seems to have yet noticed the other half of the directive on the carer leave.
(Carers Denmark)*

*One of the major missing points is the work-family balance arrangements, which are among the most significant problems noted in Belgium in the context of the health crisis.
(Aidants Proches Wallonie)*

Work-life balance is not taken into consideration. (Cuidadores Portugal)

Social inclusion: informal carers are at risk

At a time when the pandemic is leading to a major economic crisis, it is crucial for informal carers, who face a higher risk of poverty and social exclusion, to be protected. While many are in a vulnerable situation on the labour market, they often contribute to out-of-pocket payments for care services delivered to their relative, and may also chip in to maintain the care recipient’s standards of living. This is particularly the case in countries where poverty among elderly people remains an issue (e.g. Latvia and Lithuania). Attention should be paid to informal carers as a group at risk of poverty and social exclusion, leading to emergency measures addressing their needs, made possible by the increased flexibility in the use of EU funds. This is for example envisaged in Estonia, where a working group has been put in place at governmental level to assess the situation of informal carers and to design appropriate measures, The Eurocarers Estonian member reports that, beyond emergency action, informal carers will only be protected in the long run when they have access to adequate social protection. Specifically, they should be entitled to pension credits and financial compensation for caring breaks, and affordable and qualitative LTC services should be made available to all.

Conclusion

Eurocarers considers the EU Semester as a potentially powerful instrument to stimulate a much-needed improvement in policies related to care and caring across Europe, which is why our members are getting increasingly interested in the process. Although, even if the process accurately points out a series of issues of concern to informal carers, it only scratches the surface of the informal care experience. Besides, in their apparent attempt to focus on the short-term exit from the health and economic crisis, this year's CSRs tend to neglect the much-needed reforms in the health, LTC and gender equality fields. While the CSRs from previous years are meant to remain valid, we believe that the Semester should provide consistent review and guidance in these key areas over the years.

Against the backdrop of demographic changes that impact all EU countries, the challenges faced in relation to care and caring will only be addressed through ambitious integrated health, social and long-term care policies, including the recognition of and the support to informal carers, as well as the provision of adequate, affordable and qualitative LTC services (including community based care and home care). In this area, the EU can play a key role in facilitating progress through funding, research, exchange of good practices and policy guidance, building on common definitions, comparable data and agreed indicators, as part of a holistic and durable strategic approach, to be implemented both at EU and national level.

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Eurocarers is the European network representing informal carers and their organisations, irrespective of the particular age or health need of the person they are caring for. Our network currently brings together 71 carers' organisations as well as relevant research & development organisations from 26 countries. Eurocarers was established by and for its members and works from the 'bottom up' to ensure that the voices of carers are heard at local, regional, national and EU levels and that the impact of policy on their daily lives is recognised by both policymakers and politicians.