

Promoting Sustainable and Resilient Long-Term Care

Recommendations to policymakers to mitigate the gendered impacts of Covid-19 based on RESISTIRÉ findings

The pandemic had a huge impact on people in need of long-term care (LTC) because of the reduced possibility (or even impossibility) of obtaining the amount of good-quality care they needed during the crisis. At the same time, the pandemic reminded society of the value of our health and care systems, and the essential role performed by people who work as carers, whether they are formally employed in the sector or work informally as unpaid carers. Despite this, not enough attention was paid during the pandemic to the issue of how to make LTC systems more resilient, while the negative effects of the crisis on both carers and the people being cared for are likely to persist (if not worsen) in the coming years if no action is taken.



Recommendations

Improve the quality of formal care and ensure the resilience of the care sector during crises such as the COVID-19 pandemic



The European Care Strategy presented by the European Commission in September 2022 is aimed at ensuring the accessibility, affordability, and quality of care services across EU countries and at improving the situation of both the recipients of care and (formal and informal) carers. While the strategy includes a Council Recommendation on access to affordable high-quality LTC, more work should be done to highlight the importance of a care system that is resilient to external shocks. One point already raised in the Recommendation is to make the profession of care worker more attractive and to do so by improving working conditions

and making the profession more gender-balanced. Initiatives at the local level can be promoted, for example, by **involving students** (especially those in the fields of medicine, healthcare, care) in care-related activities and building a **better working environment**, so that formal carers are not burdened with too many responsibilities. **More recognition should be given to the profession of care worker** on different levels (economic, cultural, social).

On the supply side, an idea that emerged from one of the RESISTIRÉ pilot projects was to **create a 'quality' label for private care services**. The label would provide a guarantee that private care services bearing the label uphold the rights of domestic care workers and care recipients.



Consolidate a rights-based approach to LTC

A rights-based approach to LTC provides a powerful framework for ensuring equality of access to good-quality LTC services. In order to effectively implement Principle 18 of the European Pillar of Social Rights, the EU is supporting Member States' efforts towards guaranteeing equal access through the provision of LTC services that are affordable and of good quality (see the Council Recommendation on access to affordable, high-quality LTC). However, a **challenge in consolidating a rights-based approach** is how varied the nature and scope of LTC services offered across the EU currently are. **Monitoring Member States' implementation of Council Recommendations, and increasing support efforts when and where needed, will be crucial for overcoming this challenge.**

Value the work of informal care

Policies at the EU level supporting informal care should place a stronger focus on promoting formal recognition of the value of informal care work (mainly carried out by women) with the aim of effectively **supporting the people who perform this work**. While many initiatives have already been implemented (such as the <u>Work-Life Balance Directive</u>, which introduced carers' leave for workers providing personal care or support to a relative), they may not be sufficient when it comes to the many people who provide LTC informally. While care leave policies help to ease the burden on working people who are also performing informal care activities, formal support should be extended to all informal carers, irrespective of whether or not they are economically active.

Identify the most vulnerable groups of care workers and care recipients

Some care workers can be identified as more vulnerable than others because their **working** conditions are more difficult (e.g. live-in carers) or because they are the subject of intersecting inequality grounds (e.g. migrant care workers, single mothers), or because of the overlapping of these conditions. The same is true for care recipients, who may find themselves in a position of intersecting inequalities. A **gender+ perspective** should be applied when developing policies to improve the conditions of care workers and care recipients.



Building community care and community resilience and mainstreaming these approaches



COMMUNITY CARE & RESILIENCE

Community care refers to any form of care and support provided in the local community that enables people to overcome or manage any condition, disability, or life difficulties they may face. Despite available evidence that community care and resilience create more value for the persons in need of care and for those who provide (informal/formal) care, as well as for society as a whole, such approaches have not yet been mainstreamed into practice. Where face-to-face services had to be interrupted during the pandemic to stop the spread of the virus, voluntary organisations proved

to be very important, because they were able to **provide quick and effective solutions** to meet the needs of more vulnerable groups. Community care can also help to **break care silos**, thereby improving the efficiency of the services offered and increasing **community awareness** and solidarity.

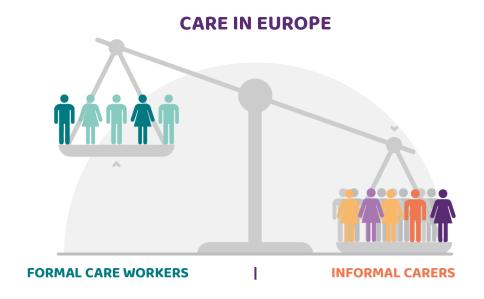
Make sure that CSOs receive adequate funding for their initiatives at the community level

More resources should be allocated to initiatives at the local level that act on both prevention and care, as these initiatives played a fundamental role during the pandemic.



Problem Statement

In the context of population ageing, demand for high-quality LTC is expected to increase in the coming years.¹ Principle 18 of the European Pillar of Social Rights states that '[e]veryone has the right to affordable long-term care services of good quality, in particular home care and community-based services'.² However, COVID-19 shone a spotlight on the systemic weaknesses of the LTC system, which were manifested through the high mortality rates in residential care facilities, difficulties in guaranteeing the continuity of quality care (both at home and in residential care settings), and the negative impact on the wellbeing of both older people and carers.³ In this context, we should not forget that most of the LTC in Europe is provided by informal or unpaid caregivers, who are thus the main suppliers of health and social care to older or disabled people.⁴ The increased burden of care responsibilities that were experienced mainly by female (in)formal caregivers caused them a great amount of stress and exhaustion.



¹ European Commission, Directorate-General for Employment, Social Affairs and Inclusion (2021). *Long-term care report: trends, challenges and opportunities in an ageing society. Volume I.* Publications Office of the European Union. https://data.europa.eu/doi/10.2767/677726

² European Commission, Secretariat-General (2018). *European pillar of social rights*. Publications Office of the European Union. https://data.europa.eu/doi/10.2792/95934

³ European Commission (2021).

⁴ D'Amen, B., Socci, M., & Santini, S. (2021). Intergenerational caring: a systematic literature review on young and young adult caregivers of older people. *BMC Geriatrics*, *21*(105). https://doi.org/10.1186/s12877-020-01976-z



Insights from RESISTIRÉ

Older adults receiving home care experienced a decline in the quantity and quality of care

Concerns about COVID-19 infection, and the restrictions that were imposed to avoid this risk, led to a decrease in the quantity and quality of the home care, which older adults (especially those over the age of 80) rely on for daily support. Based on RESISTIRÉ's analysis of <u>SHARE data</u>, there were more women than men dependent on home care both before and during the pandemic. From the beginning of the pandemic, both women and men reported **difficulties obtaining the amount of home care** they needed, in most cases because the **carer was unable to come to their home**. An overall improvement was observed in summer 2021, most likely because there were fewer restrictions in place at that time than there were during the first wave of the survey (summer 2020).



QUALITY OF CARE IN TIMES OF COVID

The policy and societal initiatives mapped in RESISTIRÉ showed that some countries designed specific measures to mitigate the difficulties experienced by people with disabilities and older adults, who were often confined to their homes without assistance when day centres were closed. In **Poland**, for example, people with disabilities were given financial compensation in the form of the co-financing of costs related to the provision of care at home in the event of loss of access to care from a rehabilitation facility and in the form of the increased monthly co-financing of their salaries and compensation for those who are employed in Vocational Activity Establishments'. In **Denmark**, funding was 'allocated to combat loneliness among people with disabilities'. In **Italy**, disability permits were strengthened, together with special funds to increase assistance and services and implement projects for people with very serious disabilities.



Residents of care facilities were deprived of their autonomy and their rights and dignity were regularly undermined



CARE FACILITIES DEPRIVED RESIDENTS OF AUTONOMY

Because of their higher risk of dying from COVID-19 and the restrictions imposed to reduce the possibility of infection, older adults living in care homes were negatively affected in their everyday lives and suffered serious effects from these restrictions. Their suffering was primarily caused by the practical difficulties associated with being isolated in their rooms to prevent contagion and by the ban on visits from family and external friends.⁵

Many of the experts interviewed by RESISTIRÉ highlighted these difficulties: clients suffering because of the no-visit policy or restricted visits; some clients being confused and unable to recognise staff or family members because of medical protections such as masks or over-the-body covers. As one worker in a residential care home said, the **'human touch' was missing**: 'It was hard that we couldn't help. Even us, we had little time to stay in the room, it was just to give them their tray' (family assistant working in Belgium). Care home residents described their experience as having to live for many days like 'a prisoner sentenced to solitary confinement' (72-year-old woman from Croatia). The restrictions on visits to nursing homes and the resulting isolation created a feeling of loneliness among those who were living in care facilities, but also among the relatives who were not allowed to visit their loved ones:

'I could not touch or hug my parents and I lost my freedom. too. Calling my family and friends [...] helped me with my loneliness, but I still missed the physical aspect'

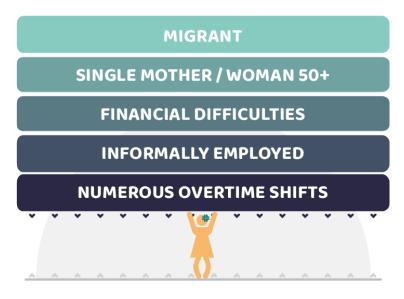
59-year-old woman in the Netherlands

⁵ Brooke, J., & Jackson, D. (2020). Older people and COVID-19: Isolation, risk and ageism. *Journal of Clinical Nursing*, *29*, 2044-2046. https://doi.org/10.1111/jocn.15274

Gordon, A. L., Goodman, C., Achterberg, W., Barker, R. O., Burns, E., Hanratty, B., Martin, F. C., Meyer, J., O'Neill, D., Schols, J., & Spilsbury, K. (2020). Commentary: COVID in care homes—challenges and dilemmas in healthcare delivery. *Age and Ageing*, 49, 701-705. https://doi.org/10.1093/ageing/afaa113



Care workers were at risk of burnout as a result of numerous overtime shifts, stress, and fatigue



IDENTIFYING THE MOST VULNERABLE

The pandemic and the policy responses to it had a significant impact on the sphere of care work, with care workers being more likely to be exposed to the virus, suffering various physical conditions as a result of their heavy workload, and often experiencing anxiety, stress, and depression, without receiving any state support. As a consequence, they became a **new vulnerable group**. The conditions were particularly difficult for care workers with multiple or intersecting inequalities, such as **sex and ethnicity**. As highlighted by experts in the project's interviews, migrant women care workers, who were already in a precarious situation before the pandemic (for example because they were single mothers, women 50+, or women in a difficult financial situation), had to deal with the **fear of losing their job and income**, as well as **worries about their family health and safety back home**. As reported by one person working as caregiver far away from her home country:

'I stayed with my client for a long time, which came with a massive physical and mental burden. [...] During that time, I was constantly under pressure. Even when my mother passed away, I did not take the time to mourn. [...] Living with my client felt like "a prison to me". My client felt the same way, he often missed his family.'

50-year-old woman living in Austria



The burden of informal care fell primarily on women, with detrimental consequences for their work-life balance and mental and physical health

People who needed long-term care and were unable to receive home care had to rely on the support of relatives for this task. Most informal long-term care for older adults in Europe continues to be provided by **middle-aged women**; however, **younger adults** are taking up an increasing share of care responsibilities as a result of labour market and family changes.⁶ Ample evidence has shown that **caregiving** has a significant impact on the mental health of the carers,⁷ their wellbeing,⁸ and their ability to balance work and care duties in everyday life.⁹ Emerging evidence from the pandemic confirms that there was an increase in **mental health inequalities** among **young adult carers** of ill parents or family members compared to non-carers,¹⁰ most likely related to factors such as increased social isolation, school closures, and concerns about the health of the care recipients and their family's economic situation.¹¹

Increased care responsibilities - **especially among women** - during the pandemic as a result of school closures and the loss of formal and informal support were reported both in the Rapid Assessment Surveys (RAS) mapped by RESISTIRÉ throughout the three cycles and in the narratives of respondents recorded during the research, such as the experience of a 68-year-old woman in Poland:

'Three days a week I care for my mother who lives far away. I combine professional work with caring for my mother and my daughter. Caring for my mother is very challenging, physically and mentally tiring, and time consuming. It is hard to work afterwards. My mother [...] has a serious disability and requires 24/7 care. [...] I have two other female carers who support me in care when I am away. Our caring plans changed due to the pandemic. We already had a situation where one of the carers became infected with the coronavirus and [...] I constantly had to take her place and care for my mother.'

https://doi.org/10.3390/ijerph19063391

⁶ D'Amen et al. (2021).

⁷ Hoyt, M. A., Mazza, M. C., Ahmad, Z., Darabos, K., Applebaum, A. J. (2021). Sleep quality in young adult informal caregivers: Understanding psychological and biological processes. *Int. J. Behav. Med., 28*, 6-13. https://doi.org/10.1007/s12529-019-09842-y

⁸ Hamilton, M. G., & Adamson, E. 2013. Bounded agency in young carers' lifecourse-stage domains and transitions. *Journal of Youth Studies, 16*, 101-117. https://doi.org/10.1080/13676261.2012.710743

⁹ ME-WE Consortium (2019). Enabling young carers to pursue their goals in life and reach their full potential: Converting research findings into policy actions. https://carers.org/resources/all-resources/107-enabling-young-carers-to-pursue-their-goals-in-life-and-reach-their-full-potential-converting-research-findings-into-policy-actions ¹⁰ Landi, G., Pakenham, K. I., Grandi, S., & Tossani, E. (2022). Young adult carers during the pandemic: The effects of parental illness and other ill family members on COVID-19-related and general mental health outcomes. *International Journal of Environmental Research and Public Health*, 19, 3391.

¹¹ King, T. L. (2021). Young carers in the COVID-19 pandemic: risks for mental health. *The Lancet Regional Health - Western Pacific, 16.* https://doi.org/10.1016/j.lanwpc.2021.100307



The importance of community for care and the role of technology

Neighbourhoods and local communities can provide a great sense of mutual support among people, and the importance of living in a caring and supportive environment was a recurring theme in the narratives collected by RESISTIRÉ. Community-level initiatives played a fundamental role for people living alone who needed help with basic daily activities such as buying groceries, as reported by a woman living alone:

'The neighbourhood was really good. The neighbours were very friendly towards me. After my husband died, they often, despite the fear of contagion, came knocking on my door to ask how I was. [...] With another lady, we have another habit that started during COVID. On Tuesdays, we go to a distant supermarket for discount day. We go together in her car.'

80-year-old woman in Italy

Technology seems to have played a fundamental role in maintaining contact among neighbours, as demonstrated by the experiences of many people interviewed who mentioned that they used WhatsApp groups to stay in touch with other people and to make sure that those in need could be helped:

'We have a WhatsApp group with the neighbours, and during the lockdown we went to the window clapping, but we also cooked for each other and left the food on the doorstep as a gift. We already had a great relationship, but it grew even stronger. We are always ready to help each other. These bonds that were established in such a difficult time are of great importance.'

66-year-old woman in Spain

However, social media and technology were not always effective at reaching the people most in need, as reported in one narrative:

'Many people offered their help [in an app for neighbours], and some found help. However, many who would have needed help probably were not able to find it. I think it is very important to find other ways to connect people with others who live near them. If everyone had a few phone numbers of neighbours they know they can call for help and support, this would create a lot of resilience during a crisis. I understand that people are hesitant to connect with their neighbours because they don't want to lose their anonymity in the neighbourhood.'

51-year-old woman in Finland



Better Stories

In RESISTIRÉ we use 'Better Stories', a concept borrowed from Dina Georgis¹², to refer to promising practices that identify how a given societal situation can be ameliorated to improve existing practices.

Outdoor concerts organised at care homes for older adults



In the Netherlands, a small local organisation arranged more than 250 outdoor concerts at care homes for older adults between March and September 2020. The events were co-organised by cultural and art institutions, care institutions, and the residents themselves. After the lockdown brought a sudden halt to activities, the organisation came up with the idea of giving concerts outside, so that residents could still enjoy activities through the window. What began as a local initiative became a national one, as the organisation issued a call on social media

to anyone interested in participating in the initiative and were able to reach many artists and other care facilities.

Improving working conditions for domestic workers: 'Allied Employers'



The idea for this pilot action stemmed from the recognition that the working conditions of the most marginalised and vulnerable care workers working in private households were largely neglected during the pandemic. The project was developed by the SOS Racismo Gipuzkoa organisation based in the Basque Country and was aimed at mobilising employers of domestic workers, raising their awareness of domestic workers' rights and needs, highlighting the importance of acting as allies, strengthening the voices of migrant women domestic workers, and informing other employers and the public of the project's

results. The project created a safe space for dialogue between domestic workers and employers, in which a list of shared proposals for the improvement of the sector was developed (see Recommendations). These proposals were presented to municipal and provincial institutions, and an awareness-raising campaign was created to present the project's results to the stakeholders involved in the process and to the public. Find out more here.

¹² Georgis, D. (2013). The better story: Queer affects from the Middle East. State University of New York Press.



Connecting neighbours with each other: 'Nappi Naapuri' service



Nappi Naapuri is a social web service focused on local cooperation, where everyone can send messages on a neighbourhood map and answer to other people's messages. The platform is designed to promote neighbourly help and create a positive community of neighbours, with the aim of increasing social capital and employing proximity as a common resource. During the pandemic, a special Corona Help category was quickly launched, and many people joined the platform to offer help (such as shopping) to those neighbours in vulnerable positions. Find out more here.



> About RESISTIRÉ

This factsheet is based on data collected in RESISTIRÉ's third research cycle, which ran from December 2022 to February 2023. In this research, 30 national researchers worked with the consortium to map policies, societal responses, and qualitative and quantitative indicators relating to the pandemic in EU-27 countries (except Malta), along with Iceland, the UK, Serbia, and Turkey. This research activity was accompanied by workshops and interviews with gender equality experts whose input informed the main findings from expert consultations.

RESISTIRÉ is an EU-funded Horizon 2020 project, the aim of which is to 1) understand the impact of COVID-19 policy responses on behavioural, social, and economic inequalities in the EU-27 (except Malta), Serbia, Turkey, Iceland, and the UK on the basis of a conceptual gender+ framework, and 2) design, devise, and pilot policy solutions and social innovations to be deployed by policymakers, stakeholders, and actors in different policy domains.

Find out more about the project and discover all other outputs at https://resistire-project.eu.







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