

Study: Family carers' voices and experiences need to be formally recognized and responded to

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A Trinity study has highlighted the need for family carers' voices and experiences to be formally recognized and authentically responded to as

equal key stakeholders within the health, social care and education system in Ireland. The study, which took place from September 20th 2021 to November 17th 2021, showed that the COVID-19 pandemic provided a flashpoint which exacerbated many pre-existing challenges for family carers.

Although the [pandemic](#) impacted every level of society, family carers have been forced to accept a much higher care responsibility as services were reduced or totally suspended. They are a taken for granted workforce. Based on an extrapolation of the CSO (2020) Irish Health Survey, Family Carers Ireland estimates that the number of family carers is approximately 500,000 who provide up to 19 million hours of unpaid care and replacing such care could cost the State up to €20bn.

They are a vital, yet unrecognized, part of health and [social care](#) systems.

Key findings of the study

Researchers found that the pandemic exacerbated existing challenges that family carers experienced and also created new difficulties for them, the care recipient and their families. It also found that those caring for loved ones and their families struggled to compensate for gaps in familiar supportive care services (health, social care and education).

Most family carers voluntarily shielded to protect their care recipient but many reported increases in negative physical, psychological and social well-being in themselves and in their care recipients.

Despite the resilience show by family carers through the pandemic, these findings highlight the difficult experience where they had services suspended or reduced based on the assumption of being able to cope with additional responsibilities. Many participants described multiple struggles in this additional caring role as well as a deterioration in their

own psychological, physical and social well-being and also spoke of significant impacts on the health of the care recipient.

Supporting family carers is a fundamental concern to facilitate community living for many care recipients and as a partner in health, social and education systems. Uniquely, family carers have experienced a perfect storm which has been aggravated by the intersectionality of existing challenges such as marginalization, gender and being an invisible, taken for granted workforce.

Recommendations from researchers

- Financial support is needed to assist with [additional costs](#) that occur in pandemics/public health -crises (household bills, equipment, modifications to house).
- Prioritizing access to and provision of personal protective equipment is required as many care recipients are within the medically at-risk groups due to age or health condition.
- Similar to proposals from Family Carers Ireland, this study supports the establishment of care advisors who would champion the needs of individual family carers, assisting them in person centered planning, advice and connections to required services.
- System fragmentation needs to be addressed within the context of ease of access when needed and to address care transition challenges. Importantly, family carers' representation and voices are required in political, service and policy discourses to promote person centered co-ordinated care.

Professor Amanda Phelan, professor of aging and community nursing, School of Nursing & Midwifery at Trinity, said:

"The study highlights how existing and new challenges in COVID-19 translated to daily struggles for family carers in Ireland. While family

carers demonstrated resilience, many also reported personal negative impacts in their health and social well-being as well as adverse impacts for their care recipients. Family carers' voices and [experiences](#) within this study emphasized the need to be formally recognized and authentically responded to as equal key stakeholders within the health, social care and education system. In future pandemics, the [public health](#) response needs to incorporate family carers' explicit and equal contribution to emergency planning."

Dr. Nikki Dunne, research officer at Family Carers Ireland, said:

"Prior to the COVID-19 pandemic, many family carers already experienced difficulty accessing important supports such as homecare or respite. This has been clearly exacerbated by this crisis, with many family carers and their loved ones going without vital services throughout this emergency. This study lays bare the daily challenges [family](#) carers face since the onset of the pandemic. Whilst they have risen to the [challenge](#) of the COVID crisis, it has come at a considerable cost to their own physical and mental [health](#). Despite the enormity of their contribution many [family carers](#) continue to care without appropriate support. Without the right support, the stress and [challenges](#) of the past two years could lead to more reaching crisis point. It is essential that they are recognized and supported."

More information: Exploring Experiences Of Carers In The COVID-19 Pandemic: www.tcd.ie/tcphi/assets/pdf/irc-fci-report.pdf

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