

New study reveals impact of lockdown on the mental health of informal carers

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The challenges faced by informal carers—usually mothers—of children and adults with intellectual disability have been largely overlooked during the coronavirus crisis.

Professor Peter Langdon of Warwick's Center for Educational Development, Appraisal and Research (CEDAR) has been one of a team working in partnership with the Challenging Behavior Foundation to document the mental [health](#) of informal carers of children and adults with intellectual disability during the [coronavirus](#) pandemic through an online study. The project team was led by Professor Paul Willner from the University of Swansea and included researchers from the universities of Birmingham and Kent.

The team found that carers of adults and children with intellectual disability were five times more likely to report severe anxiety and between four and ten times more likely to report major depression than parents of children without intellectual disability.

The study, "Effect of the COVID-19 pandemic on

the mental health of carers of people with [intellectual disabilities](#)," (*Journal of Applied Research in Intellectual Disabilities*), also finds that carers of children and adults with intellectual disability reported mental health problems well in excess of what might have been expected on the basis of the pre-pandemic literature, and at the same time experienced lower levels of social support relative to parents of children without intellectual disability.

The data for the study were collected in the second half of the strict March-April-June coronavirus lockdown. Researchers analyzed 244 online surveys, completed by carers of adults with intellectual disability, children with intellectual disability, and a comparison group of carers for children without intellectual disability. More than 90 percent of the carers taking part were female. Eleven households had had direct experience of COVID-19.

Carers of children and adults with intellectual disability reported significantly greater anxiety and depression than carers of neurotypical children. These feelings were worsened by stress but improved by [social support](#).

- Moderate to severe anxiety—43% of carers of children with intellectual disability reported this, compared with 8% of parents of children without intellectual disability.
- Moderate to severe levels of depression were reported by 45% of carers of children with intellectual disability, compared with 11% of parents of children without intellectual disability.
- Social support—compared to parents of children without intellectual disability, carers of children with intellectual disability received significantly more support from professionals, but significantly less support from other sources, particularly family (parents, children, other relatives) and

friends (friends/co-workers, neighbors/local community). Social support decreased as the severity of challenging behavior increased.

For those caring for adults with intellectual disability, the closure of adult day services and respite care meant that carers of adults felt they had received significantly less support than carers of children, who were still able to send their children to school if they chose to.

The results were compared with similar studies conducted before the pandemic to explore whether the high rates of severe mental health problems were associated with the lockdown.

The authors commented: "It is likely from these data that the mental health of carers of [children](#) and adults with intellectual disability has been adversely affected by the pandemic over and above any pre-existing [mental health problems](#), and to a greater extent than parents of people without disabilities, in line with the general picture that the pandemic has amplified existing inequalities. We should acknowledge the essential role played by informal carers and take steps to ensure they are appropriately and proactively supported. There are significant costs for the carers themselves and for society more generally if mental ill health robs them of their ability to continue providing care for their loved ones."

Among the suggestions put forward in the report to better support carers are:

- Long term consistent support for carers from a named key worker
- More nurses trained in learning [disabilities](#) issues, and encouraged to regard carers' mental health as part of their remit
- More respite provision, and a policy commitment to maintain access to respite through any future lockdowns
- Professional services better equipped to offer support to carers remotely via phone or electronic media
- Access for carers to specialist mental health support
- Provision of peer support groups for carers

The authors concluded: "It will be essential to consult families as to what else might help, so that support can be planned and implemented well in advance of it next being needed."

More information: Paul Willner et al. Effect of the COVID-19 pandemic on the mental health of carers of people with intellectual disabilities, *Journal of Applied Research in Intellectual Disabilities* (2020). [DOI: 10.1111/jar.12811](https://doi.org/10.1111/jar.12811)

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