

## **Perspectives of charitable organisations on the impact of the COVID-19 pandemic on family carers of people with profound and multiple intellectual disabilities.**

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**Abstract :** Background The COVID-19 pandemic resulted in a reduction of health care services for many family carers of people with profound and multiple intellectual disabilities (PMID). Due to lack of services, family carers turned to charities for support during the pandemic. We explored the views of charity workers across the UK and Ireland who supported family carers during the COVID-19 pandemic and explored their views on effective online support programmes for family carers. Methods This was a qualitative study using online focus groups with participants (n = 24) from five charities across the UK and Ireland. Questions focused on challenges, supports, coping and resources which helped during lockdown restrictions. Focus groups were audio recorded, transcribed verbatim, and analysed through thematic analysis. Findings Four themes were identified (i) 'mental and emotional health', (ii) 'they who shout the loudest' (fighting for services), (iii) 'lack of trust in statutory services' and (iv) 'creating an online support programme'. Mental and emotional health emerged as the most prominent theme and included three subthemes named as 'isolation', 'fear of COVID-19' and 'the exhaustion of caring'. Conclusions The withdrawal of many services during the COVID-19 pandemic further isolated and placed strain on family carers. Even after the end of the pandemic family cares continue to report on the struggle to receive adequate support. There is a critical need to design services, including online support programmes, in partnership with family carers which adequately address their needs.

**Keywords :** intellectual disability, family carers, COVID-19, charities

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