

Experiences of Family Carers of People Intellectual Disabilities During the COVID-19 Pandemic

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Abstract : Background: The COVID-19 pandemic exacerbated the already significant strain placed on family carers of people with profound and multiple intellectual disabilities (PMID), given the withdrawal of many services during lockdown. The aim of this study was to explore the experiences of family carers of people with PMID during the COVID-19 pandemic. Methods: Online focus groups were conducted with family carers (n=126) from across the UK and the Republic of Ireland. Participants were asked about their experiences of the COVID-19 pandemic, coping strategies, and challenges faced. Focus groups were audio recorded, transcribed verbatim and analyzed through thematic analysis. Findings: Three themes emerged from our analysis of the data: (i) COVID-19 as a double-edged sword, (ii) The struggle for support (iii) the Constant nature of caring. These included 11 subthemes: (i) 'COVID-19 as a catalyst for change', 'Challenges during COVID-19: dealing with change', 'Challenges during COVID-19: fear of COVID-19', 'The online environment: the new normal' (ii) 'Invisibility of male carers', 'Carers supporting carers', 'The only service you get is lip service: non-existent services', 'Knowing your rights' (iii) 'Emotional response to the caring role: Feeling devalued', 'Emotional response to the caring role: Desperation of caring', 'Multiple demands of the caring role.' Conclusions: Poor or inconsistent access to services and support has been an ongoing difficulty for many family carers. The COVID-19 pandemic has only further intensified these difficulties, increasing family carers' stress. There is an urgent need to design services, such as online support programs, in partnership with family carers that adequately address their needs.

Keywords : intellectual disabilities, family carer, COVID-19, disability

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