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The needs of carers of children and adults with ID during COVID-19 pandemic

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Dear Editor,

The first confirmed case of COVID 19 Sars Co V2 infection in the Republic of Ireland was confirmed on 5th February 2020. The National Public Health Emergency Team (NPHET) was formed to coordinate the national response to the pandemic. On 12th March 2020, the World Health Organisation declared Covid 19 to be a global pandemic. All schools, colleges, and businesses deemed to be non-essential were closed, with restrictions on travel. On the advice of NEPHET the government announced the 'Plans for living with COVID-19' in September 2020, with the entire country moving to a maximum level[5] COVID 19 restrictions on 19th October 2020.

The COVID 19 pandemic posed a serious risk to the wellbeing of every child in the country, but those with disabilities were disproportionately affected[1]. Adults and children with moderate to profound intellectual disability (ID) for the most part live in the community with support from family members, home care workers, respite centres, special schools, day services and clinical supports. During the first phase of the pandemic, many staff working in intellectual disability services were redeployed to contact tracing and therapists were directed to work from home. Therapists and caregivers had to learn to adapt to telehealth consultations via phone/video as their main means of support for families.

The aim of this study was to assess the impact of supports offered to carers, and their needs during COVID 19 pandemic. The authors used two qualitative rating scales [2], the Modified Family Support Scale [3] and Beach Centre Family Quality of life Scale and a self-administered questionnaire designed by the authors for the purpose of the study.

On evaluating the results of the study, an overall negative impact was reported by families/carers due to a reduction or cessation in day services, clinical supports, respite and home support. In terms of consultations offered during this period, families indicated a preference for a phone consultation (65%) rather than video consultation (58%). They highlighted a concern about not being able to open up (90%) and that something important would be missed (88%) during a phone consultation.

There were a few advantages expressed by carers using video consultation. Families reported feeling safer attending an appointment remotely rather than travelling to a clinic, and found it easier to facilitate attendance of both parents/carers.

Families/carers highlighted that their biggest concern during the pandemic was the possibility of their family member with an intellectual disability becoming depressed, anxious, and lonely and an exacerbation of the child/family member's behaviours that challenge.

The results of our study simulate that of Neha Rani and al (2022), who found that challenges faced by caregivers of children and adults with moderate to profound intellectual disabilities reached new heights during the COVID 19 pandemic.

While some families in this study were reported to have had positive experiences using telehealth consultations, some experienced negative physical health consequences due to exhaustion and fatigue which directly impacted the level of care their children received[4].

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