

The Needs of Carers of Children and Adults with ID during COVID-19 pandemic

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Introduction

- Families remain the main providers of support for people with intellectual disability (ID) in Ireland.
- Perceived support of parents of children/adults with an ID has been associated with lower levels of parental stress. Factors associated with parental stress include family circumstances and social and systemic support. COVID-19 has led to significant service change and service loss for people with ID and their families. Among these changes include; closure of schools and day services, changes in access to keyworker and clinical supports, a move from face to face to online consultations and a significant limitation of respite supports.
- These changes might be expected to increase carer burden.

Objectives

- The aim of this study was to survey parents/carers of children and adults with an intellectual disability who were attending a mental health service during the period of the COVID-19 pandemic.
- The authors hoped to evaluate parents' experience of the challenges and stresses of caring for their child during the pandemic, with reduced access to clinical supports/respite; in addition to the challenges/benefits of accessing supports through telemedicine.

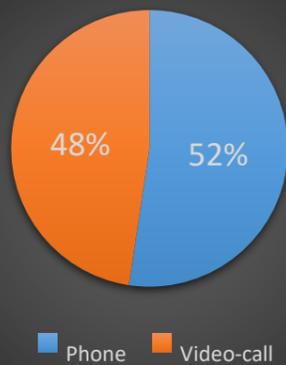
Methods

- Two Qualitative rating scales, the modified Family Support Scale and Beach Centre Family Quality of life Scale were used to evaluate carer burden and supports
- In addition, a rating scale created by the authors to assess for the impact of supports offered to carers and their needs during the lockdown.
- A stamped addressed envelope was enclosed with the study questionnaires.

Results

Demographics

- 17 parent/carers participated.
- 9 adult ID services
- 8 child ID services



During the COVID-19 pandemic period families indicated a preference for phone consultation rather than video consultation.

- Highlighted concerns with video call were about not being able to open up.
- Highlighted concerns with phone call were something important will be missed.

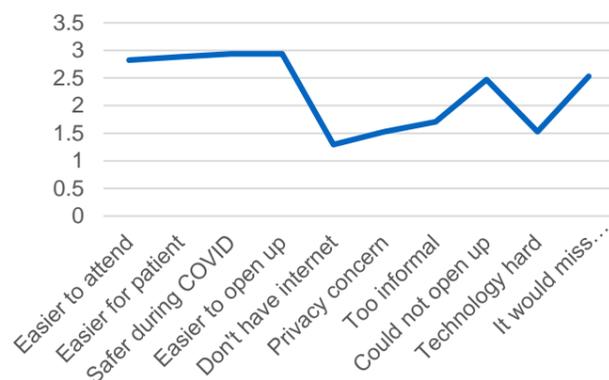
Advantages:

- Families reported feeling safer doing online consultations rather than traveling to a clinic.
- Found it easier to facilitate attendance of both parents together with child/adult.

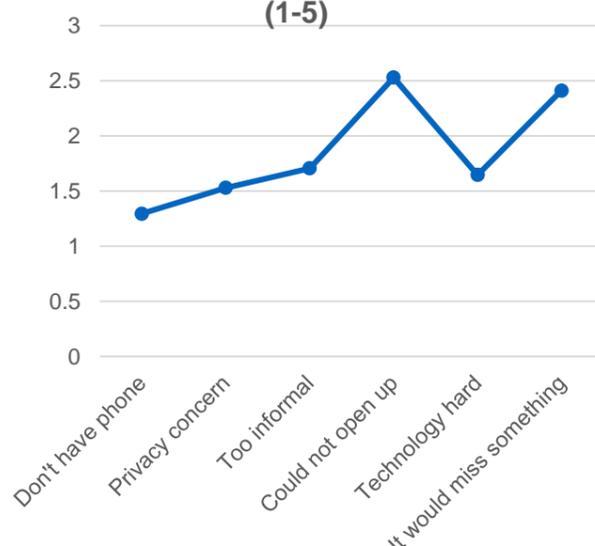
Disadvantages:

- Family member struggling to open up.
- Process too informal.

Video consultations - perceived advantages and problems



Phone consultation concerns (1-5)

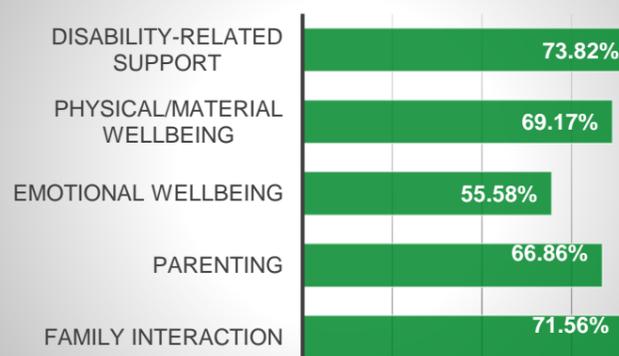


Level of concern (1-5)

STRESS GETTING PHYSICALLY CONFLICT BEHAVIOUR LONELINESS DEPRESSED
COVID UNWELL PROBLEMS

- Carers indicated that their biggest concern during the pandemic was the possibility of their family member with an intellectual disability becoming depressed or anxious, feeling lonely and an exacerbation of their challenging behaviours.

FQOL scores (out of 100)



Conclusions

- The findings revealed that families had to adapt quickly to new ways of phone and video consultations with mental health services.
- Respite, day services and family support for all families were either reduced or suspended having a big impact on carer stress burden.