



Partners' Report March 2022

Welcome to our first partners' report which is intended to keep you up to date with progress and developments on the Carers-ID study. As you know, the purpose of the project is to capture the experiences of carers of people with severe or profound and multiple learning disabilities during the COVID-19 pandemic with a view to create a programme to better support its impact on them.



Completion of our systematic review: Our review, to examine key characteristics and barriers and facilitators of using online support in family carers of people with intellectual disabilities, has ended. The paper will be submitted for publication in a peer reviewed journal. The review showed:

- Most programmes target carers as a means to intervene with their loved ones,
- Few programmes have been co-designed with carers,
- Barriers to using programmes include access to technology and technical difficulties,
- Facilitators include accessibility to treatment, reduced costs and flexibility.



Completion of voluntary sector partners' focus groups (FG): We held five focus groups across the UK and Ireland to see what our partners could tell us about carers' lives during the pandemic. Preliminary analysis identified four key themes:

- 'They who shout the loudest' – carers in a constant fight/campaign for support/services.
- 'Mental health' – impact of the pandemic on feelings of loneliness, isolation, fear, anxiety and uncertainty.
- 'No plan B' – the ultimate fear of what would happen if the family carer became ill or was somehow now longer able to care for their family member.
- 'What our programme should look like' – a one stop shop for honest, reliable, clear and easily accessible information; a means by which people can be connected for peer support.

Ongoing work:

- Our project website will soon be live.
- Recruitment will continue in all four regions of the UK and Ireland. We have 15 FG to go.
- Completion of focus group analysis and drafting of a paper for publication

If you know of anyone interested in taking part in our project please contact Dr Trisha Forbes (Trisha.Forbes@qub.ac.uk) or Dr Mark Linden (M.Linden@qub.ac.uk)

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