



Partners' Report May 2022

Welcome to our third 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.

Below we present the main themes from focus groups with our voluntary sector partners:

1 'Mental health'

I think families were scared and then confused and I think they have went through different stages of emotions since then. There has been anger, frustration and a lot of negative emotion. [Voluntary sector worker; female] **Subthemes:** Isolation; Confusion; Fear; Exhaustion

2 'They who shout the loudest'

You can see, I get really worked up about it because I think the system lets those who shout the loudest get the most and it's wrong. [Self-advocate; female]

3 "No one arrived to help out" - Lack of trust in statutory services

I'm not trying to blow the trumpet but lots of families have said if it hadn't been for our organisation they don't know where they would have been. [Voluntary sector worker; female]

4 What an online support programme should look like

I think anything that you create needs to be created alongside involving experts by experience be that carers themselves, people with learning disabilities, they will come up with the best suggestions. [Voluntary sector worker; female]

Ongoing work:

- Recruitment will continue across the UK and Ireland until the end of June 2022.
- Our systematic review will be presented at the Society for Social Medicine Annual Scientific Meeting in September 2022.

If you know of anyone interested in taking part in the Carers-ID project please contact Dr Trisha Forbes (Trisha.Forbes@gub.ac.uk) or Dr Mark Linden (M.Linden@gub.ac.uk)

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