



Partners' Report April 2022

Welcome to our second 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.



In this report, Carers-ID team member Dr Lynne Marsh, describes her work focusing on fathers of children with intellectual disabilities:

It has been very welcome to see an increase in the published work exploring views of fathers of children with intellectual disabilities. From research with fathers we have begun to gain a more in-depth understanding of their roles as carers to their children with intellectual disabilities.

- From the moment a diagnosis of intellectual disability is shared with a family, most fathers want and expect to be involved in caring for their child.
- Fathers have taken on and continue to learn new roles to support their child at home.
- Becoming a father of a child with intellectual disabilities has many challenges such as worry for their child's long-term future and worries about who will look after their child when they are no longer able.
- Fathers shared many positive stories which include their unconditional love for their child and not allowing them or their family to be defined by disability.
- Increasing our understanding of fathers' roles will enable us to better support them and their children in the future.

Marsh, L., Brown, M. and McCann, E., 2020. The views and experiences of fathers regarding their young child's intellectual and developmental disability diagnosis: Findings from a qualitative study. *Journal of Clinical Nursing*, 29(17-18), pp.3373-3381.

Ongoing work:

- Our project website is now live and can be accessed here: www.carers-id.com
- Recruitment will continue across the UK and Ireland. We have 13 focus groups to go.
- Findings from our voluntary sector partners are being prepared for publication.

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

Twitter: @Carers_ID