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Supporting family carers' mental health

Names of all Researchers: Dr Rachel Leonard, Dr Mark Linden, Prof Michael Brown, Dr Lynne Marsh, Dr Maria Truesdale, Prof Nathan Hughes, Prof Stuart Todd, Dr Trisha Forbes.

You are being invited to take part in a research study. Before you decide whether you want to take part it is important for you to understand why this research is being undertaken and what it will involve. Please take the time to read the following information carefully. If there is anything written below which is not clear please ask Rachel for more information.

What is this study about?
We know that the COVID-19 pandemic has had a disproportionate impact on families with intellectual disabilities and with the help of carers and charities we have developed the Carers-ID programme to support their mental health. We now need to see whether the programme, and the methods we use to assess it, are capable of bringing about improvements to carers mental health.

Why have I been chosen to take part?
You are the parent/carer of someone with an intellectual disability and may be interested in taking part in the Carers-ID programme to improve your mental health.

Do I have to take part in the study?
No, you do not have to take part. Participation in this study is entirely voluntary; you are free to decide whether or not to take part. If you decide to take part and later change your mind, you are still free to withdraw at any time without giving a reason. Any data you provide up to this point will be kept.

What will happen if I agree to take part?
If you are interested in taking part, you should contact Rachel (rachel.leonard@qub.ac.uk) who will answer any additional questions you have. Prior to taking part in the study you will be asked to sign a consent form saying that you understand what the study is about. You will then either

1. be sent four questionnaires to complete followed by details on how to access the Carers-ID programme, you will look at the programme over a two week period and answer the same questionnaires following completion and again three months later,

OR

2. Be sent the four questionnaires followed by the same questionnaires 2 weeks later, and again after 3 months. Following the 3 months you will be sent details on how to access the programme.

Around 12 participants will also be invited to take part in an interview to see what they thought worked and did not work about the programme.

What are the possible benefits or risks to me taking part?
Your participation will help increase our understanding of the how the Carers-ID programme works or does not work to improve the mental health of carers. It is possible that taking part will be upsetting. In the event that you do become upset we will endeavour to offer support and will allow time for you to decide whether you wish to continue with the survey or not.

Who will know about what I tell you?
Only members of the research team (See above) will have access to your answers. If you take part in an interview, we will record this to produce an accurate account of what you say. We will use a transcription service to produce written accounts of these recordings. The person who transcribes the interview will have to sign an agreement to say that they will not discuss what you say with anyone else. If you tell us anything that might cause harm to yourself or to others we are required to report this to the relevant agencies.

What will happen to the results of the study?
When the study has finished the findings will be published in academic journals. You will not be identified in any of these publications. This research will be conducted in compliance with relevant data protection legislation. For more information about how we look after your information, how to access your rights and who to contact if you have any queries or concerns about data protection please visit the Queen's University Belfast website - https://www.qub.ac.uk/privacynotice/Research/ListofResearchPrivacyNotices/PrivacyNoticeforResearchParticipants.html

Who has reviewed the study?
This study has been reviewed by the Baily Thomas Foundation who has funded this project. It has also been reviewed by the Faculty of Medicine, Health and Life Sciences research ethics committee, at Queen's University Belfast, and has been given full ethical approval.

What if I have a complaint about the study?
If you have any concerns about any aspects of the study, you can contact the Chief Investigator, Dr Mark Linden (Email: m.linden@qub.c.uk).

Should you remain unhappy and wish to make a formal complaint, you can contact the Research Governance Team at Queen's University Belfast (Email: researchgovernance@qub.ac.uk).

Thank you for taking time to read this information sheet.

Yours faithfully

Dr Mark Linden