



Parent-Carer Information Sheet Interview and Focus Group (WP3)

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Resetting Services to Disabled Children

We'd like to invite you to take part in our research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read this information carefully. Talk to others about the study if you wish. Please ask us if there is anything that is not clear to you, or you would like more information.

What is the study about?

Many disabled children have complex health needs and they and their families receive services from health, social care, and education. During COVID-19, non-essential services paused and then restarted but often in a different way, usually online. Many families have struggled to cope during the pandemic.

We want to find out what impact the changes in services have had on children's health and wellbeing. We want to find out which service changes have worked, which were not supportive for families and their disabled children, and why. We aim to work with families and professionals to show how services could be better delivered to provide high quality care to disabled children as the NHS is remodelled. We are also seeking to define minimum acceptable, effective core health service provision for future emergencies and lockdowns.

The project has several stages:

1. A review of reports on the effects of changes to services in the UK and abroad;
2. Analysis of NHS and social care information on children's contacts with health and social care services before and during COVID-19;
3. Interviews with parents and professionals;
4. A national survey of the views of families and professionals on how to move forward.

We are inviting you to take part in the third stage of the project. We want to talk with parents about changes to the services their child received. We will also talk to children about changes to the services they received and ask professionals about the changes in services they provided. We want to hear about how the changes have worked; which changes we should keep and what we should stop doing, so that children and families receive high quality care.

Why have I been invited?

You have been invited because you are a parent-carer of a disabled child or young person aged 0-19 years and services in your area have agreed to take part in the study.

Do I have to take part?

No, you do not have to take part. You can choose not to take part and you can decide to stop at any point in the interview.

You can change your mind about taking part at any time.

Whether you chose to participate or not this will have no impact on the services your family receives.

What will happen if I take part?

If you want to take part, we will arrange to talk with you about changes in services during the pandemic. We will ask you about what worked well, what didn't work so well and why. If we ask anything that you cannot answer or do not want to answer this is okay.

You can talk with us one to one or as part of a group. The interview will last 40-60 minutes. It will be online using Zoom or Teams. We will video record the interview so that we can listen back to what you have told us.

After the interview you will not need to do anything else for the study. However, please feel free to look at the study website for any more opportunities to get involved in our research.

Can my child take part?

Yes, your child can take part. A young person's information sheet has been provided as an attachment for you to share with your child and discuss with them. If they want to take part, you can be with them during the interview and sign a consent form on their behalf before we start. (If you did not receive the young person's information sheet, please contact the email address at the bottom of this leaflet). Your child can sign their name too on a child-friendly consent form.

If your child does not want to take part, you can still take part.

What happens if I don't want to carry on with the interview?

You can stop a one-to-one interview at any time. If you join a group interview you can leave at any time.

What are the possible disadvantages of taking part?

The interview will take up to an hour. We will arrange it for a time that is least disruptive for you.

What are the benefits to taking part?

There are no direct benefits to taking part, but what you tell us could help families in the future and influence future research.

Do I receive anything for taking part?

You will receive a voucher for £50 for taking part.

What if there's a problem?

Cumbria, Northumberland, Tyne and Wear (CNTW) NHS is the Sponsor of this research and holds overall responsibility for the project.

If you have any questions or concerns about the study, please contact Mr Simon Douglas, Research, Innovation & Clinical Effectiveness Senior Manager, Cumbria, Northumberland Tyne and Wear Foundation Trust (0191 223 2338, simon.douglas@cntw.nhs.uk).

Who will know that I am taking part?

We will ensure that your participation in this study is entirely confidential. Only the study team will know that you have taken part. When the research is published there will be no way of identifying anyone who took part in the study.

The only time we will break confidentiality is if we are concerned that you, or your child, is in danger or at risk at harm. In this situation we have a duty of care to inform the appropriate authority to make sure everyone is safe. The researcher will talk to you about this first and what they are going to do.

How will my information be used?

We will need to use information from you for this research project. This information will include

- your name
- contact details
- recordings of the interview

We will save your contact details and the interview recordings in different files on a secure server at Newcastle University. We will transcribe the interviews and make notes on what you tell us. We will then destroy the recordings.

People will use this information to do the research or to make sure that the research is being done properly. Responsible members of the Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust may be given access to research information for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

Once we have finished the study, we will keep some of the data (transcriptions and notes on the recordings) so we can check the results. We will keep this information for ten years or three years after the youngest person in the study has reached 18 years of age (whichever is sooner). After this time, information will be confidentially destroyed.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. We will write our reports in a way that no-one can work out that you took part in the study.

What are my choices about how my information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we have already analysed. Should you lose capacity to consent after the interview, we will keep your data for analysis, but your data will be fully anonymised and no longer identifiable to the research team.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

If you give permission, information gathered from this study may be used in future data analyses by us or other researchers undertaking similar research. (Anonymous information from the study will be saved in Newcastle University's data repository data.ncl)

Where can I find out more about how my information is used?

You can find out more about how we use your information:

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- by sending an email to DPO@cntw.nhs.uk
- by ringing us on Tel: 0191 246 6896

What will happen to the results of this study?

We will report our findings on the project website. The results of this research study may be published in scientific journals and may be discussed at scientific meetings. You will not be identified in any way. A written summary of the study findings will be shared with participants within two months of the study being complete.

Who is funding the research?

This study is funded by the National Institute of Health Research (NIHR) Policy Research Programme. Neither the views nor the opinions expressed in this information sheet are those of the NHS, NIHR or the Department of Health.

Who has reviewed the study?

This study has been reviewed and given favorable opinion by Preston Research Ethics Committee.

Can I talk to someone before agreeing to take part?

If you would like further information about this study you can contact the director of the study, Dr. Lindsay Pennington or the researchers Hannah Merrick and Helen Driver (see below). You are welcome to ask us any questions or discuss any worries you may have. In addition, you can ask in general about taking part in research by contacting your local Patient Advice Liaison Service (PALS) on 0800 0320202.

Thank you for considering taking part in this research project and taking the time to read the information sheets.

Contacts:

Dr Lindsay Pennington
Reader in Communication Disorders
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Dr Hannah Merrick
Researcher

Dr Helen Driver
Researcher

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