



Changes to services for disabled children

What is this study about?



This research is about the changes in services for disabled children since COVID-19.

We want to know if changes in support from therapists, doctors and social workers have been okay. We want to know if any changes have made life harder for families.

Why have I been asked to take part?



We want parents / carers of disabled children to answer questions in a survey.

We want to hear from parents of children with different conditions. For example, cerebral palsy, Down's syndrome, genetic conditions, autism.

Will it help me or my child?



We hope you will enjoy taking part in the research. We hope the study will help us improve advice given to families.

This means the study might not help you and your family – but it might help others like you in the future.

What would I have to do?



We are asking you to answer questions in an online survey. We are happy to help you, by telephone or email, to complete this survey.

The survey will ask you for some information about how services work best e.g., online or at school

We will offer you the chance to enter a draw to win **one of five** £100 vouchers as a thank you for your time.

The survey can be completed anonymously.

What happens to the information I give?



The information you give will be looked at by the research team. They will advise NHS on how to develop services for disabled children.

Do I have to take part?



No. You choose to take part, or not. Choosing not to take part will not affect your child's care in any way.

You can stop the survey at any time. We will keep the information you have already.

How will I find out the results of the study?



If you give us your email and postal address at the end of the survey, we will send you a summary of the results.



You will also be able to find a summary of the results on our website:

https://research.ncl.ac.uk/resetting servicestodisabledchildren/

Will I be asked to take part in any further research?



No. The survey is the last part of this research.

Who is doing this study?

This study is supported by Cumbria, Northumbria, Tyne and Wear NHS Foundation Trust.

Researchers from Newcastle University are leading the study with researchers from other universities and NHS trusts.

The researchers at Newcastle University will receive and store the information you give as part of the research.

Can I talk to someone before taking part?

Yes. If you would like to find out more about the study or have any questions, please contact Helen Driver or Hannah Merrick by phone or email.



Telephone number: 0191 282 1360



Email address: resetting.services@ncl.ac.uk

What if I have concerns or a complaint?

If you have any concerns about the study, you can contact:

- Helen Driver or Hannah Merrick by phone or email using the above contact details.
- Or the Patient Advice and Liaison Service (PALS) on Freephone: 0800 032 0202

If you want to make a formal complaint, please contact Simon Douglas, Research, Innovation & Clinical Effectiveness Senior Manager, Cumbria, Northumberland Tyne and Wear Foundation Trust

Telephone: 0191 223 2338

Email: <u>simon.douglas@cntw.nhs.uk</u>