

Improving toileting for children and young people with special educational needs and disability

What is this study about?



This research study is about managing toileting for children and young people with a disability.

It may be more difficult for a child with special educational needs and disability to learn to go to the toilet by themselves. We want to find out how health professionals and families assess the capability for a young person to be toilet trained, and what kind of methods they use to help them manage toileting.

Why have I been asked to take part?



We are asking young people up to the age of 25 years for their views and experiences about how they manage toileting and the support they have received. We are doing this in an online survey.

We want to hear from young people with a range of different conditions, for example, Cerebral Palsy, Down Syndrome or Autism.

What would I have to do?



You are invited to answer questions in an online survey. You can ask someone to help you to complete the survey. The questions will be short and mostly involve tick box answers.

A.

B.

C.

What happens to the information I give?

The information you give to us will only be looked at by researchers. We do not share your personal contact details with any other organisation.

Do I have to take part?



No. Taking part is your choice. If you choose not to take part it will not affect your care in any way.

You can also change your mind at any point. So if you complete the survey, but change your mind later, let us know and we can remove all the information you have given us.

How will I find out the results of the study?

If you are happy for us to keep your contact details after you have completed the online survey, we can send you a summary of the results at the end of the study. This will be in 2020.

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

No, we will not contact you again for any further research.

Who is running this study?

The study is run by the PenCRU research team at the University of Exeter. The National Institute of Health Research (NIHR) which is part of the NHS, have provided money for the University of Exeter to run the research.

Can I talk to someone before taking part?



Yes. If you would like to talk about taking part, you can contact the research team by phone or email;

Telephone – 01392 722923

Email – icon@exeter.ac.uk



What if I have concerns or a complaint?

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

- Helen Eke from the research team on the contact details above
- Or Ruth Garside who is the Chair of the University Ethics Committee who makes sure that the research is carried out correctly. Ruth can be contacted at uemsethics@exeter.ac.uk.