

Improving continence in children with neurodisabilities



Dr Chris Morris, Chief Investigator, said: "Research to evaluate ways to improve continence for children with neurodisability was Number 7 in our Top 10 research priorities for children with neurodisability shared by families and clinicians. So we are pleased to be addressing this often neglected topic in research that is central to the everyday lives of children and families."

Julia, a parent carer and Coinvestigator, said: "I am particularly motivated to be part of this research because of my personal experience and because I know the massive impact on the child and family's life and cost of products and services to the NHS."

Learning to manage going to the toilet independently is an important milestone in growing up. Being continent involves knowing you need to go, delaying until an appropriate place can be found, weeing and pooing, cleaning up afterwards, and re-dressing. Children with special educational needs and disability may be slower to learn to manage going to the toilet, or they may need extra help. Many children with special educational needs and disability can improve their continence with training and support. Interventions to improve continence include toilet training programmes, products, aids and equipment, medicines and surgery. Currently it is uncertain which ways are most effective.

The National Institute for Health Research (NIHR) has commissioned research to find out how continence is assessed and managed in the NHS for children with special educational needs and disability. A series of surveys with clinicians and families will be undertaken to find out what is being done currently, in conjunction with a systematic review which will examine evidence about assessment and treatments. From this informed recommendations can be made for research and clinical practice in the NHS.

What we are going to do

The research team consists of specialists in continence from the Paediatric Continence Forum and ERIC, The Children's Bowel & Bladder Charity, and research methodologists including our PenCLAHRC Evidence Synthesis Team and PenCRU (Peninsula Cerebra Research Unit) childhood disability research group.

The systematic review will look at all existing studies that examine and assess ways to improve continence for children with special educational needs and disabilities. This review will provide a comprehensive and unbiased summary of existing research.

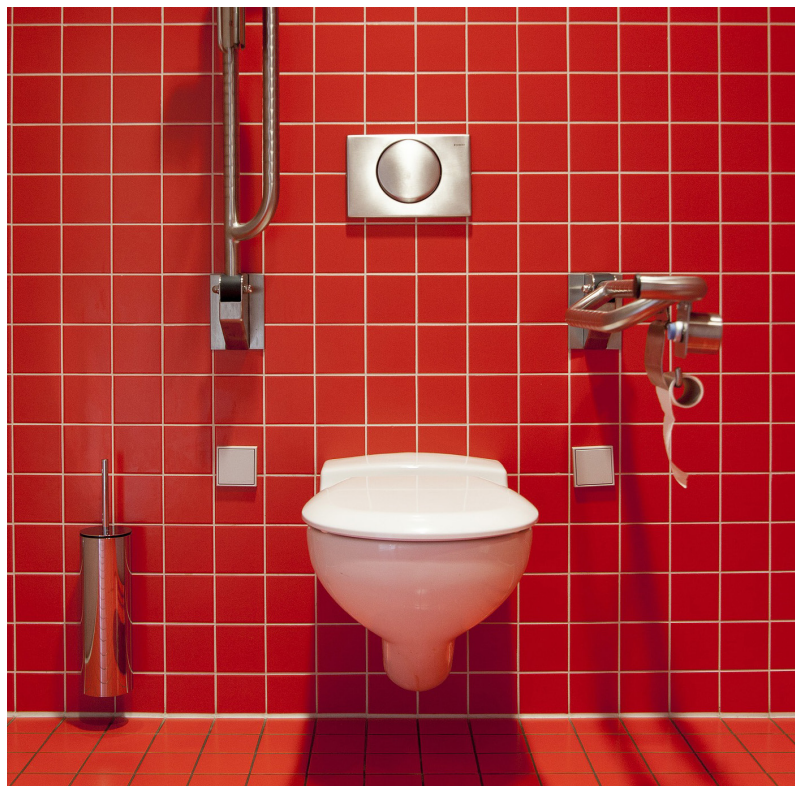
The surveys will consult health professionals working with children with neurological conditions through various professional societies and other networks, and families who have experience using NHS services to promote continence. This will help us understand how NHS staff assess and treat children with special educational needs and disability to help them become continent.

Findings from the surveys and systematic review will be brought together, and we will consult with families and professionals for their impressions of what has been found. Following this, discussions about gaps in the evidence and potential priority questions will take place for future research.

If you would like to help and be part of this research please contact penclu@exeter.ac.uk

For further information visit:

www.clahrc-peninsula.nihr.ac.uk



Useful Links:

clahrc-peninsula.nihr.ac.uk/research/improving-continence
www.pencru.org

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