



CLAHRC BITE

Brokering Innovation Through Evidence

Improving continence in children with neurodisability

May 2019



Learning to manage using the toilet can be more difficult for children with a disability.

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/or a 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/or a 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.

What is the aim of the project?

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/or a disability.

A survey with clinicians, families and education and social care staff 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.

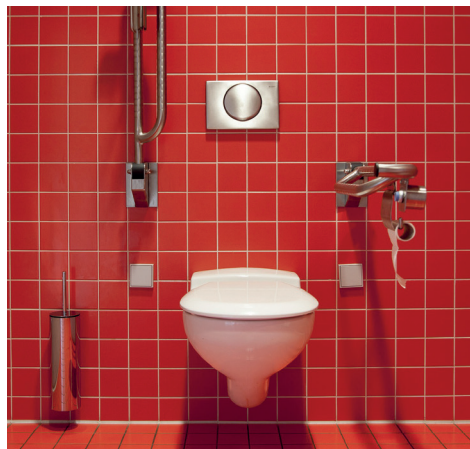
From this informed recommendations can be made for research and clinical practice in the NHS.



What will we 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 Childhood Disability Research Unit).

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



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

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."*

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 will take place about gaps in the evidence and potential priority questions to inform future research.

Dr Chris Morris, Chief Investigator, said: *"We are pleased to be addressing this often neglected topic in research that is central to the everyday lives of children and families."*

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

For further information visit:

<http://sites.exeter.ac.uk/iconstudy>

Useful Links:

clahrc-peninsula.nihr.ac.uk/research/improving-continence

www.pencru.org

This research is funded by NIHR Health Technology Assessment Programme (17/20/02), and supported by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care South West Peninsula (NIHR CLAHRC South West Peninsula). The views expressed are those of the researchers and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care. View more BITES at clahrc-peninsula.nihr.ac.uk/bites.

ICoN

improving continence
for children and young
people with neurodisability