Improving continence in children and young people with neurodisability: a systematic review and survey

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Declared competing interests of authors: Nicholas Madden, June Rogers, Davina Richardson and Claire Lindsay are or have been members of the Paediatric Continence Forum (PCF), an independent multidisciplinary group of health-care professionals campaigning for better care of bladder and bowel problems in children and young people. Anne Wright was previously a member of, and is currently an honorary consultant (on an ad hoc basis) to, the PCF. We declare that (1) the PCF has commercial members who support its work: Coloplast UK Ltd (Peterborough, UK), Ferring Pharmaceuticals (Saint-Prex, Switzerland), Kimberly-Clark Europe Ltd (Reigate, UK), Norgine Pharmaceuticals Ltd (Norgine B.V., Amsterdam, the Netherlands), and Essity UK Ltd (formerly SCA Hygiene Products Ltd; Stockholm, Sweden); (2) commercial partners have no input into PCF documents; (3) members of the

PCF are eligible for honorarium and travel expenses for PCF activities, although not members all apply for reimbursement. June Rogers and Davina Richardson are or have been employed by the charity Disabled Living, which received unrestricted funding grants from the following organisations to support the work of the charity: Ferring Pharmaceuticals, Ontex (Aalst, Belgium), TENA (Stockholm, Sweden), iMEDicare (Watford, UK) and INNOVO (Atlantic Therapeutics, Galway, Ireland). The company Coloplast Ltd gave a donation in 2017 to Disabled Living to support a Bowel Award Prize. Disabled Living runs conferences and study days throughout the year that are supported through payments made by a range of companies to exhibit. June Rogers is a member of the NHS England Excellence in Continence Care Programme Board and is the Paediatric Advisor for the Association for Continence Advice. Davina Richardson is on the Executive of the Association for Continence Advice, is editor of its newsletter, and is a member of its education and conference organising groups (there is no financial gain for this). Anne Wright is General Secretary to the Board of International Children's Continence Society, but receives no compensation or commercial gain). Anne Wright is also a member of the Drug and Safety Monitoring Board for Astellas (Astellas Pharma Inc., Tokyo, Japan) regarding trials of Mirabegron in children; compensation payments for this work are made to the Departmental Renal Research Fund. Lecture fees from Ferring Pharmaceuticals are paid to the Departmental Renal Research Fund. Anne Wright is involved in research funded by the British Kidney Patient Association. She is president of the Professional Advisory Committee for ERIC (The Children's Bowel and Bladder Charity), but receives no compensation or commercial gain. Julia Melluish was a member of National Institute for Health Research (NIHR) Health Technology Assessment (HTA) Prioritisation Committee C (Mental Health, Women and Children's Health) (2018–20) and is a member of the HTA Prioritisation Committee A (Out of hospital) (2020-present). Eve Hutton was a member of the NIHR HTA Mental Health. Women and Children's Health Panel (2017–18) and is a member of the HTA Prioritisation Committee A (Out of Hospital) (2017–21). Rob Anderson was a member of NIHR Health Services and Delivery Research Researcher-Led Panel (2016–19). Jo Thompson Coon is a member of the NIHR HTA General Committee (2019-present). Stuart Logan, Christopher Morris, Jo Thompson Coon, Rob Anderson, Susan Ball, Helen Eke, Harriet Hunt, Morwenna Rogers and Rebecca Whear have previously been or are currently funded or supported by the NIHR Applied Research Collaboration South West Peninsula.

Published November 2021 DOI: 10.3310/hta25730

Plain English summary

Improving continence in young people with neurodisability Health Technology Assessment 2021; Vol. 25: No. 73 DOI: 10.3310/hta25730

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Plain English summary

Learning to go to the toilet is an important skill. Becoming continent involves knowing when you need to go, holding on until you find the right place, going to the toilet, cleaning and getting dressed again.

Many children and young people with special educational needs or disability can learn to become clean and dry, sometimes with help or equipment. Advice is not consistent about the best ways to assess and treat continence problems for children and young people with neurodisability.

This research aimed to find out how families and professionals measure and improve continence, and if there was evidence about which treatments are useful.

We brought together the results of studies that have tested ways of assessing and improving toilet training for children and young people with special educational needs or disability.

We carried out four online surveys with health professionals, education and care staff, parent carers, and disabled young people.

We brought together and explained the findings from the surveys and the studies with help from parent carers and professionals.

Approaches to improving continence vary depending on whether or not the child or young person's nerves and muscles that control their bladder and bowel work properly. Children and young people with conditions affecting the nerves and muscles of their bladder and bowel are often helped by medical or surgical treatments. Children and young people with conditions such as learning disability or autism may benefit from behavioural therapies to help them learn to use the toilet.

There is poor evidence for how well treatments work and whether or not they are value for money. More and better research is needed to make sure that children and young people are able to be clean and dry without pads, maximising their independence, dignity and comfort. This also requires an adequate number of fully accessible toilets in the community.

Health Technology Assessment

ISSN 1366-5278 (Print)

ISSN 2046-4924 (Online)

Impact factor: 4.014

Health Technology Assessment is indexed in MEDLINE, CINAHL, EMBASE, the Cochrane Library and Clarivate Analytics Science Citation Index.

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This report

The research reported in this issue of the journal was funded by the HTA programme as project number 17/20/02. The contractual start date was in October 2018. The draft report began editorial review in September 2020 and was accepted for publication in May 2021. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HTA editors and publisher have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HTA programme or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the HTA programme or the Department of Health and Social Care.

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