Guidance on integrating children’s continence care

In this article...
- Variations in continence care for children and young people
- The effects of inadequate continence care on children
- Resources to assist health professionals

Two organisations have developed resources to help improve and increase provision and reduce fragmentation of continence services for children and young people.

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Abstract

At a time of increased financial pressure on healthcare budgets, clinical and financial effectiveness is crucial. Yet children’s continence services remain fragmented and are under increased pressure due to the recent transfer of school nurses under local authority control. The provision of community-based continence services for children and young people also varies considerably, with England well behind the rest of the UK.

The Paediatric Continence Forum and Education and Resources for Improving Childhood Continence (ERIC) has produced resources to help support professionals in assessing and treating children and young people with continence problems.

Approximately 10% of children and young people are affected by bladder and bowel (continence) problems (Paediatric Continence Forum, 2015). These problems occur at a sensitive time in children’s physical and emotional development, and can influence their health and wellbeing (National Institute for Health and Care Excellence, 2010a; 2010b). There is also evidence of an association between continence problems and behavioural problems, including bullying – both as recipients and perpetrators (Joinson et al, 2006) – and a link between soiling accidents and child punishment, including physical abuse by parents (NICE, 2010a).

Increasing pressure on continence care
The NHS should be playing an important role in assessing and treating continence problems and helping these children and young people have the best start in life. However, as outlined by Rogers (2016), cuts to community services serving as the cornerstone of effective and cost-effective continence care are making it increasingly difficult for the NHS to provide these services.

Continence services have not escaped the effects of financial pressures on the NHS. England’s public health budget for 2016-17 is facing cuts of up to £100m; children’s services, including health visiting and school nursing, account for 14% or £7m of the total (Santry, 2016). In addition, the recent transfer of school nursing from public health to local authority funding has reduced the number of school nurses. Since these nurses provide vital first-line (Level 1: assessment and treatment) services, this has increased the pressure on continence services. In areas with more advanced paediatric continence services (Level 2: treating more complex bladder and bowel problems), many of these remain fragmented, despite a recognition in the NHS of the benefits of integrated, coordinated care.

The Paediatric Continence Forum (PCF), an independent national campaign group, carried out a Freedom of Information study on the commissioning of continence services in 2014. This revealed...
that just 40% of clinical commissioning groups (CCGs) and health boards across the UK commissioned all four main continuity services – covering toilet training, bedwetting, daytime wetting and constipation/soiling, while just 27% commissioned ‘joined-up’ services. This demonstrated relatively little change from a similar survey carried out in 2011 (PCF, 2015). The study also highlighted a variation in standards across the UK: Scotland, Wales and Northern Ireland were more likely than England to commission all four services.

Why are integrated services so important?
Integration is important because children and young people often have a combination of wetting and constipation/soiling problems. A coordinated approach is necessary to engage children and their families, and to ensure treatment is effective. A national audit of continence care by the Royal College of Physicians concluded that clinical outcomes are higher when a service is integrated (RCP, 2010). As discussed below, disjointed services inhibit young people from coming forward for help. Box 1 lists the characteristics of an integrated children’s continence service.

Experiences of disjointed services
Recent research undertaken at the University of Bristol, and funded by the Medical Research Council, explored the secondary impacts of continence problems on young people. The findings underlined the harmful impact of disjointed services on care experiences. Young patients who saw different doctors and nurses “did not feel like they could get to know them or establish a positive relationship”, while those who experienced continuity of care with the same health professional “felt” more comfortable talking about their problems and reported being more likely to disclose information” (Whale et al, 2016). This information is often personal and sensitive, but important in treating their bladder and bowel problems.

Ensuring children and young people develop trusting relationships with their clinicians is vital if their bladder and bowel problems are to be assessed, managed and treated in a timely and efficient manner. Research by Whale et al (2016) indicated that patients responded best to treatment “when they were given a full explanation of why they were being asked to do something, and they were involved in the decision-making process”. This reinforces the importance of engaging properly with children and young people, and their families, with a service that is integrated by design. Identifying and treating bladder and bowel problems early is also crucial, thereby reducing inappropriate and expensive referrals by GPs to secondary care (Rogers, 2016).

Motivation to improve services
Despite risks to the wellbeing of children and young people with continence problems, and the economic argument for reconfiguring services, there appears to be little motivation to improve services. The PCF’s (2014) research indicated that only 44% of CCGs and health boards reported an intent to review or commission new paediatric continence services (Fig 1). The geographical breakdown of the 2014 results is more mixed: only 14% of Welsh health boards planned to review their services, and none intended to commission new provision; these figures were 71% and 7% respectively for Scotland, and 43% and 16% for England.

Improving the continence care journey
The PCF and ERIC have produced a number of resources (Box 2) aimed at helping care providers to improve the services they offer to children and young people with continence problems. These are discussed below.

Paediatric continence commissioning guide
This NICE-accredited guide gives those commissioning, setting up and running services a full description of what a good, integrated, community-based service looks like and what needs to be done to put this into practice. It was published by the PCF in 2014 and updated in 2015.

Generic children’s continence pathway
Regardless of where they live, children should receive the same assessment of their continence problem as well as appropriate intervention. ERIC has developed a new generic children’s continence pathway that puts children at the centre of their continence care journey to ensure all children, no matter where they reside, receive the same standard of continence care (Fig 2).

The pathway is a free-to-use interactive online resource that will be accessible on ERIC’s new website (www.eric.org.uk) when it is launched at the charity’s Paediatric Continence Care Conference in Birmingham on 12 October 2016. The pathway should be used by a wide range of professionals involved in children’s continence care.
FIG 2. CHILDREN’S CONTINENCE PATHWAY

Parent/carer identifies concern regarding continence

Child seen by local service such as Learning Disabilities Team. Symptoms documented eg using continence assessment form

Child seen by School Health Nurse Team or Health Visiting Team. Symptoms documented eg using Continence Assessment Form

Child seen by GP. Symptoms documented eg using a continence assessment form

Parent/carer contacts ERIC via helpline or visits website. Information obtained and self-help measures employed

Parent/carer identifies concern regarding continence

Contingency problem identified

Provide structured follow up

Select appropriate flowchart – follow treatment plan

Toilet training
Constipation
Daytime wetting
Night Time wetting
Children with additional needs

Red flag symptoms identified

Provide information and leaflets as appropriate and discharge

Refer to Paediatric Continence Service or equivalent local service using referral form

Symptoms ongoing

Symptoms improved

Continue to follow treatment plan

Provide structured follow up

GP to complete physical examination to rule out underlying organic cause for symptoms as appropriate. GP to record BP/urinalysis as appropriate

Complete product assessment if required

Paediatric urology/neurology/gastroenterology

Product assessment
professionals including health visitors, school nurses, education staff and anyone working with children. It can also be used by parents, carers and children themselves to better understand the care they receive and help them navigate the system.

The peer-reviewed pathway was developed by Brenda Cheer, a paediatric specialist continence nurse. The idea for it emerged during the ERIC Nurse project: a three-year pilot project led by Ms Cheer and funded by a Department of Health innovation grant, which sought to improve early intervention for children’s continence problems and promote excellence in paediatric continence care in Bristol and South Gloucestershire. The initial intention was to update the existing Bristol Children’s Continence Pathway, but it was later decided that a generic pathway adaptable for use in other parts of the UK would be a more useful resource.

The ERIC pathway begins with an overarching flowchart describing the child’s journey from identification of the problem, to implementation of self-help measures, on to assessment, then demystification of the condition, leading to treatment and then possible ongoing referral to specialist services and/or assessment for pad provision (Fig 2). Assessment is an essential part of the process. The pathway includes a comprehensive continence assessment form, which provides a useful tool for health professionals, and explains the rationale for gathering information and what it might mean for the treatment the child will need. The assessment form can therefore be used to document a child’s bladder and bowel behaviour, and as a teaching aid. This means the resource can be used by anyone providing a Tier 1 service, thereby helping to promote early intervention in primary care.

The pathway links to NHS England’s Excellence in Continence Care report (NHS England, 2015). This is necessary reading for anyone seeking to provide the best continence service to children and teenagers. The report stresses the need for comprehensive assessments by appropriately trained staff, followed by a correct treatment and management programme being put in place.

The child’s journey continues through the pathway via symptom-specific flowcharts for toilet training, constipation, daytime wetting and night-time wetting; there is also a section for children with additional needs. As service provision varies so greatly from region to region, the pathway does not stipulate who will provide care, but instead suggests who might do so. It can therefore be used as a generic model that can be adapted to suit local provision and ensure local needs are met.

The symptom-specific flowcharts link to further resources that provide all the information and practical support needed to provide the best care for children. Resources include a full set of assessment charts, information sheets, template referral letters, reward charts and ERIC’s guides to children’s bowel and bladder problems. The flowchart for constipation, for example, links to:

- The NICE (2010a) guideline Constipation in Children and Young People;
- ERIC’s Guide to Children’s Bowel Problems; a parent’s guide to disimpaction;
- Information on the correct way to prepare macrogol laxatives;
- A ‘poo’ diary (Fig 3);
- Template letters to GPs and schools;
- A toileting reward chart and information about constipation in breast-fed babies.

**Conclusion**

Budgetary constraints and national service reorganisation have resulted in cuts to and increasing fragmentation of continence services for children and young people; this can have a profoundly negative effect on those with continence problems. Resources have been produced by the PCF and ERIC to help health professionals and service commissioners improve and integrate these important services. **NT**

**References**


National Institute for Health and Care Excellence (2010a) *Constipation in Children and Young People.* nice.org.uk/cg99

National Institute for Health and Care Excellence (2010b) *Bedwetting in Under 19s.* nice.org.uk/cg117


**For more on this topic go online...**

- Helping schools to manage continence problems
- Bit.ly/NTSchoolContinence

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**BOX 2. USEFUL RESOURCES**

**ERIC, The Children’s Bowel and Bladder Charity**

Provides information, support, training and resources to help manage or overcome child and adolescent bowel and bladder problems. www.eric.org.uk

**The Paediatric Continence Forum**

An independent national group that campaigns to improve awareness amongst policy-makers of the needs of children and young people with continence problems and to improve NHS continence services. It has representation from the Royal College of Nursing, ERIC, PromoCon, the Royal College of Paediatrics and Child Health, the Community Practitioners’ and Health Visitors’ Association and the School and Public Health Nurses Association, plus companies working in this field. www.paediatriccontinenceforum.org.uk

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**FIG 3. THE ‘POO’ DIARY**

<table>
<thead>
<tr>
<th>CHILD’S NAME:</th>
<th>Date</th>
<th>Time</th>
<th>Poo in toilet – amount</th>
<th>Any soiling? – amount</th>
<th>Type</th>
<th>Comments</th>
<th>Laxatives given</th>
<th>Suppositories/ena/ washout</th>
</tr>
</thead>
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