

Health and Social Care Committee inquiry into Integrated Care Systems: autonomy and accountability

Response from the Paediatric Continence Forum

About the Paediatric Continence Forum

The Paediatric Continence Forum (PCF) is an independent national campaign group of health professionals, patient representatives and commercial members that seeks to raise awareness of children's and young people's bladder and bowel problems, and to improve NHS services in this often-neglected area of paediatric health.

It has close links to the charities ERIC (The Children's Bowel & Bladder Charity) and Bladder & Bowel UK, with a membership that includes formal representation from the Royal College of Nursing (RCN), Royal College of Paediatrics and Child Health (RCPCH), the Community Practitioners' and Health Visitors' Association (CPHVA) and the School and Public Health Nurses Association (SAPHNA), as well as representation from across the devolved nations.

The PCF's vision is for every child to be able to receive the support they require so that any bladder or bowel condition is identified, assessed, and treated promptly to allow them to achieve their maximum quality of life and full potential and maximise efficient use of finite NHS resources.

What scope is there for variation between ICSs, to enable them to improve the overall health of the populations they serve and tackle inequalities?

Variation between ICSs may in certain instances enable the reduction of inequalities.

Data from the PCF's latest Freedom of Information project ([see report here](#)) has shown vast disparities in the ability of ICSs to deliver adequate and accessible paediatric continence care (see pages 27-30), defined by the PCF as a single integrated, community-based, nurse-led service covering all aspects of bladder and bowel care (see PCF's [Children's Continence Commissioning Guide](#)). The disparities in service provision are evident with only 51.8% of CCGs in England commissioning for all of the main children's bladder and bowel services: daytime wetting, bedwetting, constipation, soiling, delayed toilet training and product supply to children who are unable to be continent. Disparities are further reflected in the staffing levels and caseloads where services exist, with some caseloads as low as 50, with others reaching over 11,000. Regardless, sparse levels of staffing for very high caseload numbers – with an average number of whole-time equivalent (WTE) staff of just 1.85 for an average caseload number of 495.1, inevitably restricts the quality, responsiveness, and effectiveness of services for children and young people that need it.

Given that the data – which was collected by CCGs but mapped onto ICSs in the PCF's report – shows vast variation in the quality of paediatric continence service provision within individual ICSs, there is equally a need for variation in how each ICS's integrated care strategy addresses the local provision of paediatric continence care. For example, those ICSs that encompass former CCGs which have stated an intent to commission a new paediatric continence service and/or improve their current service (such as Bedfordshire, Luton and Milton Keynes ICS), should be allowed to preserve their local autonomy to enable service leaders to undertake the commissioning or improvements. However, for those ICSs with a lack of appropriately resourced community-based, nurse led bladder and bowel services for children and where there are varying levels of intent to update paediatric continence provision (such as East London Health & Care Partnership), a degree of oversight and accountability from the overarching ICS would be useful. This would ensure services have the expected level of resource and accessibility to be able to provide appropriate levels of care for affected children and their families to improve outcomes. Furthermore, this has been demonstrated to be highly cost-effective (see the [Children's Continence Commissioning Guide](#)).

How can it be ensured that quality and safety of care are at the heart of ICB priorities?

Embedding the establishment (where not already in place) and maintenance of a properly resourced integrated, nurse-led continence service into all ICBs' priorities will ensure that the quality and safety of care of children is prioritised.

The PCF's data indicates that, in 2021, only 37.7% CCGs had a service led by a specialist paediatric continence advisor. Lack of integration and appropriate leadership for children's continence services across the country, together with a general lack of plans to commission new paediatric continence services where they are missing, presents a threat to the quality and safety of care that is provided to children with bladder and bowel issues. There is evidence that bladder and bowel issues are highly stressful for children, young people and their families, as well as damaging to the child's emotional and physical development and their school attainment. While issues can be faced by any child and have a high prevalence (up to 30% of children have constipation, which becomes chronic in about a third and is closely linked to bladder problems), there is an increased prevalence for those with additional needs. Additionally, bladder and/or bowel issues can be associated with safeguarding concerns.

Without greater availability of services children will continue to present inappropriately at A&E, will continue to be referred to more expensive consultant-led care, rates of admissions for faecal impaction will not fall and product provision for children with additional needs who could be toilet trained will remain higher than it should be. Without integration of children's continence services, primary healthcare professionals (GPs, school nurses and health visitors) and families will continue to face significant administrative challenges in accessing appropriate care and in coordinating different clinics, which in turn affects the experience of the child in receiving care and increases costs to the NHS.

How can a focus on prevention within ICSs be ensured and maintained alongside wider pressures, such as workforce challenges and the electives backlog?

Ensuring that each ICS's integrated care strategy mandates integrated, community-based, nurse-led paediatric continence provision, would play a vital role in early detection, and effective intervention for childhood continence problems. A key role for the ICS's is enabling the promotion of good bladder and bowel health from birth. Providing support, education and resources for families so they can adopt good practice, identify concerns and know how to get appropriate help will reduce the demand on specialist continence services. This is a responsibility for all professionals working with children families and must be integral to Family Hubs and the Best Start in Life – both high profile early years programmes under the remit of ICS's.

These actions will not only reduce the postcode lottery of access to good quality continence services and reduce the risk of an overburdening an already depleted school nurse and health visiting sector, but this would also prevent unnecessary and costly referrals to secondary care, reduce the need for provision of continence containment products (such as nappies and pads), and therefore make better use of restricted NHS resources.

Furthermore, appropriate paediatric continence provision would ensure that there were specialist nurses available to support and teach primary healthcare and education professionals about childhood bladder and bowel issues, including early potty training which reduces likelihood of later bladder issues and about the symptoms of constipation. If addressed proactively and promptly constipation is less likely to become chronic. Chronic constipation can take months or years to resolve and is more costly to treat.

An effective system of early detection and prevention can radically reduce the likelihood of children with functional bladder and bowel issues having to be hospitalised for treatment. This in turn prevents further exacerbating hospital backlogs across the country, while also reducing the burden on workforce of

children needing multiple review appointments and repeat prescriptions. The PCF has previously calculated that an optimised care pathway for a typical child with bedwetting would cost approximately £318, compared with £2,118 for a sub-optimal pathway¹. With each case saving an average of £1,800, prioritising the prevention agenda has the potential to free up vast resources across NHS services. Similar and significantly greater cost savings were demonstrated for a typical child with constipation and with intractable constipation^{2 3}.

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¹ Paediatric Continence Forum, 2018, 'Children's continence care: sub-optimal pathway versus optimal pathway'. DOI: <https://www.bbuk.org.uk/wp-content/uploads/2018/05/PCF-Tobys-sub-optimal-versus-optimal-pathway.pdf>.

² [The 'Right Care' approach for treating intractable idiopathic constipation in children.](#)

³ [The 'Right Care' approach for treating idiopathic constipation in children.](#)