

## **Health Select Committee – Shortage of nurses inquiry Written evidence from the Paediatric Continence Forum**

---

### **Executive summary**

- This submission argues that there are significant threats to the delivery of paediatric continence care related to the nursing workforce.
- Firstly, the difficulties in recruiting and retaining nurses more broadly will impact upon the availability of specialist paediatric continence nurse specialists to lead dedicated community-based paediatric continence services (Level/Tier 2).
- Secondly, changes to the commissioning of school nurses and health visitors which were introduced in 2015 has had a negative impact upon the provision of Level/Tier 1 services, as many cash-strapped local authorities are not commissioning in this area of child health. School nurses and health visitors play an important role in the prevention and early identification of toilet training and continence (bladder and bowel) difficulties – plus early assessment and treatment. Reductions to this service are having a negative impact on both primary and secondary care services, particularly in areas where there are no Level/Tier 2 services. This results in more pressure on GPs and inappropriate and costly referrals to secondary care (see point 4.2 of this submission).
- Thirdly, the consequences of this de-commissioning school nurses and health visitors at Level/Tier 1 is resulting in the loss of their skills in relation to toilet training and assessment and treatment for continence problems built up over many years, via day training courses run by the voluntary sector, including ERIC, The Children’s Bowel and Bladder Charity, and Bladder and Bowel UK. The considerable experience and expertise in this area of child health will be lost unless something is done to redress the situation. There are estimated to be over 750,000 children and young people over the age of 5 in England with bladder and bowel difficulties – not an insignificant number.

### **Background to the Paediatric Continence Forum**

1.1 The Paediatric Continence Forum (PCF) is an expert group of patient representatives and healthcare professionals, campaigning to improve services for children with continence problems (sometimes called bladder and bowel dysfunction, or bedwetting, daytime wetting and constipation/soiling) in all settings across the UK. Established in 2003, it works closely with the national charities ERIC and Bladder and Bowel UK, and with representation from the Royal College of Paediatrics and Child Health, the Royal College of Nursing, the School and Public Health Nurses Association and the Community Practitioners’ and Health Visitors’ Association.

1.2 The PCF campaigns to ensure that every area in the UK has a proper community-based integrated paediatric continence treatment service, nurse-led by an expert paediatric continence specialist, with a clear system of referral and care pathways across primary and secondary NHS care, education and social services. Better paediatric continence services will support the ambitions of the Five Year Forward View and STPs, delivering significant savings for the NHS and vastly improving the quality of care for children – as bladder and bowel dysfunction can worsen if not treated in an appropriate and timely manner.

1.3. The PCF has published a NICE-accredited Paediatric Continence Commissioning Guide, which advises commissioners and providers how to commission integrated paediatric continence services.

This explains the difference between Level/Tier 1 and Level/Tier 2 paediatric continence services. This can be found at [www.paediatriccontinenceforum.org/resources](http://www.paediatriccontinenceforum.org/resources), and was last updated in October 2015.

1.4. UK-wide data suggests that about one in 10 children have a continence problem, with NICE estimating in 2010 that 900,000 children between the age of five and 18 in the UK suffer from bladder and bowel dysfunction<sup>1</sup>. This figure is likely to be an underestimate because of under-reporting of conditions.

### **Shortfall in nursing staff**

3.1 The PCF welcomes the Committee's focus on an emerging shortfall in nursing staff and the impact that this could have on patient care. The PCF conducted a Freedom of Information audit in 2011, 2014 and 2017 to explore the provision of paediatric continence services by CCGs and Health Boards across the UK, and in 2014 and 2017 this included a question asking whether the services were led by a specialist paediatric continence nurse adviser. Bearing in mind that only 39% of CCGs provided all four paediatric continence services in 2014, rising to 43.20% in 2017, a worryingly small proportion of CCGs offered services led by a specialist adviser – 20% in 2014, and 23.3% in 2017.<sup>2</sup>

3.2 The PCF is therefore concerned both with this existing shortfall, and the possibility of this worsening in future if new entrants to the nursing workforce do not receive training and guidance from experienced professionals because they are already in short supply. As well as wider expertise around treatment for continence problems, there are particular risks around the loss of skill sets relating to toilet training and assessment built up through years of training delivered by voluntary sector partners such as ERIC, The Children's Bowel and Bladder Charity and Bladder and Bowel UK.

3.3 The consequences of this shortfall are considerable. A staff shortage will put pressure on community services, lengthening waiting times and impacting upon the quality of care given to each child. There will also be more pressure placed on GPs. The ultimate consequence of this is an increase in inappropriate and costly referrals to secondary care services.

3.4 There are further concerns around a similar shortfall impacting the school nursing workforce. In areas where there is not a Level 2 integrated, community-based paediatric continence service, school nurses and health visitors have traditionally been a first point of contact for concerned parents. A combination of budgetary pressures and the transfer of school nursing commissioning in 2015 has resulted in anecdotes of school nurses working across multiple schools and experiencing greater pressures, therefore reducing their ability to address childhood continence problems. This has been exacerbated by an assertion from Public Health England that "...clinical support for enuresis [bedwetting] and incontinence lies with NHS England", which has also resulted in many school nurses having continence removed from their list of responsibilities.

---

<sup>1</sup> NHS Modernisation Agency (2003) Good practice in paediatric continence services – benchmarking in action. London: Department of Health

<sup>2</sup> 'An examination of paediatric continence services across the UK', Paediatric Continence Forum, available at <http://www.paediatriccontinenceforum.org/wp-content/uploads/2017/10/An-examination-of-paediatric-continence-services-across-the-UK-PCF-August-2017.pdf>, p.8.

## **Evidence on the financial implications of poor paediatric continence services**

4.1 As referenced above, if paediatric continence problems are not diagnosed and treated in a timely and appropriate manner, this often results in a deterioration of symptoms and the risk of referral to secondary and tertiary outpatient care. The PCF has estimated in the Paediatric Continence Commissioning Guide that if children and young people are seen by paediatric continence services, this costs at least £17.66 per hour before any additional costs, whereas the average cost of an outpatient attendance is £108, the average cost of an A&E attendance is £114 and the average cost of a day case is £693. This indicates the substantial additional costs arising from unnecessary secondary care referrals.<sup>3</sup>

4.2 Moreover, the PCF has also undertaken work to compile two typical care pathways for children's continence care, showing a sub-optimal care pathway without referral to a community-based paediatric continence service and an optimal pathway when the service is utilised.<sup>4</sup> These highlight that following a sub-optimal pathway could incur costs of up to £2,118, while following an optimal pathway – involving specialist paediatric continence nurse advisers – would only incur costs of £318. This demonstrates the value for money that can be achieved by properly resourcing an integrated, community paediatric continence service – a feat that will be jeopardised if the nursing workforce is not adequately trained or resourced itself.

4.3 Finally, recent analysis by Bladder and Bowel UK has identified that following an optimal over a sub-optimal patient journey for idiopathic constipation in children can result in a saving of £6,769 per child – as an optimal pathway includes identifying and treating the constipation at an early stage in the community – thereby preventing expensive interventions in an acute setting.<sup>5</sup>

**Submitted by the Paediatric Continence Forum  
November 2017**

For further information, please visit [www.paediatriccontinenceforum.org](http://www.paediatriccontinenceforum.org), or contact us at [paediatriccontinenceforum@whitehouseconsulting.co.uk](mailto:paediatriccontinenceforum@whitehouseconsulting.co.uk) / 020 7463 0697.

---

<sup>3</sup> Paediatric Continence Commissioning Guide, available at <http://www.paediatriccontinenceforum.org/wp-content/uploads/2015/09/Paediatric-Continence-Commissioning-Guide-2014-PCF.pdf>, p. 46.

<sup>4</sup> Children's continence care: sub-optimal pathway versus optimal pathway, available at <http://www.paediatriccontinenceforum.org/wp-content/uploads/2017/07/PCF-Tobys-sub-optimal-versus-optimal-pathway-14th-March-2017.pdf>.

<sup>5</sup> Further information on this can be obtained from Bladder and Bowel UK on request from [June.Rogers2@disabledliving.co.uk](mailto:June.Rogers2@disabledliving.co.uk).