

A manifesto for improving paediatric continence services across the UK

About one in 10 children and young people are affected by continence (bladder and bowel) problems, causing them significant difficulties in terms of family relationships, bullying and self-esteem. These problems can be alleviated – and NHS resources saved – through referral to an appropriate paediatric continence service, but this unfortunately does not happen consistently across the UK. In this manifesto, **the Paediatric Continence Forum (PCF)*** outlines what policy changes are needed to improve the situation for this often-neglected group of children and young people.

➤ **All children should have access to integrated, well-resourced paediatric continence services**

Bedwetting, daytime wetting, constipation and soiling can all substantially impact upon a child's emotional and physical development, but can be alleviated with timely and appropriate treatment. Each area of the UK should have equitable access to **an integrated** (offering services for each area of continence “under one roof”), **well-resourced, community-based paediatric continence service**, led by a specially-trained paediatric continence nurse specialist, to provide the best quality of care for children and their families. However in practice this provision varies considerably across the UK; only 31% of English CCGs have an integrated service, compared with 60% of Health Boards in Northern Ireland, 21% in Scotland and none in Wales.

➤ **The PCF's Commissioning Guide should be utilised to improve the quality of services**

The PCF's [Commissioning Guide](#) is accredited by NICE and endorsed by the Royal College of Paediatrics and Child Health (RCPCH), the Royal College of Nursing (RCN) and the Community Practitioners' and Health Visitors' Association (CPHVA). It provides **clear advice to commissioners and healthcare professionals** on how to commission proper integrated, community-based paediatric continence services. It outlines how identifying and dealing with these problems early saves children from unnecessary emotional distress - and saves NHS resources by reducing expenditure on complications that require acute hospitalisation. This Guide should be used widely to improve the quality of paediatric continence services nationwide - but recent PCF research indicates that only 50% of English CCGs; 80% of Northern Ireland Health Boards; 30% of Scottish Health Boards and 42% of Welsh Health Boards are utilising this crucial resource.

➤ **Continence should be considered when making policy on childhood health, disability and education**

While continence services are largely determined at a local level by CCGs and Health Boards, continence also impacts upon other policy areas, including education. For example, of the 800,000 children and young people with a physical or learning disability, approximately half have continence difficulties. Continence can also affect a child's educational experiences, with a 2014 survey by the Association of Teachers and Lecturers finding that only 31% of nursery and primary schools had a written policy covering continence. We are calling on all four nations of the UK to **consider the role of paediatric continence services when considering issues relating to childhood health, disability and education** in a “joined-up” manner, so that continence issues are fully addressed as part of wider policy making.

**The Paediatric Continence Forum (PCF) is an independent group of parents and healthcare professionals that engages with the Government and healthcare organisations, with the aim of improving paediatric continence services nationally. Formed in 2003, the PCF has close links to the charities ERIC - The Children's Bowel and Bladder Charity and Bladder and Bowel UK (formerly PromoCon) - and formal representation from the RCPCH, the RCN, the CPHVA and the School and Public Health Nurses Association (SAPHNA).*