

## A manifesto for improving paediatric continence services

About one in 12 children and young people are affected by continence problems, causing them significant difficulties in terms of family and social relationships, as well as for some the risk of medical complications. Constipation and bedwetting are now the most common reasons for referral to paediatric outpatient clinics. In this manifesto **The Paediatric Continence Forum (PCF)\*** outlines four key policy areas which are needed to improve the situation for this often neglected group of children.

### All children should have access to timely and effective treatment

Bedwetting, daytime wetting, constipation and soiling, occur at a sensitive time in a child's emotional and physical development. They contribute to family stress, to the very real risk of bullying and can hinder children from taking full advantage of social and educational opportunities at school. Complications, such as kidney infections and chronic constipation/impaction are also a clear risk for acute hospitalisation. Prevention, early detection and effective intervention are therefore vital to deal with these problems effectively.

### All areas should have an integrated paediatric continence service which provides the four key services (bedwetting, daytime wetting, toilet training and constipation/soiling)

A single, integrated, community-based service under the leadership of a specialist paediatric continence adviser provides the best quality of care. A Freedom of Information (FOI) survey conducted by the PCF in August 2014 revealed that clinical commissioning groups (CCGs) in England are failing to provide proper integrated paediatric continence services. Only 35% of the 208 responding CCGs commission all the four services - with just 24% commissioning services that are fully "joined up". Responses from Scotland and Wales indicated that 64% and 67% of Boards respectively provided all 4 services, but 36% and 33% of these were "joined up". Action is needed at local and national level to improve this situation; in short, effective local services are needed to correct the continence problem, not just provide expensive nappies!

### The Paediatric Continence Forum's Commissioning Guide should be used widely to improve the quality of services

Accredited by NICE and endorsed by the RCPCH, the RCN and the CPHVA, this [Guide](#) 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.

### 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, continence also impacts on a wide variety of policy areas. For example, of the 800,000 children and young people with a physical or learning disability, approximately half have continence problems. Incontinence can also affect a child's educational opportunities - but despite this, a February 2014 survey by the Association of Teachers and Lecturers found that only 31% of nursery and primary schools had a written policy to cover this area. In addition, many schools have poor quality toilet and washroom facilities, which exacerbate these problems. These examples demonstrate the need for "joined-up thinking" - so that continence issues are properly considered as part of wider policy making.

*\*The Paediatric Continence Forum (PCF) is an independent group of concerned doctors and nurses which was set up in 2003 to improve NHS continence services and to increase awareness amongst policy-makers of the needs of children and young people with continence difficulties. It has close links to the charities ERIC (Education and Resources for Improving Childhood Continence) and PromoCon and formal representation from the Royal College of Paediatrics and Child Health (RCPCH), the Royal College of Nursing and the Community Practitioners' and Health Visitors' Association (CPHVA). It is an effective and influential campaign group: more details on [www.paediatriccontinenceforum.org](http://www.paediatriccontinenceforum.org)*