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Dear Mr Stevens,

We are writing to you as organisations with an interest in ensuring the provision of effective continence care across England to express our concern about the poor state of NHS community-based services for the one in ten children and young people with bladder and bowel (continence) problems. Services in this area of child health are fragmented and inadequate – and have deteriorated further as a result of the recent transfer of responsibilities for school nurses and health visitors from NHS England to local authorities. We have learnt from practitioners in this field that in line with Public Health England's advice many local authorities have already withdrawn continence from the list of school nursing duties, which has led GPs to inappropriately refer these children to secondary or tertiary care, a situation that is also in part due to limitations in the availability of specialist nursing support. The consequence is poorer patient experience and without the close follow-up necessary for better clinical outcomes.

Failure to improve effective community continence services for these children also has significant financial implications. A secondary and tertiary outpatient referral costs the NHS £160 to £220 for first appointments and £94 to £123 for follow-ups. This is compared to referral to a specialist nurse in primary care costing on average £80 for an assessment appointment and £56 for each follow-up appointment (considerably less for a telephone follow-up). Additionally there is an increased likelihood of avoidable A&E attendances costing on average £114 and the risk of admission.

Against this background we welcome the recent publication of NHS England's Excellence in Continence Care Guidance and applaud its stated aim of improving services and the lives of people with bladder and bowel problems. We are keen however to be reassured that NHS England and the Department of Health will take steps to ensure that this guidance is properly implemented.

We particularly welcome the recommendations that:

- paediatric continence services should provide treatment for all children and young people from birth to 19 years old, including those with learning difficulties and physical disabilities;
- there should be one community-based service for children and young people with all wetting (daytime and bedwetting), constipation and soiling problems;
- services should be led by a paediatric continence nurse specialist with input from a multi-disciplinary team; and
- there should be clear and effective referral and care pathways to secondary/tertiary care, education, Child and Adolescent Mental Health Services (CAMHS) and to social services.

As I am sure you are aware, there is good evidence that if not effectively treated, continence problems can have a significant and negative impact on children and young people and their families. They can increase the risk of bullying and the onset of behavioural and emotional problems – leading to difficulties

at school. While most parents are supportive, there is also some evidence of a direct link with child punishment and abuse – as was the case for Victoria Climbié.

Public Health England, in its January 2016 guidance for directors of local authorities on commissioning of health visitor and school nursing services, states that through identifying and referring continence problems early, school nurses and health visitors can contribute to year-on-year improvements in the number of children achieving their potential through better school attendance. It also explicitly states: “commissioning clinical support for enuresis or incontinence lies with NHS England and clinical commissioning groups (CCGs), to ensure co-ordinated support across the life course. There will need to be joint working and collaboration with local authority commissioners and providers of public health nursing services”.

The national picture confirms that much more work needs to be done to improve the current state of paediatric continence services. A Freedom of Information (FOI) survey conducted by the Paediatric Continence Forum in August 2014 revealed that CCGs in England are failing to provide proper integrated services. All 211 CCGs responded to the survey, yet with only 39% saying that they commission all the four main continence services (covering toilet training, bedwetting, daytime wetting and constipation/soiling) – with just 26% commissioning services that are fully “joined up”. The situation has barely improved since CCGs took over responsibility from primary care trusts in April 2013.

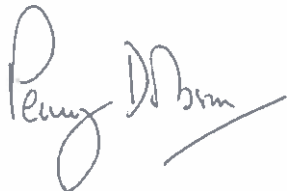
Current government policies seem to be reducing community services provided by local authorities, which is contrary to the vision expressed in the Five Year Forward View. We are keen therefore to see that the important Excellence in Continence Care Guidance is used effectively to make a difference for this often neglected group of children.

With this in mind, we would appreciate your clarification on the plans NHS England has to:

- encourage commissioners to implement the guidance
- audit the success of its uptake

We look forward very much to your reply.

Yours sincerely,



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Chair, Paediatric Continence Forum



Janet Davies
General Secretary, Royal College of Nursing



Professor Neena Modi, President
Royal College of Paediatrics and Child Health



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