

Transparency in Outcomes – A Framework for the NHS Consultation Response from Paediatric Continence Forum

Executive Summary

- Continence (bladder and bowel) problems affect about 1 in 12 children and young people and are associated with bullying, loss of self-esteem and family stress, including parental punishment. Continence was a symptom of maltreatment in the tragic death of Victoria Climbié, which was not picked up by healthcare staff
- NHS treatment services are currently fragmented and inadequate, with bladder and bowel problems often being treated in separate services, causing inappropriate referrals, additional stress to families and unnecessary cost to the NHS
- Services need to be commissioned to treat bladder and bowel problems as one integrated service (usually community-based), each with a trained paediatric continence adviser as “lead”. This would save NHS money and provide better outcomes for the child or young person
- There should also be an identified “lead” allocated within each GP consortium to liaise with the paediatric continence service lead
- Physical (health, social, psychological and educational elements) within these conditions require a “joined up” approach to achieve better outcomes and a cost effective service
- Early identification and effective treatment would prevent additional problems developing and reduce the number of families attending outpatient or A&E Departments
- Improvements to water and toilet provision and access in schools would prevent bladder and bowel problems from developing
- There needs to be a Quality Standard on bladder and bowel care in children and young people
- The NICE guideline on childhood constipation (published May 2010), the forthcoming NICE guideline on bedwetting (due October 2010) and a NICE commissioning guide on paediatric continence are welcomed, but need to be taken up by healthcare staff and commissioners

About the Paediatric Continence Forum

1 The Paediatric Continence Forum (PCF) is a national group of patient representatives and healthcare professionals, supported by industry members, concerned about the poor state of services for children with continence (bladder and bowel) problems. The Forum came together in 2003 to discuss ways forward with policy-makers and the NHS around the formation of the Children’s National Service Framework (2004). It works closely with the national charity ERIC (Education and Resources for Improving Childhood Continence).

About Bladder and Bowel (continence) problems

2 Bladder and bowel problems affect about 1 in 12 children and young people, yet are often hidden, due to their social stigma. They can cause children to be bullied at school, result in loss of self esteem – and cause stress to families. Research indicates that

about 22% parents punish their children for wetting or soiling episodes¹ and there is a link with child abuse (as in the case of the late Victoria Climbié). They are mostly treatable conditions.

3 This is an area of child health in which coordination between health, education, psychology and social services is particularly essential. Yet the 2004 National Service Framework (NSF) acknowledged that there were “ *big gaps in service provision for children with continence problems, which lead to inappropriate referrals and wasted resources*. It recommended “ *an integrated, community-based paediatric continence service, informed by Good Practice in Paediatric Continence Service and ensures that accessible, high quality assessment and treatment is provided to children and their parents/carers in any setting*” (NSF 2004 Standard 6 p30)

The above policy has been confirmed by “Achieving Equity and Excellence for Children” with a holistic approach to healthcare.

4 ERIC research (2008: see para 22) and recent service case histories, indicate that paediatric continence services (mostly community-based) remain fragmented and inadequate, with few properly trained paediatric continence nurse “leads”. The situation is being further decimated with PCT savings. One difficulty is that children and young people who have more than one continence condition (e.g. daytime wetting or soiling, as well as bedwetting”) are being passed “from one service to another”, with long delays and a compromised treatment programme.

5 In addition, many children who have specialised bladder and bowel surgery are reliant upon the tertiary centres sending out specialist nurses to complete follow up as there is no specialist nurse locally. Domiciliary visits are being reduced and this leaves children with no regular follow up, leaving them vulnerable to post operative complications, particularly if they have to catheterise. This can lead to infection, reduced kidney function and the need for more technical and costly interventions.

6 The PCF therefore welcomes the NICE guideline on constipation in children (published in May 2010) and the forthcoming publication of a NICE Guideline on nocturnal enuresis (due October 27th 2010). The PCF also welcomes the publication of a NICE Commissioning Guide on paediatric continence (due to be published early 2011). However there needs to be a mechanism to encourage these to be effectively used by healthcare staff and commissioners.

7 In conjunction with the organisation ERIC and the PCF, the Department of Health has published a second Care Pathway (exemplar) on paediatric continence as a tool to help healthcare staff put the 2004 National Service Framework into practice: *The National Service Framework for Children, Young People and Maternity Services – Continence issues for a child with learning difficulties*.² This complements the first Exemplar, with a child with a bedwetting problem, published by the DH in 2007 and available on the DH website at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_079004.

¹ Butler R ALSPAC study Child: Care, Health & Development 31,6,659-667

² Available from: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets@dh@en@ps

The PCF welcomes the opportunity to respond to the following consultation questions:

1. Do you agree with the key principles which will underpin the development of the NHS Outcomes Framework (page 10)

8 The PCF agrees with the key principles of the NHS Outcomes Framework, especially the development of strategies that ensure organisations provide integrated healthcare services. This was also recognised by the Sir Ian Kennedy report, It is particularly important in the case of children's continence services, where there are often clinical, social, psychological and educational issues for any one child and family. The principle of "promoting excellence and equality" is one that the PCF and the charity ERIC fully support. In this area of child health there are well worked out tools (NICE Guidelines as mentioned above, guidelines for service delivery and well attended accredited training programmes run by ERIC) However the highly committed nurses and doctors running the services are not given the time or resources to carry out the "excellence"!

9 The recent Royal College of Physicians audit on continence services for adults identified patchy service provision, lack of diagnosis, treatment and reliance on using continence pads, rather than prevention techniques. This situation is also consistent for children's continence services. There is evidence that, with financial restrictions tightening, even the provision of continence pads are being restricted.

10 The PCF agrees that outcome measures are a good way of measuring and improving standards. Those who are working in this area of child health are keen to develop appropriate outcome measures.

11 The PCF recognises the practical challenges of integrating services at a local level. The above Care Pathways (Exemplars) provides clinicians and commissioners with practical examples of how to work in partnership with other services.

12 The care pathways/ Exemplars (see para 7) highlight a set of standards in treating paediatric continence problems through early identification and intervention, multi-agency cooperation between partners, and timely access to the appropriate services. It also notes the importance of listening to children and their parents, providing them with information about services and treatments, and coordinating health, social care and education services to meet individual needs.

5. Do you agree with the five domains that are proposed in Figure 1 (page 14) as making up the NHS Outcomes Framework?

13 The PCF agrees with the five domains proposed in the document, however, an additional domain could be included. This domain could be directed at early identification of illness and intervention. This could be linked to the domain to help people recover from illness. For example, the NICE Guideline on the treatment of constipation in children emphasises that early identification and effective treatment is crucial to outcome. The Children's NSF also emphasises the importance of promoting the health and well-being of all children through a co-ordinated programme of action, including prevention and early intervention wherever possible, to ensure long term gain. This would be led by the NHS in partnership with local authorities. This domain, while being taken from the *Children's NSF*, would be relevant to patients of all ages.

14 The PCF would like to raise the need for proper transitional arrangements for young people between child and adult health services.

15 The new commissioning frameworks must have access to expert opinion before developing service specifications. The risk for continence provision for children is that it is currently treated as a low priority, and that commissioners will continue to provide mediocre services. This will cause stress and anxiety for children and young people who have a bladder or bowel problem. It is hoped that the new commissioning guide for continence, to be published by NICE during early 2011 will be widely used to improve commissioning in this area of child health.

6. Do they appropriately cover the range of healthcare outcomes that the NHS is responsible for delivering to patients?

16 The Five Domains of the NHS Outcomes Framework do not address sufficiently the issue of early detection of conditions in childhood – to prevent further complications and therefore prevent additional costs to the NHS. For example, as the NICE guidelines on constipation outline, early detection and effective early treatment of constipation avoids the onset of impaction, with its associated and often long-term difficulties to the child and family – and extra costs to the NHS (childhood constipation is the cause of 25% of Outpatient Dept visits and a significant cause of families attending A&E Departments)³ In the case of daytime wetting, early detection and effective treatment will prevent the potential onset of kidney complications.

17 The NHS Commissioning Board should be developing *national* service level agreements based on NICE guidelines, DH guidance and benchmarks. For bladder and bowel services the national service level agreements should be sent for comment to patient's associations; ERIC, the Royal College of Nursing, UK ICS (International Children's Continence Society) and the Association for Continence Advice.

18 As outlined in the review by Professor Sir Ian Kennedy, in addition to an emphasis on early intervention, is the importance of prevention. For children with continence problems access to and use of good water and toilet facilities in schools is a major preventative issue. It is known that when children drink good levels of fluids during the school day and feel comfortable about using the toilets, problems such as bedwetting and constipation can be prevented or resolved. Unfortunately this is not the case in many schools, with evidence that poor toilet provision (dirty, lack of privacy, sites for bullying) cause children not to use them. A formal review of the 1999 School Premises Regulations relating to water and toilet provision carried out immediately prior to the Election by Partnership for Schools, in conjunction with the charity, ERIC, produced Amendments to the Regulations that were not in time for ministerial "sign off" before the purdah period. The Amendments and the associated reports have been brought to the attention of and remain tabled with the current ministerial team.

³ Research by Dr K Price, Sheffield Children's Hospital in 2003 found that a quarter of children attending paediatric outpatient clinics had problems relating to constipation
www.bog-standard.org/adults_survey_results.aspx

13. Are either of the suggestions at para 3.19 (page 24) appropriate overarching outcome indicators for this domain? Are there any other outcome indicators that should be considered?

19 While the PCF thinks the overarching indicators for this domain are appropriate, there is still room for wider scope. Indicators specific to children could be introduced, and outcome indicators for nocturnal enuresis, daytime wetting and constipation/soiling could be developed.

15. As well as developing Quality Standards for specific long-term conditions, are there any cross-cutting topics relevant to long term conditions that should be considered?

20 An issue that requires consideration relates to children's educational performance. The co-ordination of health, social care and education services to avoid any serious effects upon the child's educational development due to continence problems is essential and should be considered seriously. As above, research has indicated that pupils in many of our schools still suffer poor facilities and restricted access. Leaving this issue to the management of individual local authorities and governing bodies has failed to produce and maintain the necessary standards. Improvements to water provision, and particularly toilet and washing facilities, are needed urgently.

We understand that the full contents of the 1999 School Premises Regulations are being reviewed – and we are concerned that this may result in losing, rather than gaining, improvements in this important area.

16. Are the suggestions at para 3.28 (page 27) appropriate overarching outcome indicators for this domain? Are there any other indicators that should be considered?

21 This domain requires an outcome indicator that addresses the problem of standards of treatment within continence care that are currently highly variable. The PCF believes that access to services to support children with continence problems and their families need to be simplified, improved and standardised if children are to recover from their continence problems without these developing into more serious, long-term conditions. Children are at high risk of inadequate care through service delivery by adult continence services and by continence advisers who are not paediatric trained. The high reliance on pads instead of assessing and treating the condition, affects children's potential to thrive and reach their full potential.

22 Services for children across the country are variable and often inadequate. A survey of 800 NHS paediatric continence clinics, carried out by ERIC in 2006 and 2008 showed that most clinics were run by a maximum of 2 nurses, usually on a part-time basis: 40% of these clinics treated wetting only and not constipation/soiling. Only 5% helped children with physical disabilities and only 1 in 3 said that they had easy access to a paediatrician⁴.

20. Do you agree with the proposed interim option for an overarching outcome indicator set out in para 3.43?

⁴ Published in ERIC Update magazine May 2008

23 The PCF agrees with the proposed interim option, particularly the following five themes:

- Access and waiting;
- Safe, high quality coordinated care;
- Better information, more choice;
- Building closer relationships; and
- Clean, friendly comfortable place to be

However the document only outlines the surveys as covering primary care, adult-in-patients, maternity services, and community mental health services. There is a clear need for children's services to be represented among these services.

21. Do you agree with the proposed long-term approach for the development of an overarching outcome indicator set out in para 3.44?

24 The PCF agrees with the proposed long-term approach, insofar as the strategy is to engage patients, thus giving them the services that matter most to them. The PCF believes in listening to children and their parents, not only when planning care but also when co-coordinating services to meet individual needs; this is emphasized in the care pathway published by the Department of Health (September 2010) Continence Services for a Child with Learning Difficulties. However, there also needs to be greater emphasis placed on informing patients so that patients are empowered by knowledge as well as by being given a voice.

25 The PCF is concerned that the specific needs of children will be overlooked and recommends the Child Health Strategy (CHS) as an example of how to engage with children's health requirements. This strategy sets out the plans for universal, targeted and specialist support across three life stages – early years and pregnancy, school-age children, and young people – as well as the additional support for children and young people in need of acute or ongoing healthcare. It also sets out how the delivery system can be supported in taking forward the recommendations – in particular, how the range of services in contact with children and young people can work better together and with families to achieve common aims.

26 Nurse Sensitive Outcome Indicators have previously included catheters because of the increasing risk and costs of treating patients with catheter acquired infection. There are no Nurse Sensitive Outcome Indicators for other paediatric bladder and bowel problems. Benchmarks for paediatric continence provision could easily be adapted to provide an outcome tool. The benchmarks were developed in conjunction with health care professionals and families.

23. Would there be benefit in developing dedicated patient experience Quality Standards for certain services or client groups? If yes, which areas should be considered?

27 The PCF considers there to be a benefit in developing dedicated patient experience Quality Standards for paediatric continence care. There is evidence that parents of children with children with continence difficulties experience a sense of hopelessness and isolation, which radically improve once the continence problem is solved. As

mentioned earlier, there is evidence that 22% of parents punish their children for continence difficulties.

28 These services have been *ad hoc* and vary significantly on a national level. A dedicated patient experience Quality Standard would make the simplification, standardisation and improvement of these services much easier to achieve across all types of continence problem, regardless of underlying, associated or concomitant medical conditions, and throughout the whole of the United Kingdom.

27. What action needs to be taken to ensure that no one is disadvantaged by the proposals, and how do you think they can promote equality of opportunity and outcomes for all patients and, where appropriate, NHS staff?

29 The Child Health Promotion Programme puts in place a framework to promote the health and wellbeing of children and help reduce health inequalities. Universal and targeted health promotion strategies also address inequalities. This includes providing support for children, and those who are homeless or living in temporary accommodation, and those who have fragile social networks. Access to targeted services is improved for those sections of the population where take-up of services has been lower, e.g. children who are not registered with a general practice, and individual children, young people and their families with particular needs, such as looked-after children and juvenile prisoners.

Dr Penny Dobson MBE, Chair: Paediatric Continence Forum 6/10/2010