Commissioning Guide for Paediatric Continence

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Introduction

The Paediatric Continence Commissioning Guide is a resource to assist commissioners, clinicians and managers to deliver integrated and evidence-based community paediatric continence services that meet the needs of children and young people with continence difficulties (bladder and bowel dysfunction) across England. Its aim is to improve the health and wellbeing of these children and young people through supporting local service redesign that is high quality and cost effective and takes into account patient experience.

The High Value Care Pathways within this document provide a clear description of what constitutes a high quality service. These Pathways, along with the Quality Dashboards, can be used to assess current performance against evidence-based measures of best practice and identify priorities for improvement. Audit and peer review measures support the implementation of the recommendations through commissioning and the contracting process.

Implementation of this guidance is the responsibility of local commissioners and/or providers, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of access. Nothing in the guidance should be interpreted in a way which would be inconsistent to compliance with these duties.

The content of this Guide and its evidence base is predominantly from existing guidance from NICE and Dept. Health, viz: NICE 2010 Clinical Guidelines: CG99 Constipation in Children and Young People; CG 111 The Management of Bedwetting in Children and Young People; NICE 2010 Paediatric Continence Service Commissioning Guide; the 2011 Department of Health Continence Service Implementation Pack (to support AQP). It provides hyperlinks to relevant sections within these documents.

Areas within the Commissioning Guide not referenced by existing NICE Guidance or the Standardisation documents from the ICCS (see 1.6) were systematically reviewed between February and March 2014. This Review included research from 2010 (see 7.1).

This Guide will enable Clinical Commissioning Groups (CCGs) to commission healthcare for their population that meets the 5 domains in the NHS Outcomes Framework:

- Domain 1 Preventing people from dying prematurely
- Domain 2 Enhancing quality of life for people with long term conditions
- Domain 3 Helping people to recover from episodes of ill health or following injury
- Domain 4 Ensuring that people have a positive experience of care
- Domain 5 Treating and caring for people in a safe environment and protecting them from avoidable harm.

Continence difficulties (or bladder and bowel dysfunction) in children and young people have been allocated primarily to Domain 2.
Summary of Recommendations

1. All children and young people from birth to 19 years with bladder and bowel dysfunction (continence problems), including children with learning difficulties and physical disabilities, should have access to an integrated, community-based paediatric continence service: the Community Paediatric Continence Service (CPCS).

2. The Community Paediatric Continence Service (Level 2) should:
   - Treat children and young people with both bladder and bowel problems
   - Consist of a multidisciplinary team led by a paediatric continence nurse specialist
   - Have clear and effective referral and care pathways to secondary care and to education, community mental health (CAMHS) and to social services
   - Train and support local primary care colleagues (community nursing/health visitor staff and GP’s) to enable them to carry out work at the preventative and early treatment stage (Level 1). (See Section 1.7)

3. The key Service Outcome is: To help children and young people to achieve complete continence, or to manage the condition discreetly and effectively if full control is not clinically possible.

Key Outcome Indicators (see Section 1.4)
   - Rates of A&E attendance and unplanned hospitalisation for constipation and urinary tract infection
   - Rates of children starting pre-school (from 3 years) in nappies and overall rates of supply of disposable continence products
   - Percentage of children and young people with bladder and bowel dysfunction successfully treated within the service or post discharge (see Section 3.2)
   - PROMS (Patient Reported Outcome Measures) /FROMS (Family Reported Outcome Measures) from the perspective of the family and child and young person. A Quality of Life Tool is currently being adapted for continence.

4. The service should respond effectively to the child’s physical, psychological and social needs in way that avoids inappropriate referral to secondary care.

5. Re-configuring the service as above can result in large savings. NICE estimate that an effective, community-based, integrated paediatric continence service can “lead to up to an 80% reduction in the number of emergency admissions to secondary care. It should also reduce the need for consultant-led outpatient appointments” (NICE Paediatric Continence Commissioning Guide, 2010: 22). (See Section 1.4)

6. All children and young people accessing the Community Paediatric Continence Service should have a comprehensive bladder/bowel assessment by an appropriately trained healthcare professional followed by a proper treatment programme/care plan. This is particularly important for those children who might need disposable continence products. (See Section 1.7)

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1 Practitioners in Community Paediatrics are obliged to see all those who have special educational needs who are in full time education.


Guidance not covered by the above NICE Clinical Guidelines is based upon evidence from a literature review carried out by the Guideline Development Group (GDG: see 7.4) during February – April 2014. The GDG also reviewed research from 2010-2014.
1. High Value Care Pathway for Paediatric Continence

1.1. Brief description of the condition

The generic term “continence” is interchangeable with the terms “bladder and bowel difficulties”, “bladder and bowel dysfunction” or “wetting and soiling problems”. For the purpose of this specification, we will use the term “continence” or “bladder and bowel dysfunction”. All relate to children and young people birth-19 years, including those with physical disabilities and learning difficulties.

See Appendix 1 for more details of Terminology and Definitions.

1.2. Epidemiology and why continence services are a priority

The National Institute for Health and Care Excellence (NICE) estimates that bladder and bowel dysfunction affects about 900,000 children and young people out of a population of 8,500,000 in the UK (NICE Paediatric Continence Commissioning Guide, 2010: 21). Of the latter, approximately 800,000 have a physical or learning difficulty (1). There is evidence that children with physical disabilities and learning difficulties have a higher incidence of continence problems, either due to an associated disorder of the bladder/bowel, or to their mobility or intellectual impairment (2, 3, 4, 5).

See Appendix 1 for a more detailed breakdown of prevalence and risk factors.

Data is also available on Public Health England: Child Maternal Health Intelligence Network (ChiMat) Website: Continence Needs Assessment module. This document was last updated in July 2013 in conjunction with the PCF: http://atlas.chimat.org.uk/IAS/profiles/needsassessments

The definition of toilet trained is a child who takes responsibility for toileting behaviour. However studies relating to toilet training use different definitions, so comparison is difficult (6, 7). Research relating to bladder and bowel dysfunction has improved, due to international agreement on definitions (see 1.6).

Continence problems are believed to be caused by biological, developmental, genetic and environmental factors. Structural or anatomic causes are rare. They occur at a formative time for children - and influence their health, their wellbeing, and their emotional development. There is evidence that they are associated with emotional and behavioural problems, including a strong association with bullying, both as recipients and perpetrators (NICE Clinical Guideline CG 99, 2010: 5; CG 111, 2010: 4).

They can also reduce self-esteem at a crucial time for a child or young person’s emotional development and risk their exclusion from normal social interaction, such as overnight school trips or sleepovers (NICE Clinical Guideline CG 99, 2010: 4; CG 111, 2010: 4).

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2 This includes children and young people with Autistic Spectrum Disorders, Attention Deficit Disorders and other sensory processing disorders.
Whilst most parents are positively involved and concerned, a significant minority (estimated to be about 30%), respond by punishing their children for wetting accidents. This can result in a ‘vicious cycle’ of increased stress, more accidents, potentially harsher chastisement and the risk of child abuse (8). The research relates to bedwetting, but is likely that constipation/soiling causes even more family difficulties and stress.

There is evidence that once the wetting and soiling is solved, the psychological problems are often resolved (9).

The cost for families can also be substantial. In 1996 it was estimated that a child or young person who wets the bed every night costs the family £1,420 a year in extra washing, bedding, bedding protection and night clothes (10). When inflated by 2.5% per year this would be £2,160 in 2013 prices and for a child who soils regularly, potentially more. It is affecting families with limited incomes even harder of late, as NHS trusts are rationing the number of pads provided to children with intractable incontinence as part of the cost cutting process.

Continence problems are treatable, but may take months or even years to resolve, so it is important that they are diagnosed and managed early. This is particularly important for children and young people with learning and physical disabilities, who have a higher risk of underlying pathology (see Appendix 1). If continence problems are not managed and become chronic, they may result in referral, treatment and/or surgery in secondary care (NICE Clinical Guideline CG 99, 2010: 5).

1.3 Current practice and why there is scope for improvement

There are clear causal links between all the above conditions i.e. children or young people who experience bedwetting may also have daytime wetting; children or young people with constipation/soiling may also have bedwetting/daytime wetting. This reinforces the need for a single paediatric continence service, rather than separating into specific symptom-based services. A key premise of the PCF’s Commissioning Guidance is therefore that NHS community-based services for children with continence problems are fully integrated.

Definition of an Integrated Paediatric Continence Service:-

- one service for children and young people with all wetting and constipation/soiling problems - for children with daytime wetting, as well as bedwetting and constipation/soiling
- treats all children and young people from birth-19 years, including those with learning difficulties and physical disabilities
- is run by a multi-disciplinary team and is led by a paediatric continence nurse specialist
- has clear and effective referral and care pathways to secondary care and to education, CAMHS and to social services.

Research carried out during 1996 and 2009 by ERIC (Education and Resources for Improving Childhood Continence; a registered charity in this field), concluded that continence problems had a greater impact upon family life than was realised; that children and young people often had a combination of wetting and soiling problems; that these were
largely "hidden" - and parents felt inhibited from coming forward for help, partly due to unclear signposting and the complications of having to go to different clinics and different venues and tell the same story (11, 12).

Further research confirmed that only 1 in 3 families seek treatment, due to lack of knowledge of where to go and the associated social stigma (8).

The Royal College of Physicians national audit of continence care concluded that clinical outcomes are higher when a service is integrated (13).

There is, however, evidence that services for children and young people with continence problems are very variable across the UK, with many neither comprehensive nor properly integrated. In 2011 the Paediatric Continence Forum issued Freedom of Information (FOI) requests to 152 PCTs in the UK to assess how their paediatric continence services were being run. Of the seventy-two PCTs that responded:

- 88% commissioned services in the 4 areas (toilet training, bedwetting, daytime wetting, constipation/soiling), but only 51% could say that these were in any way "joined-up", enabling either treatment "under one roof", or with a proper care pathway to the other services
- Only 25% of the sample provided a dedicated paediatric service i.e. most were amalgamated with the adult continence service.

Local data from this research is available on the Child and Maternal Health Intelligence Network website (http://atlas.chimat.org.uk/IAS/profiles/profile?profileId=45&geoTypeId=4).

A survey of adult and child continence services in England carried out by the All Party Parliamentary Group for Continence Care in 2013 (14) showed a deterioration in services compared to a similar survey carried out by the Royal College of Physicians in 2007 (13). This was particularly pronounced in children’s services.

These surveys suggests that little progress has been made since the government’s National Service Framework (NSF) report in 2004 (15), which acknowledged that there were ‘big gaps’ in service provision for children and young people with continence problems, which “has led to inappropriate referrals and wasted resources”.

1.4 Service Outcomes and the cost-benefits of a proper integrated service

Key Outcome
To help children and young people to achieve complete continence, or to manage the condition discreetly and effectively if full control is not clinically possible.

Key Outcome Indicators
1. Rates of A&E attendance and unplanned hospitalisation for constipation and urinary tract infection
2. Rates of children starting pre-school (from 3 years) in nappies

3. Percentage of children and young people with bladder and bowel dysfunction successfully treated within the service or post discharge

4. A Quality of Life assessment from the perspective of the child and young person and the family (the PROMS (Patient Reported Outcome Measures)/FROMS (Family Reported Outcome Measures) are currently being adapted for continence)

Evidence relating to:

Indicator 1

Evidence shows that children and young people are attending A&E and are being admitted as acutely ill for constipation/faecal impaction and the symptoms of urinary tract infections. There is some evidence that more children are being referred to general paediatric outpatients for these conditions (16).

The NICE Commissioning Guide states that an effective, integrated paediatric continence service could ‘lead to up to an 80% reduction in the number of emergency admissions to secondary care, by providing assessment and management of continence problems in primary and community settings’. NICE also acknowledge that integrated continence services would reduce the need for consultant-led outpatient appointments (NICE Paediatric Continence Commissioning Guide, 2010: 22).

Indicator 2

Children are starting pre-school (from 3 years) still in nappies and not toilet trained. Nursery staff do not have the expertise or time to deal with this problem and parents are not always receiving information and support on toilet training. In addition, many children and young people with special needs are supplied with disposable products without undergoing a bladder/bowel continence assessment or trial of toilet training.

There is the potential to reduce costs by reducing the demand for continence products such as nappies or pads (NICE Paediatric Continence Commissioning Guide, 2010: 25).

Indicator 3

See 3.2 for a breakdown of clinical outcome measures.

Indicator 4

As outlined earlier, research indicates that there is a significant link between continence difficulties and behavioural and psychological problems, such as oppositional behaviour and bullying (for perpetrators and recipients) (9). Children and young people with continence problems also feel ‘different’ and it affects their social life and interaction with others.

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3 This excludes those children with special needs who have a toilet training delay

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is evidence that once the wetting and soiling is solved, the psychological/social problems are often resolved (NICE Clinical Guideline CG 99, 2010: 33; CG 111, 2010: 35).

The Paediatric Continence Forum is working with Public Health England to collect data to enable Clinical Commissioning Groups measure how far they are achieving their Outcomes – and thereby assess the associated cost savings. For example: Public Health England is measuring rates of unplanned hospitalisation for constipation and urinary tract infections.

The data is now available and downloadable on the data atlas: http://atlas.chimat.org.uk/IAS/profiles/needsassessments

As mentioned earlier, there is evidence (in the field of adult continence services) that the better a service is integrated, the higher the standard of clinical care (13). Additionally, the NICE Commissioning Guide states “nurse led interventions (in this area) in primary care improves treatment outcomes and is cost effective” (NICE Paediatric Continence Commissioning Guide, 2010: 6).

1.5 Population to whom it applies

The 900,000 children with a continence problem (See 1.2). This includes children with toilet training difficulties relating to a learning difficulty or a physical disability.

According to the National Institute for Health and Clinical Excellence (NICE), 0.8% or 800 per 100,000 of the paediatric population would need to access a paediatric continence service. Children between the ages of birth-19 make up 24% of the total population (12.3 million) (NICE Paediatric Continence Commissioning Guide, 2010: 19).

The Child and Maternal Health Intelligence Network (ChiMat) provides a Needs Assessment module on continence, with local data on the number of children with continence problems (http://atlas.chimat.org.uk/IAS/profiles/profile?profileId=45&geoTypeld=4).

The 2010 NICE Commissioning Guide also has a Commissioning and Benchmarking Tool (http://www.nice.org.uk/proxy/?sourceUrl=http%3a%2f%2fwww.nice.org.uk%2fmedia%2f603%2f06%2fPaediatricContinenceServiceCommissioningAndBenchmarkingTool.xls).

1.6 Description of what is appropriate in each situation and with each group

See NICE Clinical Guidelines


This includes an overview of what constitutes an assessment, with history and physical examination: http://www.nice.org.uk/guidance/CN111/chapter/1-Guidance#assessment-and-investigation

This includes an overview of what constitutes an assessment: 
http://www.nice.org.uk/guidance/CG99/chapter/Key-priorities-for-implementation

**Daytime incontinence**


   **Abstract**
   This article is one of the standardisation documents of the International Children's Continence Society, and discusses how anatomical/iatrogenic and functional/urodynamic causes of daytime incontinence in children of all ages are to be diagnosed, how neurogenic bladder dysfunction or urinary tract infection is excluded as a cause of the wetting, and how further diagnostic evaluation of children with disturbances such as overactive bladder, voiding postponement and dysfunctional voiding is performed. The roles of history taking (including prenatal and perinatal issues and family history), physical examination, diagnostic bladder diaries, noninvasive urodynamic investigations and radiological imaging are delineated but therapy is not within the scope of this document.


**Assessment for toilet training**

The following guidelines and charts have been published by PromoCon:

- www.promocon.co.uk
- PromoCon, Understanding bladder and bowel comorbidities in children and young people with additional needs (2011) http://www.disabledliving.co.uk/DISLIV/media/publicationpdf/The%20Platinum%20Trust%20Resources/17549-bladder---bowel.pdf
- PromoCon, Paediatric Assessment tool for toilet training readiness and issuing of products – score sheet (2011)
1.7 Service description

A model integrated paediatric continence service is community-based, treats children and young people from birth-19 years with the full spectrum of bladder and bowel dysfunction, is run by a multi-disciplinary team and is led by a paediatric continence nurse specialist. The service should have effective referral and care pathways to medical assessment and intervention at primary and secondary care levels and to education and social services.

The service should respond effectively to the physical, psychological and social needs of children and young people with bladder and bowel dysfunction and toileting difficulties, and in a way that prevents inappropriate referral to secondary care. However, where specialist intervention is required, the aim is to transfer care back to the community as soon as appropriate.

All children and young people using the Community Paediatric Continence Service should have a comprehensive bladder and bowel assessment by an appropriately trained healthcare professional, followed by a proper treatment programme/care plan (see Section 1.6).

All children between the ages of 2-3 years with physical disabilities and learning difficulties should be assessed for their “readiness” to start toilet training (both physiologically and in relation to their social awareness and motivation), followed, as appropriate, by a toilet training care plan (see Section 1.6). For some children this will mean focusing upon areas to improve “toilet training readiness” and the necessary equipment the child might require (with, as appropriate, a referral for assessment by an occupational therapist). It might also include an assessment for the appropriate type and daily supply of disposable continence products (see Section 1.6).

The Community Paediatric Continence Service (CPCS) should work closely with (train and support) local GP, community nursing/health visitor colleagues to enable them to carry out work at the preventative early treatment stage (Level 1 – see below). It will also include nurses from special schools for children with physical disabilities and learning difficulties.

Pre-Service Level 1:
This would normally be undertaken by nurses competent in providing advice and information on nocturnal enuresis, constipation and toilet training problems and initiate first line treatments. These could be school nurses, health visitors or community nurses, but would also include GPs.

This includes basic advice and support to, for example, help promote “healthy” bladders and bowels – to reduce the risk of problems, such as constipation, developing, or, once
developed, being missed. It would also include toilet training programmes, assessing and reviewing input and output charts (bladder/bowel/fluid diaries) and introducing first line treatments, including; toileting and fluid/diet advice, treatments for bedwetting e.g. enuresis alarm or medication and treatments for constipation e.g. use of stimulant laxatives or macrogols (via the GP or a nurse prescriber).

**Level 2: The Community Paediatric Continence Service (CPCS)**

The CPCS assesses and treats children and young people with daytime wetting and those with special needs and more complex bladder/bowel problems. It also treats children and young people where first line treatment (pre-service, Level I above) has not led to a resolution of the problem.

NICE guidance (2010) makes specific recommendations for children and young people who have not responded to treatment and should be referred to and seen by a specialist continence service (Level 2) ([NICE Paediatric Continence Commissioning Guide, 2010: 12](#)): viz: NICE clinical guideline CG99 on constipation in children and young people recommends referring children and young people with idiopathic constipation who do not respond to initial treatment within 3 months to a locally identified practitioner with expertise in the problem ([NICE Clinical Guideline CG 99, 2010: 27](#)). NICE clinical guideline CG 111 on nocturnal enuresis recommends referring children and young people with bedwetting that has not responded to courses of treatment with an alarm and/or desmopressin for further review and assessment of factors associated with a poor response ([NICE Clinical Guideline CG 111, 2010: 25](#)).

At Level 2 children and young people will have a more in depth assessment and treatment programme. The assessment should include: a more detailed health and social history; a physical examination, such as an abdominal examination to assess faecal loading and for a full bladder; assessment of lower limb neurology e.g. assessment of gait and the lower sacral spine (but NOT including digital rectal examination) and ultrasound assessment of bladder emptying.

As above, the treatment programme may include the prescription of stimulant laxatives or macrogols for constipation, desmopressin for enuresis and anticholinergic medication for overactive bladder syndrome. This could be prescribed by a nurse prescriber, a community paediatrician linked to the service, or by the GP – according to the local care pathway.

**Level 3:** This might require referral to a paediatrician in the community, or specialist secondary care - as per the local care pathway.

There are other situations where children with specific conditions need to be identified early and require referral for a medical assessment to a paediatrician in the community, or specialist secondary or tertiary care as per the local care pathway. For example:-

- **A child who has ‘red flag’ symptoms:** NICE clinical guideline CG99 on constipation in children and young people recommends that children and young people with ‘red flag’ symptoms that indicate an underlying disorder or condition that is not idiopathic constipation should be referred urgently to a healthcare professional with experience in the specific aspect of child health that is causing concern ([NICE Clinical Guideline CG 99, 2010: 12](#))
- Children with recurrent febrile UTI’s, abnormal spine, abnormal gait, lower limb neurology, continuous dribbling incontinence in girls, abdominal distension, upper urinary tract abnormality, children with developmental delay or significant behavioural issues

- A child who is suspected of being maltreated: children and young people may develop problems such as bedwetting as a response to emotional difficulties (NICE Clinical Guideline CG89, 2009: 15; CG 99, 2010: 4; CG 111, 2010: 12). NICE clinical guidelines CG99 on constipation in children and young people, CG111 on nocturnal enuresis and CG89 on when to suspect child maltreatment identify when child maltreatment should be considered. Local pathways should identify the action that should be taken if maltreatment is suspected.

1.8 Criteria for referral and care pathways

All children and young people with bladder and bowel dysfunction from birth-19 years should be considered for referral (including those with learning difficulties and those with other special needs). Children and young people should not be excluded from referral to the CPCS purely on the grounds of lack of potential to be toilet trained.

Referral can be via the patient’s GP, health visitor, school nurse, or other local professional, or directly from the parent, carer or young person concerned, for all patients contracted within the CCG area.

Children and young people will access the CPCS at level 2, although the CPCS should provide specialist training, education and support to primary and community care staff delivering services at level 1. This is to include GPs.

Referrals to be triaged on a daily basis and support only appropriate referrals for Level 2 assessments. Triage to be carried out by a specialist paediatric continence nurse(s) who will direct children/parents to the available Level 1 professionals where Level 2 management is not indicated.

Exclusion criteria

- Those living outside the boundaries of the CCG concerned.
- Children and young people who have not been triaged by the clinical specialist.
- Children and young people should not be excluded for assessment and treatment on the basis of their age alone, but at the age of 19 the young person should be transferred into the adult service. This should be a pre-arranged, with a seamless transition.
Care Pathways

Map of Medicine and NICE have produced evidence-based care pathways for paediatric continence services (evidenced algorithms) that can be adapted for local service specifications and the needs of the local population.

NICE care pathway for constipation: http://pathways.nice.org.uk/pathways/constipation


See Appendix 2 for an example of a Care Pathway for bedwetting. Additional sample care pathways will be available on the website of the Paediatric Continence Forum: www.paediatriccontinenceforum.org

1.9 Interface with local services and the third sector: responsibilities of the service

It is the responsibility of the service to provide an integrated model of service delivery and to link seamlessly with all primary care and secondary care specialist services. This includes link nurses, nurses in special schools, allied health professionals (e.g. dieticians, clinical and educational psychologists and the CAMHS team), the school (see School Information Tool Kit http://www.eric.org.uk/InformationZone/Leafletsandresources) and the independent sector. Any contractual relationships should be the responsibility of the service provider.

1.10 Service location

The service must be provided in a geographically convenient, easily accessible community-based location which:

- complies with health and safety legislation
- has disabled access
- has appropriate waiting and treatment areas
- is appropriately furnished and equipped with necessary equipment
- meets cleanliness and hygiene standards
- is easily accessible via public transport
- has available parking for patients.

The service should be well publicised to all local agencies, including GPs, school nurses, health visitors and in local directories and web-based resources.

Clinical assessment and reviews can also take place in a variety of settings, either face to face; for example in clinics in special schools for children with complex needs, or via telephone, as appropriate. The amount of follow-up should be as necessary, but sufficient to reduce the risk of relapse (it is well known that continence difficulties sometimes take years to resolve). In following up it is important to also “touch base” with the child or young person – and to ask their views on how treatment is progressing.
1.11 Staff – numbers, minimum band, experience, skill mix

Key appointments to the CPCS are the service manager and the senior lead clinician (in some services this may be covered by one person, in others two; for example, continence may be managed within the child health services, with the manager also responsible for school nurse and health visiting services). The manager could be a nurse, physiotherapist, or occupational therapist, preferably with an appropriate Masters’ Degree and a management qualification. It is recommended that the senior clinical lead is a paediatric continence adviser - a registered children’s nurse, with at least 5 years’ experience in the continence field.

It is also recommended that there is a community paediatric consultant as part of the multidisciplinary team – or closely linked to the team.

The lead paediatric continence adviser should be on Band 7 as a minimum.

Team size: it is recommended that there is one whole time clinician post equivalent re 100,000 population (see cost effective commissioning for continence care http://www.appgcontinence.org.uk/pdfs/CommissioningGuideWEB.pdf)

The PCF website will have examples of business plans: www.paediatriccontinenceforum.org

It is the responsibility of the service to:

- provide fully skilled, trained and appropriately qualified personnel (see competency schedule within the AQP Continence Service National Implementation Pack: DH 2011, 89) and a competency – based training programme to ensure staff have the required knowledge and skills to deliver safe and effective practice. This will include competencies relating to assessing and treating children and young people with physical disabilities and learning difficulties. Training is available from ERIC www.eric.org.uk PromoCon (Promoting Awareness through Product Awareness) Promocon@disabledliving.co.uk, BAPUN (British Association of Paediatric Urological Nurses) http://www.bapu.org.uk/, BAPU (British Association of Paediatric Urologists) www.bapu.org.uk
- ensure that the specialist nursing staff hold the following qualifications: Registered Children’s Nurse (RCN), health visitor or degree level school nurses. Non-medical prescribing qualifications are desirable
- support continuing professional development for all staff with clinical leadership and supervision. This must involve attendance at secondary care clinic sessions and attendance at conference at least annually
- enable all clinicians where appropriate to attend regular meetings, including Multi-Disciplinary Team training for peer support. Clinicians must be encouraged to engage with any relevant networks across the health economy and should be multi – professional.

NB: ‘Good Practice in Continence Services’ (Department of Health, 2000) good clinical governance principles viz the service should:
• work to best practice evidence-based policies, procedures, guidelines and targets and use locally agreed evidence-based policies, procedures and guidelines where appropriate:

• identify a governance lead, with responsibility for National Patient Safety Agency (NPSA) alerts. Risk management must include the reporting of all clinical incidents to the NPSA anonymously and have a broadcasting system to all health professionals within the service regarding NPSA, MDA (Medical Device Alerts) and medication alerts. The provider must demonstrate the evidence on how this mechanism functions. A governance framework should stipulate the operational management, resources and identify staff numbers, title and Whole Time Equivalent. Information governance toolkit must demonstrate level 2 and above

• ensure the safe delivery of clinical services and provide a leadership structure and governance that is fit for purpose. The provider will be expected to promote a culture of learning within its organisation ensuring the following are provided:
  - Clinical leadership;
  - Integrated governance;
  - Clinical safety and medical emergencies;
  - Safeguarding procedures;
  - Incident reporting

• provide information and advice leaflets, DVDs, visual tools, website for patients (see www.eric.org.uk and www.promocon@disabledliving.co.uk). Other formats, such as Braille, large print, audio cassette or CD, must be made available if the need has been identified. The service should facilitate a group approach and expert patient involvement where appropriate and support carers as required. Information should be age and language appropriate

• be responsive to people with learning disabilities, mental health problems and those from ethnic minority groups. The provider must ensure that all staff undertake mental capacity training, equality and diversity training and conflict resolution training: http://www.equalityhumanrights.com/uploaded_files/EqualityAct/PSED/essential_guidance.pdf

• ensure that staff are specialist, trained and experienced and can fully understand the implications/impact of incontinence on the health and wellbeing. Patients feel that the sensitivity and nature of the condition requires an understanding and empathetic approach, promoting dignity and respect, with a focus on empowering and encouraging patients on all aspects of self-care as part of a value base.

1.12 Access to treatment (response times)

Waiting times from referral to assessment should comply with nationally and locally agreed and commissioned pathways. The service should communicate with the patient’s GP (and the referrer if not the GP) after the first consultation within 5 working days.
1.13 Discharge and aftercare (including transition to adult services)

The patient’s clinical progress, and discharge management/further treatment plans should be reported to the GP by the service provider within 5 working days of discharge. Providers will be responsible for ensuring the accuracy of this information and medication notifications. Any plans for transition to adult continence services should be made in advance and organised in a way that the effect for the young person is positive and “seamless”.

1.14 Impact upon hospital admissions

As a key Outcome Indicator of this service is to reduce rates of hospital admission, it will result in cost savings. National admission rates in this area are being measured by Public Health England, which will allow individual CCGs to measure progress on service outcomes and associated cost savings (see 1.15).

1.15 Cost savings

Baseline data on hospital admissions for a particular CCG area enables ongoing measurement of Outcome Indicators and savings to be assessed. Liaison with Public Health England will continue in order to work towards measuring the remaining Outcome Indicators e.g. rates of A&E attendances, rates of referrals to secondary care (Out Patient Appointments). Achieving continence for children with special needs will save money on continence products (pads and nappies) See case study 2 (5.3).

Sample service business plans with estimated savings will be available on the PCF website (http://www.paediatriccontinenceforum.org).

1.16 Predicted activity volumes

Patients should receive one hour long initial appointments and follow-up appointments as required.

It is anticipated that the clinic will need healthcare assistant and administrative support. Time will be needed to liaise with other services e.g. schools.

There will be premises, equipment, IT and phone costs; also cost of products e.g. pads, musical potties and enuresis alarms and cost of patient information literature.

2. Procedures Explorer for Paediatric Continence

The Commissioning Guide includes two summary case studies (see section 5.3) to demonstrate how the recommendations within the Continence Commissioning Guide have been put into practice. It is being piloted in another CCG area.

There are currently no OPCS4 codes for paediatric continence conditions being treated in the community.
3. Quality Dashboard for Paediatric Continence

3.1 Service outcome measure and key indicators

To help children and young people to achieve complete continence, or to manage the condition discreetly and effectively if full control is not clinically possible.

Key Outcome Indicators
1. Rates of A&E attendance and unplanned hospitalisation for constipation and urinary tract infection
2. Rates of children starting pre-school (from 3 years) in nappies and overall rates of children supplied with disposable continence products
3. Percentage of children and young people with bladder and bowel dysfunction successfully treated within the service or post discharge
4. A Quality of Life assessment from the perspective of the child and young person and the family (the PROMS (Patient Reported Outcome Measures)/FROMS (Family Reported Outcome Measures) are currently being adapted for continence).

Supporting Outcomes
- children, young people and their families to have an improved perception and understanding of continence issues and to have gained knowledge about how to effectively self-manage
- a reduction in the use of disposable products
- more effective use of care pathways and toileting programme
- a reduction in the need for children and young people using specialist secondary care services e.g. using secondary care because no equivalent primary care service in place.

3.2. Clinical outcomes

Outcome 1: Percentage of children and young people with bladder and bowel dysfunction successfully treated within the service or post discharge

Outcome Measures: For nocturnal enuresis and daytime wetting

There is international agreement on the following:

Initial success measures
- non-response: 0-49% decrease in wet nights/days
- partial response: 50-89% decrease in wet nights/days
- response: 90% or greater decrease in wet nights/days
- full response: 100% decrease or less than one symptom occurrence monthly.

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6 This will be available on the PCF website www.paediatriccontinenceforum.org in late 2014

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Long-term success measures
- relapse: More than one symptom occurrence monthly
- continued success: No relapse in 6 months after interruption of treatment
- complete success: No relapse in 2 years after interruption of treatment.

Clinical Indicators
- Number of children and young people entering treatment
- Treatment duration
- Treatment response.

Outcome Measures: For constipation/soiling
A substantial improvement in the number of children and young people achieving the passage of regular, soft-formed stools at least three times a week with no soiling problems, including those on medication and after the final withdrawal of medication.

Clinical indicators
- number of referrals and children treated: primary and secondary care
- frequency of bowel movements (before and after treatment)
- frequency of soiling episodes
- frequency of treatment in secondary care for constipation, soiling and faecal impaction.

Outcome Measures

Outcome 2: Percentage of children and young people who are able to manage their continence problem to their satisfaction.

Outcome Measures
The service should gather opinions from a cross-section of children and young people with continence difficulties and their parents/carers via a self-completion questionnaire. A Quality of Life Questionnaire will be available later in 2014. Baseline and end-point data should be collected for comparison.

Outcome 3: Percentage of children and young people and their parents/carers who feel that the treatment has improved their quality of life.

Outcome Measures
The service should make use of validated, reliable and reproducible quality-of-life (QoL) measures developed for children with bladder dysfunction. A new Quality of Life tool for childhood continence is currently being devised and will be publicised on the PCF website www.paediatriccontinenceforum.org
4. Levers for Implementation

4.1 Audit and peer review measures

Clinical audit is a quality improvement cycle that involves measurement of the effectiveness of healthcare against agreed and proven standards for high quality – and taking action to bring practice in line with these standards so as to improve the quality of care and health outcomes.

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<tr>
<th>Impact</th>
<th>Activity</th>
<th>Measure</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Number of children and young people self-managing</td>
<td>Questionnaire at 9 months (may be conducted by telephone)</td>
</tr>
<tr>
<td></td>
<td>Reduction in avoidable secondary care attendance, admission</td>
<td>Difference from baseline data (commissioner responsibility)</td>
</tr>
<tr>
<td></td>
<td>Reduction in UTIs</td>
<td>Difference from baseline data (commissioner responsibility)</td>
</tr>
<tr>
<td></td>
<td>Reduction in unnecessary treatment and inappropriate reliance on products for the containment of urinary/faecal incontinence</td>
<td>Difference from baseline data (commissioner responsibility)</td>
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<table>
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<tr>
<th>Outcome</th>
<th>Activity</th>
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<tbody>
<tr>
<td></td>
<td>Number of children and young people cured, treated or symptoms alleviated whilst within the service or post discharge</td>
<td>Repeat symptom questionnaire at 6 and 9 months (may be conducted by telephone)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outputs</th>
<th>Activity</th>
<th>Measure</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Number of children and young people referred to, triaged and treated within the service</td>
<td>Child and family experience of the service and quality questionnaire</td>
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<tr>
<td></td>
<td></td>
<td>Individualised management plan</td>
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<table>
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<tr>
<th>Intervention</th>
<th>Activity</th>
<th>Measure</th>
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<tbody>
<tr>
<td></td>
<td>Child care pathway as per activity data collected</td>
<td>Intervention data collected (see activity plan)</td>
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</table>

<table>
<thead>
<tr>
<th>Inputs</th>
<th>Activity</th>
<th>Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Child or young person with bladder/bowel dysfunction</td>
<td>Base line symptom and quality of life questionnaire completed</td>
</tr>
</tbody>
</table>

Service user views and preferences were obtained by the Guideline Development Group (see 7.4) via: the patient organisation ERIC, including direct feedback from three parents and the Bristol Parent Carers Network. The Commissioning Guide was also independently peer reviewed by the Royal College of Paediatrics and Child Health; the Strategic Clinical Network for Child Health and Wellbeing, East of England; two CCG commissioners. Comments were considered and acted upon, as appropriate, by the GDG. The Commissioning Guide was available for public review from 23 April 2014 for 4 weeks.

4.2 Quality specification/ CQUIN

The CQUIN payment framework enables commissioners to reward excellence by linking a proportion of providers’ income to the achievement of local quality improvement goals (DH, 2008).

It is recommended that Parties use the on-line standard template for CQUIN schemes 2011/12 available on the website of the NHS Institute for Innovation and Improvement (http://www.institute.nhs.uk/world_class_commissioning/pct_portal/cquin.html). This scheme is however poorly developed for children’s continence services – but some guidance relating to adult services can be found on the DH Any Qualified Provider: National Implementation Pack: Continence Service (https://www.supply2health.nhs.uk/AQPResourceCentre/AQPServices/PTP/ImplementationPacks/Continence%20Children%20-%20Implementation%20Pack.doc)

5. Directory

5.1 Patient Information

Paediatric Continence Forum (PCF)

The Paediatric Continence Forum is an independent national campaign group, set up in 2003 to improve awareness amongst policy-makers of the needs of children and young people with continence problems and to improve NHS services in this often neglected area of child health. It has strong links with the registered charity ERIC and PromoCon, plus formal representation from the Royal College of Paediatrics and Child Health, the Royal College of Nursing and the Community Practitioners’ and Health Visitors’ Association.

The PCF is actively supported by the companies Coloplast Ltd, Ferring Pharmaceuticals Ltd, Kimberly-Clark Europe Ltd, and Norgine Pharmaceuticals Ltd. It employs the services of the Whitehouse Consultancy, which acts as advisers and provides a secretariat service for the Forum.

Chair: Dr. Penny Dobson MBE
Address: The Paediatric Continence Forum, 222 Southbank House, Black Prince Road, London SE1 7SJ
Tel: 020 7089 2607
Email: paediatriccontinenceforum@whitehouseconsulting.co.uk
Website: www.paediatriccontinenceforum.org
ERIC (Education and Resources for Improving Childhood Continence)
A national charity that provides information and support to children, their families and the professionals who treat them. ERIC runs a number of training courses for health professionals every year, covering all aspects of childhood continence.

Address: 36 Old School House, Britannia Road, Kingswood, Bristol BS158DB
Helpline: 0845 370 8008
Email: info@eric.org.uk
Website: www.eric.org.uk

PromoCon (Promoting Continence through Product Awareness)
Working under the umbrella of Disabled Living, Promocon provides impartial advice and information regarding the whole range of continence products, equipment and services. PromoCon also provides training and has a range of resources and information booklets which are free to download from the website.

Address: PromoCon, Disabled Living, Burrows House, 10 Priestly Road, Wardley Industrial Estate, Worsley M28 2LY
Helpline: 0161 607 8219
Email: promocon@disabledliving.co.uk
Website: http://www.promocon.co.uk

BAPU (British Association of Paediatric Urologists)
Contact via email: http://www.bapu.org.uk/contact/contact-access-request/
Website: http://www.bapu.org.uk

BAPUN (British Association of Paediatric Urology Nurses)
Operating under the umbrella of BAPU
Contact via email: angela.downer@OUH.nhs.uk

5.2 Information for Commissioners and Clinicians and supporting tools

NICE Clinical Guidelines: CG111 Nocturnal Enuresis: the management of bedwetting in children and young people (October 2010)
http://guidance.nice.org.uk/CG111

NICE Clinical Guidelines: CG99 Constipation in Children and Young People (May 2010)
http://guidance.nice.org.uk/CG99

Rogers J Understanding bladder and bowel co-morbidities in children and young people with additional needs: the importance of assessment (2014)
http://www.disabledliving.co.uk/DISLIV/media/publicationpdf/The%20Platinum%20Trust%20Resources/17549-bladder---bowel.pdf

Paediatric Continence Service Commissioning Guide NICE (2010). Includes a commissioning and benchmarking tool
Continence service implementation pack Department of Health (2011)
http://www.hsj.co.uk/Journals/2012/03/21/i/h/n/120302-Implementation-Pack-Continence-FINAL.docx

Improving Children and Young People’s Health Outcomes: A system wide response
Department of Health (2013)

Child and Young People’s Outcomes Forum: Report Child Health Forum (2013)

APPG Continence Care: cost-effective commissioning for continence care All Party Parliamentary Group (2011)
http://www.appgcontinence.org.uk/pdfs/CommissioningGuideWEB.pdf

Specifying a Paediatric Continence Service NICE


Operational Guidance to the NHS extending patient choice or provider Department of Health 2011


Childhood Soiling: Minimum Standards of Practice for Treatment and Service Delivery: Benchmarking guidelines, ERIC, 2001 Bonner L

Promoting Continence in Children with Disabilities: Minimum Standards of Practice for Treatment and Service Delivery, ERIC, 2005 Bonner L

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Supporting tools

Public Health England Needs Assessment Tool for Continence:
http://www.chimat.org.uk/usingchimat/assessing

Paediatric Continence Service Commissioning Guide (NICE 2010): commissioning and benchmarking tool:
http://www.nice.org.uk/proxy/?sourceUrl=http%3a%2f%2fwww.nice.org.uk%2fmedia%2f603%2f06%2fPaediatricContinenceServiceCommissioningAndBenchmarkingTool.xls

Map of Medicine: http://www.mapofmedicine.com/

Paediatric Continence Forum website (http://www.paediatriccontinenceforum.org) with:
- sample care pathways
- model service specifications for service delivery, including models to support the procurement process
- financial models that support the business case for an integrated service
- further case studies of good integrated practice

This content will be developed over the next 6 months

http://portal.efh.org.uk/Account/logon
To access the open-access sessions on MindEd go to https://www.minded.org.uk/ or follow: https://www.minded.org.uk/course/category.php?viewtype=program&id=25

The Essence of Care: Patient-focused benchmarking for health care practitioners
Department of Health 2001:

School Information Tool Kit, ERIC/Promocon
http://www.eric.org.uk/InformationZone/Leafletsandresources

5.3 NHS Evidence: case studies

Case Study 1

Blackpool Continence Service

In early 2012 discussions were held with commissioners to develop a Paediatric Continence Service for children and young people in Blackpool registered with Blackpool GP practices.

Staff were recruited to set up the service and, with the support of June Rogers MBE, work began on developing the pathways and policies for the service, using the draft PCF Commissioning Guide as a basis. As part of this process, it was recognised that to offer a fully comprehensive service discussions needed to be held with the paediatric consultants.
in secondary care. In April 2013 the community trust amalgamated with the local acute trust, so it became easier for contact to be made with the paediatric consultant who is also Head of Families Division within the new Clinical Commissioning Group. He identified one of the paediatric consultants in his team to be the link person between secondary care and the community. Over a 6 month period all paediatric consultants, paediatric outreach nurses and the School Nursing and Health Visiting Services were consulted to develop appropriate pathways and training packages for 2 levels of service delivery:

Level 1 service is delivered by the generic Health Visitor and School Nursing Service, thereby ensuring good early intervention at community level to educate parents/carers in early identification of bladder and bowel problems. This prevents constipation and facilitates early recognition of both constipation and wetting problems, thereby preventing their escalation to referral to secondary care.

Level 2 service is delivered by the specialist continence nurses within the community, with only severe or “red flag” issues being referred to secondary care. Ongoing communication, training and advice are offered by the nominated consultant.

Case Study 2

PromoCon worked with Liverpool Community Health NHS Trust between 2005 and 2010 to provide a comprehensive paediatric continence service.

PromoCon is a third sector provider, working as part of Disabled Living, Manchester, to improve the quality of life for people with bladder or bowel problems. It employs a multidisciplinary team of people who work with other services and organisations to develop improvements for people who have continence difficulties.

PromoCon and Liverpool Community Health NHS Trust established a model for a service based upon available guidelines and best practice to improve care for children and young people with continence problems. The service focused upon ensuring appropriate continence assessment for children and young people, supported by a training programme for all staff.

The service also worked closely with families of service users to encourage self-management of continence problems, which has encouraged higher levels of compliance with treatment and a reduction in DNA rates.

As a result of training, health visitors and school nurses are better able to assess and begin first line treatment for children and young people with continence problems. They only refer the child or young person to the paediatric continence service when necessary:

- Between 2005 and 2010 the number of children and young people receiving free nappies dropped from 700 to less than 300 per year. This helped to reduce the budget for products by over half, as well as ensuring all children reached their potential for toilet training.
- Referrals of children and young people with idiopathic constipation to secondary
The Commissioning Guide is being piloted at a further CCG – and evidence from this will be added to the PCF website.

6. Benefits and Risks

Benefits of this commissioning guidance:-
- it is underpinned by NICE clinical and commissioning guidance
- it includes; clear service outcomes and outcome indicators with evidence to support these; clinical outcome measures for children and young people based upon international agreement of effectiveness; audit and peer review measures
- it has proven cost savings, through more effective service delivery, plus reduced referrals to secondary care and a reduction in the need for continence products
- it provides an integrated model that: is clinically more effective; improves access for families, particularly for those who have children with more than one continence problem
- it allows a level of service audit via the Public Health England (ChiMat) website, Continence Needs Assessment module: (http://atlas.chimat.org.uk/IAS/profiles/profile?profileId=45&geoTypeld=4) through:-
  - data on service outcomes (currently unplanned hospital admissions for constipation and urinary tract infections)
  - data on the local delivery of services (currently based upon a 2011 review of services carried out by the PCF. This will be repeated in 2014.
- and it signposts commissioners to local prevalence data (ChiMat Continence Needs Assessment) to aid the process of formulation of local continence needs assessments.

Risks associated with the implementation of this Commissioning Guidance are:-
- insufficient professional training courses for the post registration qualification of a paediatric continence adviser
- process on integrated working needs time to “win the hearts and minds” of local agencies in order to agree a care pathway e.g. GPs, medical consultants
- underfunding for the provision of products e.g. for children with special needs
- current poor signposting of services
- and lack of recognition/understanding of the needs (and risks associated with) this group of children.

Satisfaction with the service was greatly improved, and service users were generally treated and discharged within six months.

The service has won a number of awards, including the Nursing Times’ Continence Award in 2007 and June Rogers, Director of PromoCon, co-author of this service specification, won a Nursing Standard Child Health award in 2011 for her involvement in this work.
7. Further Information

7.1 Literature Review and Research Recommendations

Literature Review

The Literature Review was carried out by the Author/Editor and two additional members of the Guideline Development Group (the “Literature Review Sub Group” see 7.4) and the results shared with and agreed by the full GDG. The search strategy was overseen by Dr. Carol Joinson, Senior Lecturer in Developmental Psychology, School of Social and Community Medicine at the University of Bristol. The research source was the PubMed database.

The search included the following study types: systematic reviews, case control or cohort studies and accredited guidelines. The search exclusions were: non English language studies; research before year 2000; evidence below 2- in the Criteria for Selecting Evidence table (see below). There were about 30 excluded studies.

Criteria for selecting evidence

The relatively small amount of evidence outside the NICE Guidance and the International Children’s Continence Society Standardisation documents was graded by the GDG according to its strength as follows:-

<table>
<thead>
<tr>
<th>Type of Evidence</th>
<th>Description</th>
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<tbody>
<tr>
<td>1++</td>
<td>High-quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias</td>
</tr>
<tr>
<td>1+</td>
<td>Well-conducted meta-analyses, systematic reviews of RCTs, or RCTs with a low risk of bias</td>
</tr>
<tr>
<td>1-</td>
<td>Meta-analyses, systematic reviews of RCTs, or RCTs with a high risk of bias*</td>
</tr>
<tr>
<td>2++</td>
<td>High-quality systematic reviews of case–control or cohort studies High-quality case–control or cohort studies with a very low risk of confounding, bias or chance and a high probability that the relationship is causal</td>
</tr>
<tr>
<td>2+</td>
<td>Well-conducted case–control or cohort studies with a low risk of confounding, bias or chance and a moderate probability that the relationship is causal</td>
</tr>
<tr>
<td>2-</td>
<td>Case–control or cohort studies and cross sectional surveys, with a high risk of confounding, bias, or chance and a significant risk that the relationship is not causal</td>
</tr>
<tr>
<td>3</td>
<td>Non-analytic studies (for example, case reports, case series)</td>
</tr>
<tr>
<td>4</td>
<td>Expert opinion, formal consensus</td>
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</table>
Results from the Literature Review and Reasons for Inclusion/Exclusion from the Commissioning Guide

The research evidence in this area of child health is limited, with few good quality trials. This is particularly the case relating to children with special needs. For example, there was little evidence of research of standard 1++, 1+ and 1-. There were a few studies graded as 2++ but most were graded as 2+ and 2-.

The evidence from all studies graded as 2++ was added to the Commissioning Guide where not previously referenced.

The areas added to the Commissioning Guide as a result of the Literature Review were:
- additions to prevalence factors and the risk statements for children and young people, including children and young people with learning difficulties and physical disabilities (see Appendix 1: 2.5)
- a section on risk factors for continence (see Appendix 1: 3).

It was agreed that there were no significant additions necessary as a result of the post 2010 review of the literature.

Recommendations for future research

- Research into the impact of incontinence on the quality of life of children with learning difficulties and physical disabilities.
- PROMS/FROMS measures benchmarked for children with continence problems.
- Further evaluation of the cost effectiveness of this integrated model of service delivery.

7.2 Other recommendations

1. Assumptions should not be made about the ability of children with learning difficulties and physical disabilities to become toilet trained, neither should assumptions be made about the cause of their continence problem. All children should be assessed and provided with the correct equipment and therapy (including occupational therapy), as appropriate, in order to achieve continence. The result will be that fewer incontinence products will need to be issued, thereby reducing costs for the NHS.

2. Where incontinence products need to be issued, this should, again, be following a proper assessment by a competent professional – and the daily supply should be sufficient for the needs of the individual child or young person.

3. The CQUIN scheme should be better developed for paediatric continence.

4. OPCS4 coding should be devised for the treatment of paediatric continence problems in the community.

5. Data on A&E attendance and Out Patient Department appointments should be obtainable to enable service audit.
7.3 Evidence base

References (additional to references from NICE)


7.4 Guideline Development Group

This Commissioning Guide was developed during 2012-2014 by the Paediatric Continence Forum (PCF), an independent group of patient representatives and healthcare professionals, which campaigns to improve services for children and young people with bladder and bowel dysfunction (see 5.1).

It was initially developed with guidance from the Department of Health, particularly Dr Sheila Shribman CBE, who until February 2013, was National Clinical Director for Children and Maternity. The principles behind it have the support of Dr Jacqueline Cornish OBE, National Clinical Director for Children, Young People and Transition to Adulthood. It was put together by the Guideline Development Group (GDG), drawn from members of the PCF:

The Guideline Development Group (GDG)

Sue Affleck, Clinical Nurse Specialist in Paediatric Bladder and Bowel Dysfunction, St George’s Hospital, Tooting
Liz Bonner, Lead Nurse, Bladder Bowel Service, Haringey. Representative from the Royal College of Nursing
Brenda Cheer, Paediatric Continence adviser and ERIC Nurse
Dr Penny Dobson MBE, Chair of Paediatric Continence Forum. Lead author/editor*
Anita Finlay, Joint Commissioning Manager, Children, Young People and Maternity Services, East Sussex
Dr Jenny Gordon, Head of Learning and Development Services, HCA International (during development of Commissioning Guide was Programme Manager, Evidence into Practice Team, Royal College of Nursing)
Mr. Nicholas Madden, Paediatric Surgeon/Urologist, Chelsea and Westminster Hospital*
Lorna Montgomery, Parent representative. Member of the Management Committee of ERIC
Jenny Perez, Chief Executive, ERIC
June Rogers MBE, Specialist Continence Adviser/Stoma Care Nurse, PromoCon Project Manager. Lead author.*
Dr Sameena Shakoor, Consultant Paediatrician, Kent Community Health NHS Trust. Representative from the Royal College of Paediatrics and Child Health
Norma Wilby, School Nurse Manager, Cambridgeshire Community Services NHS Trust. Representative from the Community Practitioners’ and Health Visitors’ Association
Dr Anne Wright, Consultant Paediatrician, Guy’s and St Thomas’ NHS Foundation Trust*
The GDG met every 4 months, with additional interaction taking place via email. Decisions were made on a consensus basis through discussion. The Guidance was put together independently, with no commercial input and with no additional funding outside the Paediatric Continence Forum. The GDG members signed Conflict of Interest Declarations; there were no identified actual or potential conflicts of interest.

*Members of the Literature Review Sub-Group. This Group oversaw the review of research additional to NICE Guidance. Results and recommendations were approved by the GDG in April 2014.

External Consultation

An account of service users’ views and preferences, including a four week public review, plus peer review measures undertaken, is outlined in 4.1.

Dissemination of Guidance

Accreditation by NICE is an important factor in the validation and therefore the dissemination and uptake of this Guidance.

Successful “co-badging” with the Royal College of Paediatrics and Child Health will also assist its successful dissemination. Similarly, endorsement from the PCF’s other member organisations: the Royal College of Nursing and the Community Practitioners’ and Health Visitors’ Association, will aid the dissemination process.

Public Health England will add this Guidance to the CHIMAT website as part of the Continence Needs Assessment module.

A service specification, based upon a draft version of this Commissioning Guidance, is currently being used by an East of England CCG for the commissioning of an integrated paediatric continence service. It has also been used by Blackpool CCG.
Appendix 1

Paediatric Continence: Terminology, Definitions, Prevalence and Risk Factors

1. Terminology and Definitions
The generic term “continence” is interchangeable with the terms “bladder and bowel difficulties” and “bladder and bowel dysfunction” or “wetting and soiling problems”. For the purpose of this specification, we will use the term “continence” or “bladder and bowel dysfunction”. More specific definitions are as below. All relate to children and young people 0-19 years, including those with special needs.

1.1 Bedwetting (sometimes called nocturnal enuresis)
A definition of bedwetting: “the symptom of involuntary wetting during sleep without any inherent suggestion of frequency or pathophysiology” (NICE Clinical Guideline CG 111, 2010: 4).
The term bedwetting is for all children 0-19 years, but the term “nocturnal enuresis” is sometimes used for children and young people 5-19 years.

1.2 Daytime bladder symptoms (or Lower Urinary Tract Symptoms)
This is sometimes called daytime incontinence or daytime wetting.
Definition: Symptoms associated with voiding or storage problems, including overactive bladder and voiding dysfunction. These are considered relevant over the age of 5 years. (ICCS Standardisation documents, 2010) (1)

1.3 Constipation/impaction and faecal incontinence (soiling)
Faecal incontinence is the passage of stools in an inappropriate place. Faecal incontinence can be either organic, due to neurological damage, caused by trauma or congenital conditions, or, more commonly, it can be functional or idiopathic in origin (2). Functional faecal incontinence can be further sub divided into:-

- Constipation-associated faecal incontinence, which is often termed overflow soiling, is when stools ‘leak’ round the enlarged, constipated bowel.

- Non-retentive faecal incontinence (which is often termed ‘encopresis’ in the UK) is much less common than constipation-associated faecal incontinence. This is defined as ‘the passage of stools in an inappropriate place by a child with a mental age of 4 years and older, with no evidence of constipation by history and/or examination’. In some cases there is an emotional element, such as anxiety that contributes to the faecal incontinence without the child being aware, or it might be that the child has simply never achieved bowel control at the toilet training stage and there is no underlying emotional factor. This would include children with a recognized learning disability, such as an Autistic Spectrum Disorder or Attention Deficit Hyperactive Disorder.

The 2010 NICE guideline Constipation in Children and Young People (NICE Clinical Guideline 99, 2010: 5) further provides practitioners with a consensus on what terms should be used:
- Chronic constipation - constipation lasting longer than 8 weeks
• Idiopathic constipation - constipation that cannot (currently) be explained by any anatomical, physiological, radiological or histological abnormalities
• Intractable constipation - constipation that does not respond to sustained, optimum medical management. This includes faecal impaction: severe constipation with a large faecal mass in either the rectum or the abdomen, sometimes with overflow soiling.

For the purpose of this Guidance we will use the generic terms “constipation” and “soiling”.

1.4 Urinary Tract Infection
Urinary tract infection (UTI) has been identified as a common bacterial infection causing illness in children. There is an association with the above conditions (NICE Clinical Guideline 54, 2007).

There are clear causal links between all the above conditions i.e. children who experience bedwetting may also have daytime wetting; children with constipation/soiling may also have bedwetting/daytime wetting. This reinforces the need for a single paediatric continence service, rather than separating into specific symptom-based services.

2. Prevalence
The prevalence tables in this section are taken from the Continence Needs Assessment module: Public Health England (last data review July 2013). They can be accessed by region here:

http://atlas.chimat.org.uk/IAS/profiles/needsassessments

2.1 Nocturnal enuresis:
The prevalence of nocturnal enuresis decreases with age and with an annual spontaneous resolution rate of 15-21% per year (3, 4). The majority of studies show that nocturnal enuresis is more common in boys than girls (almost 2:1 in western countries) and this appears particularly true at younger age groups, in milder severity wetting and with monosymptomatic nocturnal enuresis (absence of any daytime lower urinary tract symptoms), suggesting a maturational component (5).

Children with nocturnal enuresis, estimates by age

- aged 5 (prevalence 16.7%)
- aged 7 (prevalence 14.3%)
- aged 9 (prevalence 9.1%)
- aged 11-12 (prevalence 4.7%)
- aged 13-19 (prevalence 2%)
- aged 15-16 (prevalence 1.1%)

2.2 Daytime wetting
The prevalence of daytime wetting decreases with age, with an annual spontaneous cure rate of 14.4-22% (4, 6, 7). There is an increasing ratio of girls with increasing age (7, 8, 9, 10).
Children with daytime wetting, estimates by age

- aged 7 (prevalence 4.9%- 11.7%) (4, 7, 11)
- aged 11-12 (prevalence 16.6% in girls and 7.2% in boys) (34, 27) One Iranian study showed a much lower overall prevalence of 0.8% : (27)
- aged 16-17 (prevalence 0.5%) (27)

2.3 Soiling (faecal incontinence)

There is some evidence for a decrease in prevalence of faecal incontinence with age and it is more common in boys (11, 12, 13, 14). Data analysed from 8,000 parents and children aged 7.5 years who took part in the Avon Longitudinal Study of Parents and Children (ALSPAC) indicated that 1.4% of children suffered from soiling (faecal incontinence) at a frequency of once a week or more and a further 5.4% soiled less than once a week (15).

Age-specific estimates for faecal incontinence.

- aged 4-5 (prevalence 3.3%)
- aged 5-6 (prevalence 2.0%)
- aged 7-10 (prevalence 1.3%)
- aged 11-12 (1%)

2.4 Constipation

NICE estimates that constipation is prevalent in about 5-30% of the child population (NICE Clinical Guideline CG 99, 2010: 4). This large range is likely due to the differing criteria used to define constipation and to differing cultural norms regarding acceptable bowel habits. There can also be an identification issue. In an Australian study, 36% of children in the sample (4.8-17years with associated nocturnal enuresis) were identified by the clinician as constipated, compared to 14% as identified by the parents (16).

2.5 Children with associated learning and physical disabilities

Approximately 800,000 children and young people in the UK have a physical or learning difficulty (17). There is some evidence that children and young people with learning difficulties and physical disabilities have a higher incidence of continence problems. (18-21), although the research in this area is limited. For example; a recent study showed that attention deficit disorders are more common in children with wetting problems compared to non-wetting children (16.8% c/f 3.4%) (22). This confirmed an earlier study (18); children and young people with Down’s Syndrome have a prevalence of renal and urinary tract anomalies that are 4-5 times higher than in the general population (23). These are not always recognized or appropriately treated. Early investigation is therefore very important.

The average prevalence rate for urinary incontinence in a study of 601 children and young people with cerebral palsy (4-18yrs) was 23.5% (20). The development of continence was also delayed in this study compared to non-disabled children.

Constipation may be a particular problem for children and young people with learning difficulties and physical disabilities for a number of reasons, including poor mobility and
altered muscle tone. This is often difficult to detect, and often the first sign is soiling due to faecal impaction. It is therefore important for the child and young person to be fully investigated at an early stage.

If untreated, urinary tract and bowel problems in these groups of children and young people can cause potential long term damage, such as renal failure or unresponsive chronic and intractable constipation (“obstipation”).

For further information see “Understanding bladder & bowel co-morbidities in children & young people with additional needs – the importance of assessment” Rogers J, PromoCon March 2014

3. Risk factors

Studies for risk factors for incontinence are often based on relatively small and/or highly selected clinic samples. Nocturnal enuresis is associated with family factors such as a family history of enuresis, large family size, birth order and parental education (24, 25) and emotional factors, such as various stressors and behavioural problems (25, 26) in the child. Other child factors include developmental delay, sleep issues and constipation (27). There is evidence that some strategies parents use to help their child achieve dryness (e.g. lifting, fluid restriction) might actually maintain bedwetting (31).

Daytime wetting is associated with a family history of incontinence and other family factors, such as family discord (8, 26), other bladder and bowel dysfunction (11, 28, 29, 30) emotional stress (26), delayed toilet training and ADHD (22).

Hard stool and constipation, developmental delay, maternal anxiety, stress, difficult temperament in the child and daytime urinary incontinence are all factors associated with faecal incontinence(11,12,13).

There is some evidence that more children whose parents initiated toilet training after 24 months of age experience delayed acquisition of daytime bladder control, compared to those who initiated toilet training between 15-24 months of age (32,33). However studies in this area use different definitions, so are difficult to compare.

References

1. The following Standardisation documents from the International Children’s Continence Society are available for daytime urinary incontinence:


The International Children’s Continence Society website can be accessed here: http://www.i-c-c-s.org


Appendix 2: Nocturnal Enuresis Care Pathway

A child presents with bedwetting
The NICE approach

Demystification
• Discuss causes
• Explain symptoms
• Explain prognosis

Initial appointment

Initial advice
• Demystify, reassure, educate
• Fluid optimisation
  - 6-8 drinks/day
• Toileting advice
  - 4-7 voids/day
• Advise on rewards for compliance
• Suggest trial without nappies or pull-ups
• Offer advice on bedding protection
Emphasise initial advice as per NICE guidance

Initial assessment (can use CMT)
• Number of wet nights/week: size of wet patches, number of times/night, time of occurrence
• Age at onset/symptom duration
• Arousal from sleep
• Daytime wetting: frequency (volds/day), urgency
• Any abnormalities of urinary stream: starting, problems with flow, problems with emptying
• Fluid intake (type/quantity)
• Maximum voided volume (bladder capacity)
• Bowel movements/any soiling
• History of comorbidities: UTI/disability/developmental, etc.
• Any intervention(s) previously tried
• Impact of the bedwetting on the child and family

Examination
• General appearance
• Urine dipstick if suspicion of UTI, diabetes, daytime wetting. Send sample with patient to GP
• Bladder diary and bowel diary: baseline recording including fluid intake, voiding, bowels, wetting

No progress after changing usual routine and implementation of initial advice. Discuss, explain and offer treatment options

First-line treatment

Child seems suitable for an alarm as first-line treatment
Follow NICE alarm algorithm

Child seems suitable for desmopressin as first-line treatment: start on 1 desmopressin (120 mcg Desmopressin or 200 mcg Desmoterol)
Follow NICE desmopressin algorithm

Safeguarding concerns
Follow local protocol

UTI/incontinence/diabetes insipidus
Assess, treat and refer as appropriate

Suspected organic cause
Refer to and liaise with consultant

More information
NICE (www.nice.org.uk/cg111):
• Guideline on nocturnal enuresis
• Nocturnal enuresis pathway
• Quality standard

Information on bedwetting for professionals, children and families:
• www.eric.org.uk
• www.promocom.co.uk
• www.stopbedwetting.org

Professional resources on bedwetting and child health:
• www.chimat.org.uk

Professional resources on bedwetting and child health: