



# Paediatric Continence Commissioning Guide

A handbook for the commissioning and running of paediatric continence services

Sponsoring Organisation: The Paediatric Continence Forum

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NICE has accredited the process used by the Paediatric Continence Forum to produce its Commissioning guidance. Accreditation is valid for 5 years from June 2014. More information on accreditation can be viewed at [www.nice.org.uk/accreditation](http://www.nice.org.uk/accreditation).

## Commissioning Guide for Paediatric Continence

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## Deletions

Key Outcome Indicator: Rates of children starting pre-school (from 3 years) in nappies and overall rates of supply of disposable continence products. This was taken out as a result of feedback from users of the Guide: difficult to measure this.

## 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 with 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.

This Guide also takes into account the recommendations of the 2014 NICE Quality Standards, [QS62 - Constipation in Children and Young People](#) and [QS70 - Nocturnal Enuresis \(Bedwetting\) in Children and Young People](#). It also takes into account the recommendations of the “Excellence in Continence Care Programme Board” set up by NHS England in 2015: [Excellence in Continence Care: Practical guidance for commissioners, providers, health and care staff and information for the public NHS England](#) (2015).

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<sup>1</sup> 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, Child and Adolescent Mental Health Services (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 early diagnosis and 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 admission for urodynamic assessment (OPCS code U26.4) (19)
  - Percentage of children and young people with bladder and bowel dysfunction successfully treated within the service or post discharge (see Section 3.2)
  - Quality of Life (QoL) assessment from the perspective of the child or young person and the family. Patient Reported Outcome Measures (PROMs) and Family Reported Outcome Measures (FROMs) can also be used. More specific Quality of Life Tools, tailored for paediatric bladder and bowel dysfunction are outlined in Appendix 4.
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 estimates that establishing an integrated, community-based paediatric continence service "could lead to up to an 80% reduction in emergency admissions (for continence problems) and a significant reduction in 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

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

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)

7. Clinical guidance within this document follows NICE Clinical Guideline: CG111 Nocturnal Enuresis: the management of bedwetting in children and young people (October 2010) <http://guidance.nice.org.uk/CG111>

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

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.

8. Recommendations also follow the 2014 NICE Quality Standards: QS62 Constipation in Children and Young People (May 2014) <https://www.nice.org.uk/guidance/qs62>

QS70 Nocturnal Enuresis (Bedwetting) in Children and Young People (September 2014) <https://www.nice.org.uk/guidance/qs70>

# 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<sup>2</sup>.

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 physical or intellectual impairment (2, 3, 4, 5).

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

Local prevalence data is available on the National Child and Maternal Health Intelligence Network (ChiMat) Website: Continence Needs Assessment Report. This document was last updated in October 2015 in conjunction with the PCF:

<http://atlas.chimat.org.uk/IAS/profiles/profile?profileId=45&geoTypeId>

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 section 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](#)) (8).

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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<sup>2</sup> 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 (9) This 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 (10).

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 (11). 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 (community-based):-

- one service for children and young people with all wetting and constipation/soiling problems – bedwetting, daytime incontinence, constipation/soiling, plus toilet training concerns
- 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 (The Children's Continence Charity), 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 (12,13)



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 (9).

The Royal College of Physicians national audit of continence care concluded that clinical outcomes are higher when a service is integrated (14).

There is 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 and again in 2014 the Paediatric Continence Forum carried out a Freedom of Information survey of Primary Care Trusts (2011) and Clinical Commissioning Groups (2014) to assess the quality of their paediatric continence services. Tables 1 and 2 summarise and compare the findings.

In 2014 there was a 100% response rate, but only 47% in 2011. If results are presented as a percentage of respondents (Table 1), there appears to have been a deterioration in services. However, taking into account the variation in response rates between the two surveys, the proportion of PCTs (2011) and CCGs (2014) confirming that they commission all four services was 41% and 39% respectively (Table 2); this would suggest there has been relatively little change during the three years.

**Table 1: Compliance, expressed as a percentage of respondents**

	2011 (PCTs)	2014 (CCGs)
Response rate	47% - 72 of 152 PCTs	100% - 211 CCGs
% of respondents commissioning all four services	88% (78%-93%)	39% (33%-46%)
% of respondents commissioning a joined-up service	51% (40%-63%)	26% (20%-32%)
% of respondents whose service is led by a specialist paediatric continence advisor	25% (16%-36%)	20% (15%-26%)

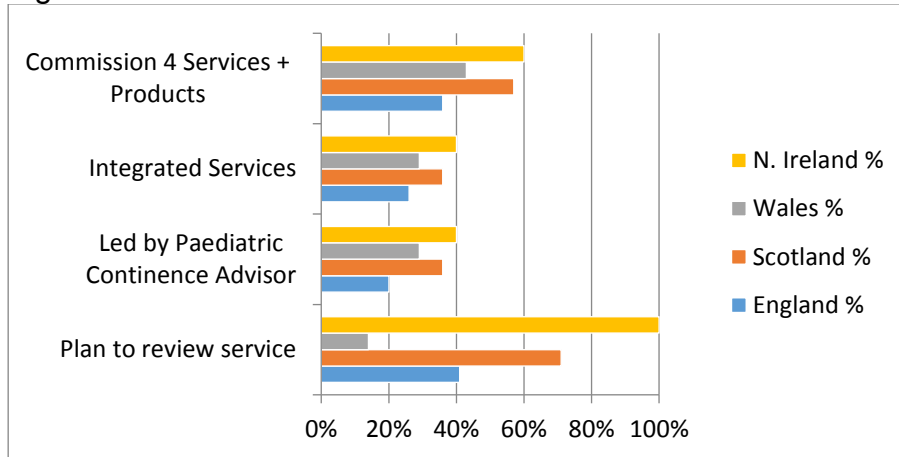
Figures shown in brackets are confidence intervals, representing inherent uncertainty in the proportions calculated, this reflects the higher proportion of respondents to the 2014 request.

**Table 2: Compliance, expressed as a percentage of all organisations**

	2011 (PCTs)	2014 (CCGs)
Response rate	47% - 72 of 152 PCTs	100% - 211 CCGs
% of organisations known to be commissioning all four services	41% (34%-49%)	39% (33%-46%)
% of organisations known to be commissioning a joined-up service	24% (18%-32%)	26% (20%-32%)
% of organisations whose service is known to be led by a specialist paediatric continence advisor	12% (8%-18%)	20% (15%-26%)

The results for the devolved nations of the UK are somewhat better; the chart below shows the results of the 2014 FOI survey for all four countries.

Figure 1



The National Child and Maternal Health Intelligence Network (ChiMat), part of Public Health England, publishes a needs assessment report on continence in children and young people. It provides national and local data in context of evidence and national guidelines and is intended to help local areas to undertake needs assessments as part of children’s and young people’s planning and joint strategic needs assessment.

<http://atlas.chimat.org.uk/IAS/profiles/profile?profileId=45&geoTypeId>

A survey of adult and child continence services in England carried out by the All Party Parliamentary Group for Continence Care in 2013 (15) showed a deterioration in services compared to a similar survey carried out by the Royal College of Physicians in 2007 (14). 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 (16), 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

- Rates of A&E attendance and unplanned hospitalisation for constipation and urinary tract infection. Rates of admission for urodynamic assessment (OPCS code 26.4) (19)
- Percentage of children and young people with bladder and bowel dysfunction successfully treated within the service or post discharge (see Section 3.2)

- Quality of Life (QoL) assessment from the perspective of the child or young person and the family. Patient Reported Outcome Measures (PROMs) and Family Reported Outcome Measures (FROMs) can also be used. More specific Quality of Life Tools, tailored for paediatric bladder and bowel dysfunction are outlined in Appendix 4.

#### 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 (17).

As outlined earlier, the NICE Commissioning Guide states that an effective, integrated community –based paediatric continence service “could lead to up to an 80% reduction in emergency admissions (for continence problems) and a significant reduction in consultant-led outpatient appointments”. ([NICE Paediatric Continence Commissioning Guide, 2010: 22](#))

#### Indicator 2

See 3.2 for a breakdown of clinical outcome measures.

#### Indicator 3

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) (8,10). Children and young people with continence problems also feel ‘different’ and it affects their social life and interaction with others. There 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 works with ChiMat to collect data to enable clinical commissioning groups measure how far they are achieving the Outcomes – and thereby assess the associated cost savings. For example, ChiMat is measuring rates of unplanned hospitalisation for constipation and urinary tract infections and rates of admission for urodynamic assessment.

The data is available and downloadable from the Continence Needs Assessment Report: <http://atlas.chimat.org.uk/IAS/profiles/profile?profileId=45&geoTypeId>

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 (14). 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

There are approximately 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 National Child and Maternal Health Intelligence Network (ChiMat) publishes a Continence Needs Assessment Report, with local data on the number of children with continence problems.

<http://atlas.chimat.org.uk/IAS/profiles/profile?profileId=45&geoTypeId>

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

### NICE Clinical Guidelines

NICE Clinical Guideline: CG111 Nocturnal Enuresis: the management of bedwetting in children and young people (October 2010)

<http://www.nice.org.uk/guidance/CG111>

This includes an overview of what constitutes an assessment, with history and physical examination:

<http://www.nice.org.uk/guidance/CG111/chapter/1-Guidance#assessment-and-investigation>

NICE Clinical Guideline: CG99 Constipation in Children and Young People (May 2010)

<http://www.nice.org.uk/guidance/CG99>

This includes an overview of what constitutes an assessment:

<http://www.nice.org.uk/guidance/CG99/chapter/Key-priorities-for-implementation>

NICE Quality Standard: QS62 Constipation in Children and Young People (May 2014)

<https://www.nice.org.uk/guidance/qs62>

NICE Quality Standard: QS70 Nocturnal Enuresis (Bedwetting) in Children and Young People (September 2014)

<https://www.nice.org.uk/guidance/qs70>

### Standardization Documents from the international Children's Continence Society (ICCS)

The International Children's Continence Society has produced a number of standardization documents and clinical tools, which are available to ICCS members on their website.

<http://i-c-c-s.org/members/clinical-tools/>

The Standardization of Terminology of Lower Urinary Tract Function in Children and Adolescents: Update Report from the Standardization Committee of the International Children's Continence Society (18)

Diagnostic Evaluation of Children With Daytime Incontinence. (19)

Management of Dysfunctional Voiding in Children: A Report from the Standardisation Committee of the International Children's Continence Society. (20)

Psychological and Psychiatric Issues in Urinary and Fecal Incontinence. (21)

Clinical Tools <http://i-c-c-s.org/members/clinical-tools/>

1 Week Voiding Diary	24-Hour Frequency/Volume Chart	Parental Questionnaire
24-28 Hour Toilet Protocol	72-Hour Frequency/Volume Chart	Dry Pie Chart
Extended History Taking	Bowel Diary	

## Assessment for Toilet Training

The following guidelines and charts have been published by PromoCon:-  
[www.promocon.co.uk](http://www.promocon.co.uk)

PromoCon, Paediatric Continence Promotion: Toilet Training skills check list (2011)

<http://www.disabledliving.co.uk/DISLIV/media/promocon/2011Toilet-TRaining-Skills-check-list.pdf>

PromoCon, Baseline Bladder/Bowel Chart (2011)

<http://www.disabledliving.co.uk/DISLIV/media/promocon/talkabout/2011bladderandbowelchart.pdf>

PromoCon, Toilet Skills Assessment (2011)

[http://www.disabledliving.co.uk/DISLIV/media/promocon/2011TOILET\\_skill\\_ASSESSMENT.pdf](http://www.disabledliving.co.uk/DISLIV/media/promocon/2011TOILET_skill_ASSESSMENT.pdf)

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 (2011)

<http://www.disabledliving.co.uk/DISLIV/media/publicationpdf/Paed-product-assess-tool.pdf>

PromoCon, Paediatric Assessment tool for toilet training readiness and issuing of products – score sheet (2011)

<http://www.promoconshop.co.uk/blog/wp-content/uploads/2013/03/Paediatric-Assessment-Tool-for-Toilet-Training-Readiness-Issuing-of-Products-Scoring-Sheet.pdf>

PromoCon, Continence assessments for children and young people with delayed bladder and bowel control (2011)

<http://www.disabledliving.co.uk/DISLIV/media/publicationpdf/Paed-product-assess-tool.pdf>

## 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<sup>3</sup> 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, secondary and tertiary 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).

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<sup>3</sup> See Section 1.11 for service skill compositions.  
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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 and support local GPs, school and community nursing/ health visitor colleagues – and provide training - to enable them to carry out work at the preventative early treatment stage (Level 1 – see below). It should also work in liaison with specialist teams at secondary and tertiary levels and with 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 (who often play the major role), 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, depending upon the service agreement, 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 1 above) has not led to a resolution of the problem.

NICE guidance (2010) makes specific recommendations that 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](#)). (See also NICE QS 2014).

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 assessment of gait and the lumbo-sacral spine and anus (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 or tertiary 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 for all patients contracted within the CCG area. Any self-referral arrangement<sup>4</sup> needs to be managed carefully to enable proper triage.

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<sup>4</sup> This can be via a self-administered questionnaire  
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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 paediatric continence nurse specialist 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 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>

NICE care pathway for nocturnal enuresis: <http://pathways.nice.org.uk/pathways/bedwetting-nocturnal-enuresis-in-children-and-young-people>

ERIC will be publishing an integrated children's continence care pathway (2015 – to follow)

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](http://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/ tertiary care specialist services, the latter according to local agreement. This includes link nurses, nurses in special schools, allied health professionals (e.g. dieticians, clinical and educational psychologists and the CAMHS team), schools (see School Information Tool Kit (<http://www.eric.org.uk/Campaigns/TheRightToGo>) and the independent sector. Any contractual relationships should be the responsibility of the service provider

It is important that “all relevant information relating to care and treatment is shared appropriately, in accordance with current legislation and guidance and the principles of information governance, in a timely manner when service users move between service providers”. CQC Guidance for Providers. Latest version available [here](#).

## 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, primary and secondary schools, 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 nurse specialist - a registered children’s nurse, with appropriate 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 specialist should be on Band 7 as a minimum.

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

On the basis of this the PCF estimates that this would be translated into one full time clinical (lead nurse) post per 10,000 child population.

The PCF website will have examples of business plans: [www.paediatriccontinenceforum.org](http://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](http://www.eric.org.uk) PromoCon (Promoting Awareness through Product Awareness) [promocon@disabledliving.co.uk](mailto: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](http://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 nurse; also encourage non-medical prescribing qualifications and support continuing professional development for all staff with clinical leadership and supervision. This must involve; attendance at secondary care clinic sessions; attendance at a conference at least annually; finance membership of the ICCS for the lead clinician.
- enable all clinicians to have access to supervision and to attend regular meetings, as appropriate, including Multi-Disciplinary Team training for peer support. Clinicians must be encouraged to engage with multi – professional networks across the health economy.

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: <http://www.nhs.uk/chq/Documents/2015%20uploads/DH%20-%20Good%20practice%20in%20continence%20services.pdf>
- 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](http://www.eric.org.uk) and [www.promocon@disabledliving.co.uk](mailto: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\\_guidance.pdf](http://www.equalityhumanrights.com/uploaded_files/EqualityAct/PSED/essential_guidance_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

A key Outcome Indicator of this service is to reduce rates of hospital admission. This will result in cost savings for the NHS. National admission rates for constipation, urinary tract infections and urodynamic assessment are being measured by ChiMat which will allow individual CCGs and local authorities to measure progress on their service outcomes, measure cost savings and benchmark against other regions.

<http://atlas.chimat.org.uk/IAS/profiles/profile?profileId=45&geoTypeId>

## 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. Work with Public Health England will continue in order to work towards measuring the remaining Outcome Indicators

e.g. rates of A&E attendances. Achieving continence for children with special needs will save money on continence products (pads and nappies) See case study 2 (5.3).

Also see Appendix 3 “Why Commission a Paediatric Continence Service” for an outline of cost savings.

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 (minimum of 20 minutes each) as required. However follow-up reviews can also be effectively managed via telephone calls. The cost of telephone follow-up should be part of the budget.

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 Healthcare Resource Groups (HRGs) nor Treatment Function Codes to identify tariffs for paediatric continence conditions 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

- Rates of A&E attendance and unplanned hospitalisation for constipation and urinary tract infection. Rates of admission for urodynamic assessment (OPCS code U26.4) (19)
- Percentage of children and young people with bladder and bowel dysfunction successfully treated within the service or post discharge (see Section 3.2)
- Quality of Life (QoL) assessment from the perspective of the child or young person and the family. Patient Reported Outcome Measures (PROMs) and Family Reported Outcome Measures (FROMs) can also be used. More specific Quality of Life Tools, tailored for paediatric bladder and bowel dysfunction are outlined in Appendix 4.

#### 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.

##### *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 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. Baseline and end-point data should be collected for comparison. See Appendix 4

**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.

See Appendix 4 for an outline of questionnaire surveys that have been validated for paediatric continence.

## 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.

	Activity	Measure
Impact	<p>Number of children and young people self-managing</p> <p>Reduction in avoidable secondary care attendance, admission</p> <p>Reduction in UTIs</p> <p>Reduction in unnecessary treatment and inappropriate reliance on products for the containment of urinary/faecal incontinence</p>	<p>Questionnaire at 9 months (may be conducted by telephone)</p> <p>Difference from baseline data (commissioner responsibility)</p> <p>Difference from baseline data (commissioner responsibility)</p> <p>Difference from baseline data (commissioner responsibility)</p>
Outcome	Number of children and young people cured, treated or symptoms alleviated whilst within the service or post discharge	Repeat symptom questionnaire at 6 and 9 months (may be conducted by telephone)
Outputs	Number of children and young people referred to, triaged and treated within the service	<p>Child and family experience of the service and quality questionnaire</p> <p>Individualised management plan</p>
Intervention	Child care pathway as per activity data collected	Intervention data collected (see activity plan)
Inputs	Child or young person with bladder/bowel dysfunction	Base line symptom and quality of life questionnaire completed

Source: [AQP National Implementation Pack: Continence Service 2011 Department of Health, Page 16](#)



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](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 (<http://www.hsj.co.uk/Journals/2012/03/21/i/h/n/120302-Implementation-Pack-Continence-FINAL.docx>)

CQUINS may be replaced by Capitated Outcome Contracts in the future.

## 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, Laborie Europe Ltd, Norgine Pharmaceuticals Ltd and SCA Hygiene Products 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, 305 The Metal Box Factory, 30 Great Guildford Street, London SE1 0HS

Tel: 020 7089 2607

Email: [paediatriccontinenceforum@whitehouseconsulting.co.uk](mailto:paediatriccontinenceforum@whitehouseconsulting.co.uk)

Website: [www.paediatriccontinenceforum.org](http://www.paediatriccontinenceforum.org)

## **ERIC (The Children's Continence Charity)**

A national charity, based in Kingswood, Bristol. ERIC provides information, support and resources to children, young people and families as well as health professionals on childhood bedwetting, daytime wetting, constipation, soiling and potty training. ERIC's confidential Helpline provides information and support and a range of resources are downloadable from the website. ERIC runs training seminars for health and other professionals and holds a Conference every two years. ERIC's online shop has a wide range of resources and continence products. A full catalogue is downloadable from the website.

Address: 36 Old School House, Britannia Road, Kingswood, Bristol BS158DB

Helpline: 0845 370 8008

Email: [info@eric.org.uk](mailto:info@eric.org.uk)

Website: [www.eric.org.uk](http://www.eric.org.uk)

## **PROMOCON (Promoting Continence through Product Awareness)**

Working under the umbrella of Disabled Living, PromoCon provides impartial advice, information and training regarding the whole range of continence products, equipment and services. A range of free downloadable resources are available on the website.

Address: Disabled Living, Burrows House, 10 Priestly Road, Wardley Industrial Estate, Worsley M28 2LY

Helpline: 0161 607 8219

Contact via email: [promocon@disabledliving.co.uk](mailto:promocon@disabledliving.co.uk)

Website: [www.promocon.co.uk](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](mailto:angela.downer@OUH.nhs.uk)

## **5.2 Information for Commissioners and Clinicians and supporting tools**

NICE Clinical Guideline: CG111 Nocturnal Enuresis: the management of bedwetting in children and young people (October 2010)

<http://guidance.nice.org.uk/CG111>

NICE Clinical Guideline: CG99 Constipation in Children and Young People (May 2010)

<http://guidance.nice.org.uk/CG99>

NICE Quality Standard: QS62 Constipation in Children and Young People (May 2014)

<https://www.nice.org.uk/guidance/qs62>

NICE Quality Standard: QS70 Nocturnal Enuresis (Bedwetting) in Children and Young People (September 2014)

<https://www.nice.org.uk/guidance/qs70>

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Public Health England: Excellence in Continence Care: practical guidance for commissioners, providers, health and social care staff and information for the public (2015)  
<https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/11/EICC-guidance-final-document.pdf>

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  
<http://www.nice.org.uk/proxy/?sourceUrl=http%3a%2f%2fwww.nice.org.uk%2fmedia%2f0A3%2f93%2fPaediatricContinenceCommissioningGuide.pdf>

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)  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/141430/9328-TSO-2900598-DH-SystemWideResponse.pdf.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/141430/9328-TSO-2900598-DH-SystemWideResponse.pdf.pdf)

Child and Young People's Outcomes Forum: Report Child Health Forum (2013)  
<https://www.gov.uk/government/publications/independent-experts-set-out-recommendations-to-improve-children-and-young-people-s-health-results>

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  
<http://www.nice.org.uk/proxy/?sourceUrl=http%3A%2F%2Fwww.nice.org.uk%2Fusingguidance%2Fcommissioningguides%2Fpaediatriccontinenceservice%2FSpecifyingPaediatricContinenceService.jsp>

Good Practice in Paediatric Continence Services—benchmarking in action NHS Modernisation Agency (2003)  
[http://collections.europarchive.org/tna/20081112112652/www.cgsupport.nhs.uk/PDFs/article/s/good\\_practice\\_paediatric\\_continence\\_services.pdf](http://collections.europarchive.org/tna/20081112112652/www.cgsupport.nhs.uk/PDFs/article/s/good_practice_paediatric_continence_services.pdf)

National Service Framework for Children, Young People and Maternity Services—Continence issues for a child with learning difficulties Department of Health (2010)  
[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_119313.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_119313.pdf)

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

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216137/dh\\_128462.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216137/dh_128462.pdf)

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

## 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.

RCPCH Mind-Ed e-learning for health. Module on paediatric continence.

<http://portal.e-lfh.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:

[http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4005475](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005475)

School Information Tool Kit, ERIC/Promocon

<http://www.eric.org.uk/Campaigns/TheRightToGo>

## 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 care services were almost eliminated, with a saving of over £250,000 per year
- 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.

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&geoTypeId=4>) through:-
  - data on service outcomes (currently unplanned hospital admissions for constipation and urinary tract infections)
  - data on the local delivery of services. Based upon a Freedom of Information surveys carried out by the Paediatric Continence Forum in 2011 and 2014 (the latter of all CCGs in England, Health Boards in Scotland and Wales and the Health and Social Care Trusts in N Ireland).
- 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
- lack of recognition/understanding of the needs (and risks associated with) this group of children. This might include using the more acceptable terms “bladder and bowel service”, rather than the term “continence”.

## 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:-

Type of Evidence	Description
1++	High-quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias
1+	Well-conducted meta-analyses, systematic reviews of RCTs, or RCTs with a low risk of bias
1-	Meta-analyses, systematic reviews of RCTs, or RCTs with a high risk of bias*
2++	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
2+	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
2-	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
3	Non-analytic studies (for example, case reports, case series)
4	Expert opinion, formal consensus



## 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 literature review tables are available on request for users who would like to see them. Email: [paediatriccontinenceforum@whitehouseconsulting.co.uk](mailto:paediatriccontinenceforum@whitehouseconsulting.co.uk)

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).

As part of the 2015 review this document has been updated to include standardizing terminology, assessment and management recommendations from the International Children's Continence Society.

## 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 and Capitated Outcome Contracts should be better developed for paediatric continence.
4. There are currently no Healthcare Resource Groups (HRGs) nor Treatment Function Codes to identify tariffs for paediatric continence conditions treated 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

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## 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)

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Juliette Randall, Chief Executive, ERIC  
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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 and endorsement from the PCF’s other member organisations: the Royal College of Nursing and the Community Practitioners’ and Health Visitors’ Association, has assisted the dissemination process.

Public Health England has added a link to this Guidance to; the National Child and Maternal Health Intelligence Network (ChiMat) website as part of the Continence Needs Assessment Report; it has also been added to the document Excellence in Continence Care: practical guidance for commissioners, providers, health and social care staff and information to the public (2015).

# 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 or 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” or “enuresis” is applicable to children and young people 5-19 years [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. This is a common presentation of functional constipation and may take the form of overflow soiling – when stools “leak” round a large faecal bolus in the rectum.

Non-retentive faecal incontinence (which is often termed ‘encopresis’ in the UK). This is much less common than constipation-associated faecal incontinence. It 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.
- 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) is 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 consistent with data in the Continence Needs Assessment module: Public Health England (last data review September 2015). They can be accessed by Local Authority and Clinical Commissioning region here:-

<http://atlas.chimat.org.uk/IAS/profiles/profile?profileId=45&geoTypeId>

### 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].

Bedwetting can be described qualitatively by the amount of distress it causes to the child or family and impairment in social, academic (occupational) or other areas of functioning [6], or quantitatively based upon the frequency i.e. at least twice a week for at least three consecutive months. The Avon Longitudinal Study of Parents and Children (ALSPAC) survey identified that at 7.5 years old the prevalence of bedwetting is high (15.5%) but only 2.6% of this large population-based sample wet at a frequency of twice a week [7].

Our figures reflect a combined prevalence; for children and young people with a frequency equal to or greater than twice a week and those less frequent than twice a week.

Extrapolating from the ALSPAC data and other studies quoted, the estimated prevalence is:

Children with nocturnal enuresis, estimates by age

<u>Age</u>	<u>Prevalence %</u>	<u>References</u>
5 to 6	21	[8]
7 to 9	12	[8]
10 to 15	2.3	[9]
16 to 19	1.5	[10]
20 to 24	2.0	[11]

## 2.2 Daytime wetting

The prevalence of daytime wetting decreases with age, with an annual spontaneous cure rate of 14.4-22% [4, 12,13]. There is an increasing ratio of girls with increasing age [13, 14, 15, 16].

The table below shows the estimates, by age, of children with (mostly infrequent) daytime urinary incontinence. More frequent daytime urinary incontinence (more than twice a week) is more commonly related to problems of urgency, bedwetting and faecal incontinence than infrequent incontinence.

Children with daytime wetting, estimates by age

<u>Age in Years</u>	<u>Prevalence %</u>	<u>References</u>
5 to 6	6.0	[13]
7 to 10	3.5	[13]
11 to 15	2.9	[16]
16 - 18	2.0	[10]
19 - 24	1.5	[17]

## 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 [18, 19, 20]. 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 [21].

In older children, van der Wal [22] reported that 1.6% of 11 to 12 year olds reported faecal incontinence, and Bakker [23] found a prevalence of 3% in over 4,000 children aged 10 to 14. A review of various studies reported a prevalence of 1.5% in adult males under 60 years of age, which is reasonably consistent with these figures in young people.

Children with faecal incontinence, estimates by age

Soiling

<u>SOILING</u>	<u>Prevalence %</u>	<u>References</u>
4 to 7	4.5	[24]
8 to 10	3.5	[24]
11 to 16	1.6	[22]
16 to 19	1.0	[25]

Source: Office for National Statistics mid-year population estimates for 2011.

## 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 [26].

Local data on unplanned hospital admission figures for constipation are available on the ChiMat website. <http://atlas.chimat.org.uk/IAS/profiles/profile?profileId=45>

## 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 [27]. There is some evidence that children and young people with learning difficulties and physical disabilities have a higher incidence of continence problems. [28-31], although the research in this area is limited. For example; a more 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%) [32], and 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 [33]. 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% [30]. 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 the first sign may be 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

<http://www.disabledliving.co.uk/DISLIV/media/publicationpdf/The%20Platinum%20Trust%20Resources/17549-bladder---bowel.pdf>

## 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 [34, 35] and emotional factors, such as various stressors and behavioural problems [35, 36] in the child. The quality of sleep is also affected [37]. There is evidence that some strategies parents use to help their child achieve dryness (e.g. lifting, fluid restriction) might actually maintain bedwetting [38].

Daytime wetting is associated with a family history of incontinence and other family factors, such as family discord [18, 36], other bladder and bowel dysfunction [18, 39, 40, 41] emotional stress [36], delayed toilet training and ADHD [32].

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 [18, 19].

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 [42, 43]. However studies in this area use different definitions, so are difficult to compare.

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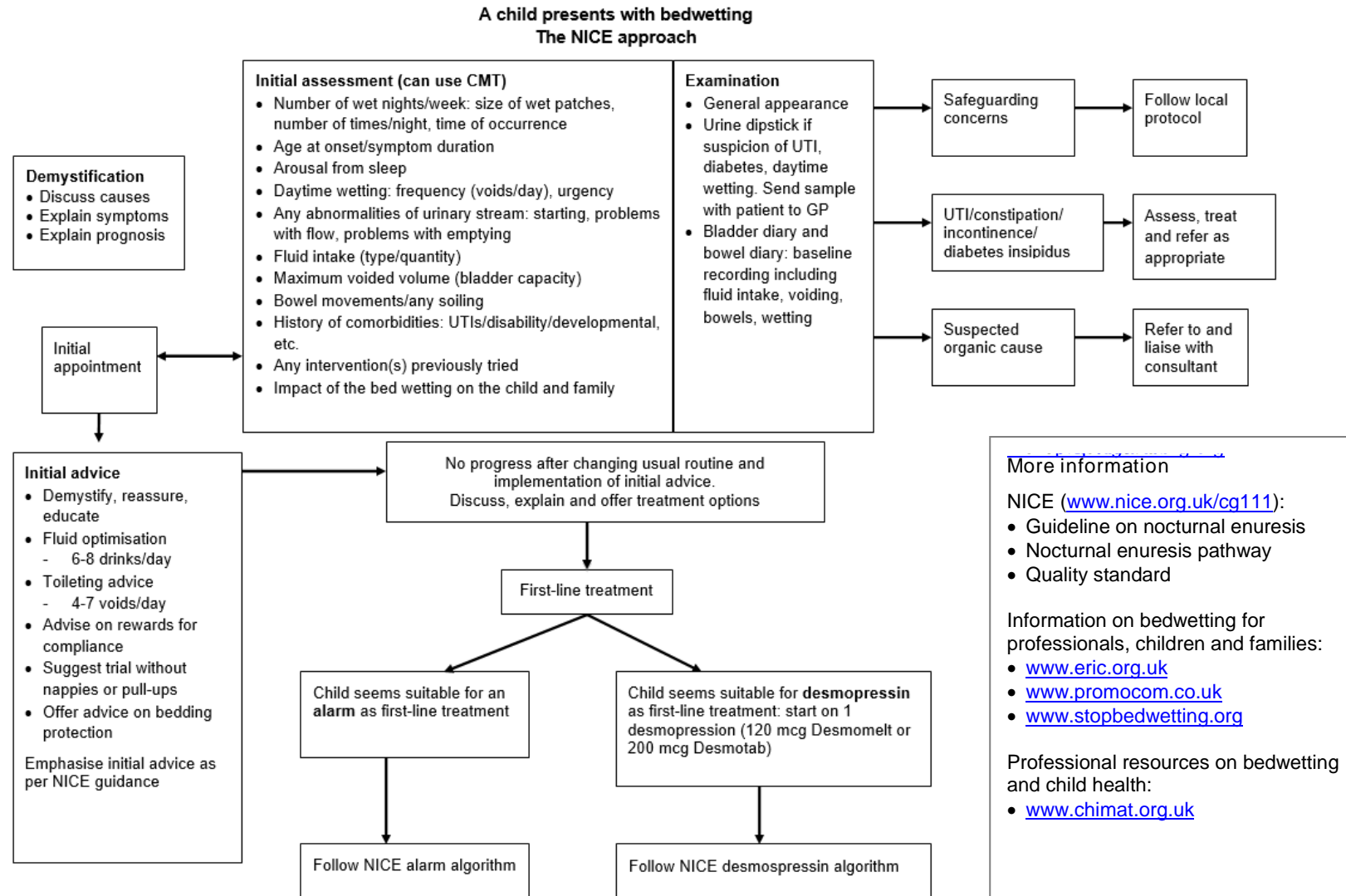
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# Appendix 2: Nocturnal Enuresis Care Pathway



# Appendix 3: Why commission a Paediatric Bladder & Bowel (Continence) Service?

## Why commission a Paediatric Bladder & Bowel (Continence) Service?

### Introduction

NICE estimates that about 900,000 children in the UK have a bladder and bowel (continence) problem, such as bedwetting, daytime wetting or constipation/soiling (National Institute for Health and Care Excellence, 2010). Despite clear recommendations to bring care closer to home (Department of Health, 2007), a significant and rising number of children with constipation are being seen in secondary care (Thompson et al, 2011; ChiMat, 2015). This is highly unsatisfactory for the children and families concerned and is wasting large sums of money for the NHS. If community-based paediatric continence services were improved nationally, this money could be saved.

Why is a community - based service for children and young people with bladder or bowel problems important?

- Easy access to a service which can treat bladder and bowel problems at an early stage would prevent them progressing and requiring referral to secondary care (it would prevent bladder and bowel problems developing in the first place, treat at an early stage and refer to secondary care only when needed). It would thereby reduce the considerable number of expensive visits to A&E and outpatient clinics.
- Proper assessment and toilet training for children with delayed acquisition of bladder and bowel control would reduce the need for 'free' nappies, thereby making considerable savings for the NHS.
- It would prevent continence conditions deteriorating/ becoming chronic and identify when there is an underlying problem, for example bedwetting can be a symptom of constipation.

What are the comparative costs?

### ***Costs if children are seen in primary care***

- The hourly rate of nursing top band 6/ mid band 7 £17.66 (before any on costs)

Source: [Royal College of Nursing, Pay rates 2014-15](#)

### ***Costs if children are seen in acute/secondary care:-***

- The average cost of an outpatient attendance is £108 (specialist paediatric urology £162)
- The average cost of an A&E attendance is £114
- The average cost of a day case is £693

Source: [NHS Reference Costs for 2012-13; 2014-15 National Tariff Payment System](#)

Regard to NICE quality standards

The Health and Social Care Act (2012) makes it clear that the care system “must have regard to the quality standards prepared by NICE” in the planning and delivery of services as “part of a general duty to secure continuous improvement in quality”.

Source: [Health and Social Care Act 2012, Section 2](#)

Section 13E relates to the functions of the NHS Commissioning Board (now NHS England) and their duties in regard to quality standards:

Source: [Health and Social Care Act 2012, Section 13E](#)

### Relevant NICE quality standards

NICE Quality Standard 70: [Nocturnal enuresis \(bedwetting\) in children and young people](#)

NICE Quality Standard 62: [Constipation in children and young people](#)

### NICE resources for Commissioning

A wide range of tools and implementation resources for nocturnal enuresis and constipation are accessible resources are accessible through the online [NICE pathways tool](#).

### NICE accredited Commissioning Guide

[NICE accredited Paediatric Continence Commissioning Guide](#): Paediatric Continence Forum (2014)

### The United Nations Convention on the Rights of the Child

The following articles from the [United Nations Convention of the Rights of the Child](#) support the provision of paediatric continence services.

- Article 23 (Children with disabilities): “Children who have any kind of disability have the right to special care and support... so that they can live full and independent lives”
- Article 24 (Health and health services): “Children have the right to good quality health care – the best health care possible... and information to help them stay healthy”

### References/further information

[Needs Assessment Tool for Continence](#). The National Child and Maternal Health Intelligence Network, part of Public Health England (2015)

[Implementing care closer to home: Convenient quality care for patients](#). Department of Health (2007):

[The epidemiology of general paediatric outpatients referrals: 1988 and 2006](#). Thompson et al (2011)

### Supporting tools

[Assessment of toilet training readiness and issuing of products](#), Royal College of Nursing (2013)

[Nocturnal Enuresis Clinical Management Tool \(CMT\)](#)

[Nocturnal Enuresis Management Algorithm](#)

[Royal College of Paediatrics and Child Health Mind–Ed e-learning Healthy School Child Programme](#)

### Contact details for further information

Paediatric Continence Forum: [www.paediatriccontinenceforum.org](http://www.paediatriccontinenceforum.org)

Contact us at: [paediatriccontinenceforum@whitehouseconsulting.co.uk](mailto:paediatriccontinenceforum@whitehouseconsulting.co.uk)

PromoCon (Promoting continence and product awareness): [www.promocon.co.uk](http://www.promocon.co.uk)

Contact us at: [promocon@disabledliving.co.uk](mailto:promocon@disabledliving.co.uk)



## Appendix 4: Sample surveys to measure service satisfaction and quality of life

There are a number of quality of life questionnaires which have been used in children and are available on-line and/or in published papers. This appendix aims to 'signpost' a few that are relevant to and have been used for children with continence problems.

### Quality of Life

PinQ is a 20 question validated assessment produced specifically for children with bladder dysfunction [1]. The full questionnaire is given in the article and it has been used in the original or modified forms elsewhere.

The PedsQL is a more general questionnaire which is commercially available on-line (<http://www.pedsq.org/>) and has been used in relation to childhood continence in a study of faecal incontinence [2] and one of school children with constipation [3].

A similar, slightly simpler 12 question assessment, the DCGM -10 has been used for children with continence and other chronic health problems [4].

A detailed questionnaire relating to bowel problems is the FIC QOL. This is available online using the link: [https://www.ucdmc.ucdavis.edu/urology/specialties/pediatric\\_urology](https://www.ucdmc.ucdavis.edu/urology/specialties/pediatric_urology) where it is to be found under *pediatric urology information handouts*, with the title "Bowel Care Survey for Adults" (the "Adults" referring to the fact that the questionnaire is to be administered by adults); it also includes some useful questions regarding symptoms in addition to the quality of life elements [5]

### Symptom Scores

The Dysfunctional Voiding Scoring System [6] and Dysfunctional Voiding and Incontinence Symptom Scoring System [7], provide symptom scoring systems for urinary problems in the same way as the FIC QOL; in the former the questions are predominantly directed to the child, the latter is addressed to the parents.

### PROM / FROM

Patient and family reported outcomes can be assessed using the Experience of Service questionnaire produced by the Commission for Health Improvement (now Healthcare Commission). ESQ (CHI-ESQ; Experience of Service Questionnaire; 0 – 18yrs) is the original measure for use with parents whose children have been seen and can be downloaded from: <http://www.corc.uk.net/resources/measures/parent/>

This questionnaire has been modified for use by the child or young person themselves (Self-report ESQ for 9-11 year olds, which can be downloaded from: <http://www.corc.uk.net/resources/measures/child/> and Self-report ESQ for 12-18 year olds can be downloaded from <http://www.corc.uk.net/resources/measures/child/>)

Sanders et al. [8] describe the use of parts of both the PinQ and CHI-ESQ questionnaires in a clinical setting.

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