Paediatric continence service

Commissioning guide
Implementing NICE guidance

December 2010
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Paediatric continence service

This commissioning guide provides support for the local implementation of NICE guidance through commissioning, and is a resource for people involved in commissioning health and social care services and public health programmes within the NHS and partner organisations in England.

Joint commissioners and people working in local authorities may find this guide useful to inform partnership working and joint planning.

This commissioning guide should be read together with the following NICE guidance:

- **NICE clinical guideline CG99. ‘Constipation in children and young people: diagnosis and management of idiopathic childhood constipation in primary and secondary care’**
- **NICE clinical guideline CG111. ‘Nocturnal enuresis: the management of bedwetting in children and young people’**

NICE guidance provides evidence based recommendations about clinically effective and cost-effective treatments and interventions to improve outcomes for local populations. Making commissioning decisions based on NICE guidance and accredited information from NHS Evidence can help commissioners to ensure that they are using their resources effectively.

Where **NICE quality standards** are available, commissioners should refer to them when commissioning services and should include quality statements and measures within the service specification element of the standard contract. Managing performance against the NICE quality standards could help improve standards of care and outcomes for patients.

This commissioning guide highlights any recommendations supporting cases for disinvestment or decommissioning of services by identifying treatments and interventions that do not add value, enabling commissioners to release resources or generate savings where appropriate.

Implementation of the guidance noted above is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement this guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in the guidance should be interpreted in a way which would be inconsistent with compliance with those duties.

The guide:

- **makes the case for commissioning a paediatric continence service**
- **specifies service requirements**
- **helps you determine local service levels**
• helps you ensure corporate and quality assurance.

The full text of this commissioning guide can be downloaded or accessed from the navigation menu on the right hand side of the screen. Download the openly available commissioning and benchmarking tool.

We are keen to improve the commissioning guides in order to better meet the needs of commissioners. Please send us your ideas for future topic-specific guides or other comments.

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• Topic-specific Advisory Group: paediatric continence service

December 2010
Commissioning a paediatric continence service

Nocturnal enuresis, or bedwetting, is involuntary wetting during sleep in a person with no physical disease at an age when they could be expected to be dry, generally considered to be a developmental age of 5 years or over. Children and young people who experience bedwetting may also have daytime urinary tract symptoms, such as daytime wetting or frequent or urgent urination[1,2].

Idiopathic constipation is difficulty, pain or straining when passing stools, and/or passing stools less often than normal[3]. Constipation is referred to as ‘idiopathic’ if it cannot be explained by anatomical or physiological abnormalities[4].

Continence problems in children and young people are common, yet there is evidence that the need and demand for continence services in some areas is significantly under-resourced when compared with services for other conditions with a comparable prevalence, such as asthma and otitis media (ear inflammation)[5,6]. Continence problems are more common in younger children, with constipation having a peak prevalence in toddlers. However, prevalence remains high in older age ranges, with 1 in 50 teenagers experiencing bedwetting and 1 in 100 children and young people aged between 11 and 18 years having idiopathic constipation[7,8].

Continence problems are more prevalent among children and young people who have some physical disabilities, such as spina bifida or cerebral palsy. Children and young people with learning difficulties such as Down’s syndrome or autistic spectrum disorders may take longer to achieve continence[2,4,9] There is also a higher prevalence of continence problems among children and young people in local authority care[10].

Continence problems can have a significant emotional impact, and can increase the risk of bullying and of behavioural problems in children and young people. Managing the problem can be stressful for parents and carers and can strain family relationships. While most parents do not get angry with their child as a result of bedwetting, there is evidence of a link with child punishment, including physical abuse by parents or carers[1,2,4].

Continence problems in children and young people may take many months or years to resolve, so it is important that they are diagnosed and managed early. If the conditions are not managed and become chronic they may result in referral, treatment and/or surgery in secondary care[2,4]. Toilet training and evidence-based treatment for continence problems can be effective using a variety of interventions, from drug treatments and bedwetting alarms to more complex and comprehensive treatment plans. It is important that treatment is adapted to the needs and circumstances of the child or young person and their family.

It is estimated that establishing a paediatric continence service for children and young people aged 19 years and under could lead to a significant...
reduction in the number of admissions to secondary care for idiopathic constipation, by providing assessment and management of continence problems in primary and community settings. There is also the potential to reduce costs further by reducing the demand for continence products such as nappies or pads.

The 2010 National audit of continence care for adults found that most continence services are poorly integrated across acute, primary and community settings, that training of healthcare professionals is inadequate and that there is no-one specifically responsible for commissioning and improving continence services. Good practice in paediatric continence services recommends that commissioners of health and social care services commission an integrated paediatric continence service.

**Benefits**

The potential benefits of robustly commissioning an effective paediatric continence service include:

- **greater awareness of continence problems resulting in improved identification**, early intervention and faster referral-to-treatment times
- **reducing costs resulting from inappropriate referrals to paediatricians** and preventing unplanned hospital admissions for children and young people with abdominal pain caused by chronic constipation
- **improving clinical outcomes and quality of life for children and young people and their families** through evidence-based treatment that promotes continence, preventing unnecessary long-term reliance on nappies and pads and the need for surgery
- **increasing clinical and cost effectiveness**: by making commissioning decisions based on NICE guidance and accredited information from NHS Evidence, commissioners can ensure that they are using their resources more effectively.

**Key clinical issues**

Key clinical issues in providing an effective paediatric continence service are:

- **increasing awareness of continence problems** so that children and young people with continence problems are identified and assessed, and where appropriate those with ‘red flag’ symptoms or safeguarding concerns are referred promptly to the appropriate service (see service components section)
- **improving assessment and reducing unnecessary invasive examinations and procedures**, leading to improved clinical outcomes, by providing evidence-based treatment for continence problems in line with NICE guidance
**providing a ‘whole child’ approach so that complex and comorbid problems** can be treated appropriately, leading to better outcomes for children and young people and their parents or carers

**providing a quality assured service.**

**National drivers**

National priorities and initiatives relevant to commissioning a paediatric continence service include:

- **Equity and excellence: liberating the NHS: Transparency in outcomes – a framework for the NHS** (draft for consultation).
- **Revision to the operating framework for the NHS in England 2010/11**
- **Procurement guide for commissioners of NHS-funded services 2010.**
- **Quality, innovation, productivity and prevention.**
- **Commissioning for quality and innovation (CQUIN):** makes a proportion of providers’ income conditional on quality and innovation.
- The **Care closer to home** initiative outlined in chapter 6 of the white paper ‘Our health, our care, our say’.
- Considering the impact of **patient choice.**
- **A stronger local voice: a framework for creating a stronger local voice in the development of health and social care services.**
- **National service framework for children, young people and maternity services.**
- **Good practice in continence services.**
- **Every child matters: change for children** and **Sure Start Children’s Centres.**
- **Healthy child programme: pregnancy and the first five years of life** and the **Healthy child programme: from 5 to 19 years old.**
- **Healthy lives, brighter futures – the strategy for children and young people’s health.**
- **Aiming high for disabled children.**
- **Essence of care 2010: benchmarks for bladder, bowel and continence care.**

Although many or all of these priorities may be relevant to the services nationally, your local service redesign may address only one or two of them.
References


Specifying a paediatric continence service

Service components

The key components of a paediatric continence service are:

- early identification, assessment and initial treatment of children and young people with continence problems
- managing long-term continence problems in children and young people
- developing a high-quality integrated paediatric continence service.

Early identification, assessment and initial treatment of children and young people with continence problems

The children’s health and social care workforce has an important role in encouraging parents and carers to seek timely help from healthcare professionals if they suspect that a child may have idiopathic constipation, bedwetting or daytime wetting, or may benefit from additional support with toilet training. Therefore health and social care commissioners should work collaboratively with the wider children’s workforce, including children’s centre staff and nursery nurses, to ensure that they have opportunities to improve their awareness of children’s and young people’s continence problems. When planning services, commissioners should address the needs, location and availability of services for parents and carers from deprived communities and from black and minority ethnic groups, since they are less likely to access treatment for their children. NICE has developed frequently asked questions for staff in children's centres to raise awareness of idiopathic constipation.

When commissioning a paediatric continence service, commissioners should specify that all primary healthcare professionals who work with children and young people and their families or carers, including GPs, health visitors and school nurses, are able to identify continence problems and provide initial assessment, primary treatment and/or referral in accordance with NICE clinical guidelines CG99 on constipation in children and young people and CG111 on nocturnal enuresis.

NICE has developed history-taking questionnaires that may assist healthcare professionals to assess children and young people with suspected constipation. This may help to provide a structured approach to identifying diagnostic criteria and signs of underlying conditions, and ensuring appropriate treatment or referral.
Commissioners should ensure that treatment pathways enable primary healthcare professionals to identify and refer the following children and young people to an appropriate specialist service:

- **A child who has not responded to treatment**: 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 CG111 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.

- **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.

- **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 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.

There is evidence that, for most children and young people with idiopathic constipation, the psychological component of their constipation is likely to be secondary to the physical element[s]. NICE clinical guideline CG99 on constipation in children and young people recommends that children and young people with idiopathic constipation are not routinely referred to a psychologist or child and adolescent mental health services (CAMHS) unless the child or young person has been identified as likely to benefit from receiving a psychological intervention. Therefore a commissioner may wish to ensure that systems are in place so that any child or young person for whom a referral to a psychologist or CAMHS may be considered appropriate is first assessed by the paediatric continence service. However, there is an established link between continence and behavioural issues, so commissioners should ensure that good communication exists between their paediatric continence service and their CAMHS.

In order that children and young people with continence problems receive timely referral and management of their condition, health and social care commissioners should collaborate to ensure that they include information about access to paediatric continence services in the service specifications that relate to the wider children’s workforce, particularly child and family
workers, social workers and foster carers. They may also wish to ensure that these services are able to raise awareness of continence problems among parents and carers within their communities, as well as encouraging self-referral.

In order to achieve optimal use of resources and to support NHS Quality, innovation, productivity and prevention (QIPP), commissioners should be aware of the assessments and interventions that are not recommended for clinical investigation of constipation in NICE clinical guideline CG99 on constipation in children and young people:

- **Do not** perform a digital rectal examination in children or young people older than 1 year with a ‘red flag’ (see tables 2 and 3 in CG99) in the history-taking and/or physical examination that might indicate an underlying disorder. Instead, refer them urgently to a healthcare professional competent to perform a digital rectal examination and interpret features of anatomical abnormalities or Hirschsprung's disease.
- **Do not** use gastrointestinal endoscopy to investigate idiopathic constipation.
- **Do not** use anorectal manometry to exclude Hirschsprung's disease in children and young people with chronic constipation.
- **Do not** use a plain abdominal radiograph to make a diagnosis of idiopathic constipation.
- **Do not** perform rectal biopsy unless any of the following clinical features of Hirschsprung’s disease are or have been present: delayed passage of meconium (more than 48 hours after birth in term babies); constipation since first few weeks of life; chronic abdominal distension plus vomiting; family history of Hirschsprung’s disease; faltering growth in addition to any of the previous features.
- **Do not** use transit studies to make a diagnosis of idiopathic constipation.
- **Do not** use abdominal ultrasound to make a diagnosis of idiopathic constipation.

In order to achieve optimal use of resources and to support NHS Quality, innovation, productivity and prevention (QIPP), commissioners should be aware of the assessments and interventions that are not recommended at initial assessment for bedwetting in NICE clinical guideline CG111 on nocturnal enuresis:

- **Do not** exclude younger children (for example, those under 7 years) from the management of bedwetting on the basis of age alone.
- **Do not** perform urinalysis routinely in children and young people with bedwetting, unless any of the following apply: bedwetting started in the last few days or weeks; there are daytime symptoms; there are any signs of ill health; there is a history, symptoms or signs suggestive or urinary tract infection; there is a history, symptoms or signs suggestive of diabetes mellitus.
Managing long-term continence problems in children and young people

Commissioners should ensure that their paediatric continence service works with children and young people, and their families or carers, to promote and achieve continence through proactive toilet training. The permanent or long-term use of continence products may be required for some children and young people, but should be considered only after other methods of management have not worked or are deemed inappropriate.

Because continence problems may take many months or years to resolve, commissioners should ensure that their paediatric continence service provides appropriate levels of ongoing support tailored to the needs of children and young people who do not respond to initial treatment. This support should be offered through a single point of contact with a specialist healthcare professional. Commissioners should also ensure that the service is accessible to children and young people, and their families or carers, both during treatment and after discharge. Commissioners are reminded that services should not exclude younger children (for example, those under 7 years) from the management of bedwetting on the basis of age alone.

When planning a paediatric continence service, commissioners should consider the needs of children and young people who have associated comorbidity, for example a disability or learning difficulty. Good practice in paediatric continence services recommends that paediatric continence services are fully inclusive and accessible for all children and young people regardless of age or disability, and that separate services should not be developed for children and young people with special needs.

Commissioners should ensure that locally agreed prescribing guidelines are in place so that oral medication for the treatment of constipation or bedwetting is prescribed in accordance with the recommendations of NICE clinical guidelines CG99 on constipation in children and young people and CG111 on nocturnal enuresis. It is anticipated that there may be an increase in the prescription costs for oral medication for constipation, including polyethylene glycol 3350 (Movicol), in primary care. However, it is also anticipated that these costs will be more than offset by a corresponding reduction in the number of inpatient and outpatient attendances for children and young people with constipation, as early treatment will prevent the problem from becoming a chronic condition.

In order to achieve optimal use of resources and to support NHS Quality, innovation, productivity and prevention (QIPP), commissioners should be aware of those assessments and interventions that are not recommended for the management of constipation in NICE clinical guideline CG99 on constipation in children and young people:

- **Do not** use rectal medications for disimpaction unless all oral medications have failed and only if the child or young person and their family consent.
Do not administer phosphate enemas for disimpaction unless under specialist supervision in hospital/health centre/clinic, and only if all oral medications and sodium citrate enemas have failed.

Do not perform manual evacuation of the bowel under anaesthesia unless optimum treatment with oral and rectal medications has failed.

Do not use dietary interventions alone as first-line treatment for idiopathic constipation.

Do not use biofeedback for ongoing treatment in children and young people with idiopathic constipation.

Do not routinely refer children and young people with idiopathic constipation to a psychologist or child and adolescent mental health services unless the child or young person has been identified as likely to benefit from receiving a psychological intervention.

In order to achieve optimal use of resources and to support NHS Quality, innovation, productivity and prevention (QIPP), commissioners should be aware of those assessments and interventions that are not recommended for the management of bedwetting in NICE clinical guideline CG111 on nocturnal enuresis:

Do not exclude alarm treatment as an option for bedwetting in children with: daytime symptoms as well as bedwetting; secondary bedwetting.

Do not exclude desmopressin as an option for the management of bedwetting in children and young people who also have daytime symptoms. However, do not use desmopressin in the treatment of children and young people who only have daytime wetting.

Do not exclude desmopressin as an option for the treatment of bedwetting in children and young people with emotional, attention or behavioural problems or developmental and learning difficulties if an alarm is inappropriate or undesirable and they can comply with night-time fluid restriction.

Do not routinely measure weight, serum electrolytes, blood pressure and urine osmolality in children and young people being treated with desmopressin for bedwetting.

Do not use an anticholinergic alone for the management of bedwetting in children and young people without daytime symptoms.

Do not offer an anticholinergic combined with imipramine for the treatment of bedwetting in children and young people.

Do not use tricyclics as the first-line treatment for bedwetting in children and young people.

Do not use strategies that recommend the interruption of urinary stream or encourage infrequent passing of urine during the day.

Do not use dry-bed training with or without an alarm for the treatment of bedwetting in children and young people.
Developing a high-quality integrated paediatric continence service

Figure 1.1 of the 2004 Royal College of Nursing publication Is policy translated into action? provides an example of a model for an integrated continence service.

The Department of Health publication Good practice in continence services sets out a model of good practice to help healthcare professionals achieve more responsive, equitable and effective continence services. It suggests that one local strategic lead is made responsible for developing and implementing integrated care pathways across relevant healthcare sectors and their partner organisations. Therefore commissioners may wish to consider providing resources for a lead continence adviser to ensure a coordinated and consistent approach to identifying, assessing and treating continence problems across all settings within health and social care. This could include developing integrated care pathways, policies and protocols and agreeing to use a single assessment and referral form.

Commissioners should specify that health and social care professionals working in paediatric continence services are competent and skilled in assessing and managing continence problems in children and young people. They may also wish to consider making resources available for paediatric continence training.

Service models

Commissioners may wish to consider commissioning a paediatric continence service in a number of different ways, and mixed models of provision may be appropriate across a local health economy.

Commissioners should consider shifting the focus of investment for children and young people’s bladder and bowel care towards community and primary care, thereby increasing productivity and reducing the number of unnecessary admissions to secondary care. A paediatric continence service may have the following characteristics:

- Be based in primary, community or secondary care. All services should be flexible, child-friendly and accessible to children and young people and their families, for example being delivered in a convenient location and providing telephone support and/or home visits. An example of a health visitor led service from Hounslow and Richmond Community Healthcare is provided in box 1 and an example of a school nurse led service from York Teaching Hospital NHS Foundation Trust is provided in box 2.

- Be delivered as a dedicated paediatric continence service or as a specialist paediatric service within an integrated whole-population continence service. Box 3 provides an example of an integrated paediatric continence service in Liverpool Community Health NHS Trust. The service should ensure good continuity of care between paediatric and adult services where long-term
management is required. See also the NICE commissioning guides on faecal continence service, urinary continence service for women and service for the management of lower urinary tract symptoms in men.

- Be led by a multidisciplinary team of dedicated paediatric continence nurse specialists, school nurses, health visitors and/or paediatricians who are trained and experienced in the management of continence problems in children and young people. It may be possible to include health visitor or nurse prescribers.

- Have varying remits, from developing care pathways and providing training to the healthcare workforce through to managing complex cases.

- Promote the management of continence problems with partners in education and social care, such as appropriate fluid intake and diet, toilet training and ensuring accessible child-friendly toilets.

**Box 1. Continence care provided by the health visiting team in Hounslow and Richmond Community Healthcare**

The health visiting team is ideally placed to provide first support to children and their families on toilet training. Initial assessments of children with continence problems are carried out in the home, with follow-up appointments provided in a clinic if needed for reasons of dignity and privacy. The health visiting team provides treatment in accordance with NICE guidance, including the appropriate use of laxatives, as well as continence information and resources. For children with more complex problems, referrals are made to a specialist continence nurse or to the specialist health visitor for children's continence and special needs.

Outcome: children achieve continence at an age appropriate to their development. Timely interventions to manage constipation prevent the situation progressing to chronic constipation, stool holding and disimpaction.

**Box 2. Accessible paediatric continence services in York Teaching Hospital NHS Foundation Trust**

The York paediatric nocturnal enuresis service has 18 school health nurses, all trained by an enuresis nurse specialist in the assessment and management of bedwetting.

The school health nurses provide an assessment in the family home after school (this has led to very low ‘did not attend’ rates) and first-line treatment for continence problems in accordance with NICE guidance. Monthly follow-up appointments are provided in the home, with phone support available between appointments. Children and young people who do not respond to treatment or who have comorbidities are referred to the enuresis nurse specialist.
Outcome: because the service is quick and easy to access, there are no waiting lists for treatment.

Box 3. Integrated paediatric continence service in Liverpool Community Health NHS Trust

Liverpool Community Health NHS Trust has a lead paediatric continence adviser who works across primary care and links with secondary care healthcare professionals to provide a comprehensive paediatric continence promotion service that includes assessment, treatment, awareness raising and training for all staff. This has transformed the service from a fragmented continence-supply (‘free-nappy’) service to a fully integrated paediatric continence promotion service in accordance with NICE guidance.

Outcome: health visitors and school nurses are more confident in dealing with children and young people with continence problems. They are proactive in starting first-line treatments, and refer the child or young person to the paediatric continence service when appropriate and in a timely fashion. Since the service started in 2005 the number of children and young people in receipt of free nappies has dropped from 700 to less than 300 per year, and the need for referral to secondary care for children and young people with idiopathic constipation has been virtually eliminated.

Further information about this service can be found in the Royal College of Nursing guidance Paediatric assessment of toilet training readiness and the issuing of products.

(Please note – these examples are offered to share good practice and NICE makes no judgement on the compliance of this service with its guidance.)

Service specification

Commissioners should collaborate with clinicians, local stakeholders and service users, including children and young people and their parents or carers, when determining what is needed from a paediatric continence service in order to meet local needs. The service should be child-centred and integrated with other elements of care for children and young people with continence problems.

The service specification needs to consider:

- the required competencies of, and training for, staff responsible for providing the service
- the expected number of children and young people (this should take into account how quickly any changes in service provision are likely to take place)
- ease of access and service location; commissioners should engage with parents and carers and other relevant individuals and organisations locally
• care and referral pathways, including discharge and follow-up arrangements and smooth transition to adult continence services where required

• measuring outcomes

• information and audit requirements, including IT support and infrastructure

• planned service development setting out any productivity improvements including redesign, quality and equitable access

• address any safeguarding concerns and promote the welfare of children and young people

• other service remits, such as raising awareness of continence problems

• service monitoring criteria.

Useful sources of information may include:

• **The standard NHS contracts for acute hospital, mental health, community and ambulance services.**

• **NHS Evidence:** provides free access to clinical and non-clinical information – local, regional, national and international.

• The clinical knowledge summaries for nocturnal enuresis and constipation in infants and children.

• The **NICE shared learning database** offers examples of how organisations have implemented NICE guidance locally.

• Implementation tools for NICE clinical guidelines **CG99 ‘Constipation in children and young people’** and **CG111 Nocturnal enuresis’**.

• The NICE guidance written for parents and carers on idiopathic constipation and bedwetting.

• **NICE clinical guideline CG54 ‘Urinary tract infection in children: diagnosis, treatment and long-term management’.**

• **NICE clinical guideline CG89 ‘When to suspect child maltreatment’**.

• The NICE template discharge advice that can be issued to parents and carers by primary healthcare professionals to provide information on the management of constipation at home.

• Web and published resources on childhood continence problems provided by a number of specialist organisations, including Education and Resources for Improving Childhood Continence (ERIC), PromoCon, Association for Continence Advice and the International Children’s Continence Society.

• Continence training is delivered by a number of national organisations, including the **Royal College of Nursing, Education**
Factors involved in best practice in continence care are identified in Good practice in paediatric continence services and the Department of Health’s Essence of care: benchmarks of bladder, bowel and continence care.

References

Determining local service levels for a paediatric continence service

Benchmarks for a standard population

Available data suggest that the indicative benchmark rate for a paediatric continence service is 0.8% or 800 per 100,000 population aged 19 years and under per year.

For the purpose of this commissioning guide the population has been defined as children and young people aged 19 years and under. Approximately 24%, or 12.3 million, of the population in England is aged 19 years and under.

For a standard population of 100,000 the number of children and young people aged 19 years and under is approximately 24%, or 24,000. Of these around 0.8%, or 200 children and young people per year, would require a paediatric continence service.

For an average practice with a list size of 10,000, the number of children and young people aged 19 years and under is approximately 24%, or 2400. Of these around 0.8%, or 20 children and young people per year, will require a paediatric continence service.

Examine the assumptions used in estimating these figures.

This service is likely to fall under the programme budgeting categories 213A ‘genito urinary system disorders’ or 223X ‘other’.

Use the paediatric continence service commissioning and benchmarking tool to determine the level of service that might be needed locally and to calculate the cost of commissioning the service using the indicative benchmark and/or your own local data.

Further information

Sources of further information to help you in assessing local health needs and reducing health inequalities include:

- Annex A of the Commissioning framework for health and well-being outlines the process and data needed to undertake a joint strategic needs assessment.
- Department of Health Delivering quality and value – focus on benchmarking.
- NICE Health equity audit – learning from practice briefing.
- **NHS comparators** provides comparator data for NHS commissioning and provider organisations to enable users to investigate aspects of local activity, costs and outcomes.

- The **Disease management information toolkit (DMIT)** is a good-practice tool for decision-makers, commissioners and deliverers of care for people with long-term conditions, which presents data on conditions that contribute to high numbers of emergency bed days. It models the effects of possible interventions that may be commissioned at a local level and helps users to consider the likely impact of commissioning options.

- **PRIMIS+** provides support to general practices on information management, recording for, and analysis of, data quality, plus a comparative analysis service focused on key clinical topics.

- **ChiMat** (child and maternal health observatory) provides a data atlas on continence.
Assumptions used in estimating a population benchmark

The assumptions used in estimating a population benchmark for a paediatric continence service of 0.8% or 800 per 100,000 population aged 19 years and under per year are based on the following sources of information:

- **epidemiological data** on the prevalence and incidence of paediatric continence problems
- **activity data** on inpatient and outpatient attendances for continence problems, including constipation, bedwetting and daytime wetting
- **current practice** where existing paediatric continence services are in place

For the purpose of this commissioning guide the population has been defined as children and young people aged 19 years and under. Approximately 24% of the population in England is aged 19 years and under.

**Epidemiological data**

A paediatric continence service provides treatment and advice for children and young people with continence problems, most commonly idiopathic constipation, bedwetting and daytime wetting. All are common conditions, affecting approximately 900,000 children and young people in the UK\(^1\). However, evidence suggests that only around 100,000 children and young people will typically access treatment, so it is likely that many potential cases remain undiagnosed or untreated.

Table 1 shows the prevalence of bedwetting, daytime wetting and daytime faecal incontinence in England. The overall prevalence rate of bedwetting and daytime wetting declines with age.

**Table 1: Prevalence of bedwetting, daytime wetting and daytime faecal incontinence (soiling and constipation)\(^2,3\)**

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Bedwetting (%)</th>
<th>Daytime wetting (%)</th>
<th>Daytime faecal incontinence (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.5</td>
<td>30</td>
<td>15.5</td>
<td>29</td>
</tr>
<tr>
<td>9.5</td>
<td>9.5</td>
<td>4.9</td>
<td>27.5</td>
</tr>
</tbody>
</table>

Constipation occurs in approximately 0.7% to 29.6%\(^4\) of children and young people, depending on the definition used and the populations considered. It becomes a chronic condition in more than one third of patients\(^5\). Approximately 95% of children referred for assessment of their constipation have no underlying pathological condition\(^6\). The peak incidence of constipation is at toddler to preschool age\(^7\).


**Activity data**

The ‘Hospital episode statistics’ (HES) database contains details of all admissions to NHS hospitals in England. It includes data on private patients treated in NHS hospitals, patients who were resident outside England and care delivered by treatment centres (including those in the independent sector) funded by the NHS.

The analysis of **inpatient** data from HES suggests that in 2008/09 there were around 14,500 hospital admissions in England for continence problems, including constipation, bedwetting or daytime wetting, among children and young people aged 19 years and under. Most of these admissions (12,500) were for constipation, of which 80% were emergency admissions.

The analysis of **outpatient** data suggests that in 2008/09 there were around 18,000 first hospital attendances in England for constipation among children and young people aged 19 years and under. It is estimated that there were few attendances for bedwetting or daytime wetting.

It was the view of the topic advisory group that in areas where there is no existing service, establishing a paediatric continence service using a primary or community care model could lead to up to an 80% reduction in emergency admissions and a significant reduction in consultant-led outpatient appointments. The potential for cost savings by reducing secondary care activity is examined further in the [commissioning and benchmarking tool](#).

**Current practice**

Data from IMS Disease Analyser, a database that holds patient data from a sample of GP practice systems, indicate that, in 2009, 0.61% of children and young people aged 19 years and under presented for treatment for and had a recorded diagnosis of idiopathic constipation. This equates to around 75,000 children and young people.

Additionally, in 2009 around 27,000 or 0.22% of children and young people aged 19 years and under presented for treatment and had a recorded diagnosis of daytime wetting or bedwetting.

Around 5000 children and young people had a dual diagnosis of constipation and daytime wetting or bedwetting.

Therefore around 100,000 children and young people presented for treatment in primary care in 2009 for idiopathic constipation and/or daytime wetting or bedwetting.

Table 2 shows the proportion of children and young people aged 0 to 5 and 6 to 19 who visited their GP in 2009 with a diagnosis of constipation or enuresis. Two thirds (66%) of visits for constipation were children aged 5 or under. Around one fifth (21%) of visits for bedwetting or daytime wetting were children aged 5 or under.
Table 2. Proportion of children and young people 0 to 5 and 6 to 19 who visited their GP in 2009 with a diagnosis of constipation and/or daytime wetting or bedwetting

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Age 0 to 5</th>
<th>Age 6 to 19</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constipation</td>
<td>66%</td>
<td>34%</td>
<td>100%</td>
</tr>
<tr>
<td>Bedwetting or daytime wetting</td>
<td>21%</td>
<td>79%</td>
<td>100%</td>
</tr>
<tr>
<td>Constipation and bedwetting or daytime wetting</td>
<td>19%</td>
<td>81%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Treatment for paediatric continence could take place in a number of settings and be delivered by a number of healthcare professionals, such as GPs, paediatricians, health visitors and school nurses. For the purpose of this commissioning guide it has been assumed that the patient record held by the GP will be updated with details of treatment by these healthcare professionals and therefore data from the IMS disease analyser will capture diagnoses made by all of these healthcare professionals.

**Conclusions**

Based on the epidemiological data and other information outlined above, it is concluded that a population benchmark for a paediatric continence service is 0.8% or 800 per 100,000 population aged 19 years and under per year. This is based on the following assumptions:

- In 2009 approximately 100,000 children and young people aged 19 years and under presented for treatment in primary care for idiopathic constipation and/or daytime wetting or bedwetting.
- The prevalence of these conditions is high and only a small proportion of the estimated population with the conditions currently present for treatment.

Use the paediatric continence service commissioning and benchmarking tool to determine the level of service that might be needed locally and to calculate the cost of commissioning the service using the indicative benchmark and/or your own local data.

**References**


The commissioning and benchmarking tool

Download the paediatric continence service commissioning and benchmarking tool.

Use the paediatric continence service commissioning and benchmarking tool to determine the level of service that might be needed locally and to calculate the cost of commissioning the service, as described below.

**Identify indicative local service requirements**

The indicative benchmark rate for a paediatric continence service is 0.8% or 800 per 100,000 population aged 19 years and under.

The commissioning and benchmarking tool helps you to assess local service requirements using the indicative benchmark as a starting point. With knowledge of your local population and its demographic, you can amend the benchmark to better reflect your local circumstances. For example, if your population is significantly younger than the average population, or has a significantly higher or lower rate of paediatric continence problems, you may need to provide services for relatively more or fewer children and young people.

**Review current commissioned activity**

You may already commission a paediatric continence service for your population, which may include referrals and admissions to paediatricians in secondary care. It is estimated that establishing a paediatric continence service for children and young people aged 19 years and under could lead to up to an 80% reduction in the number of emergency admissions to secondary care, by providing assessment and management of continence problems in primary and community settings.

The commissioning and benchmarking tool provides tables that allow you to calculate the potential savings associated with a reduction in the number of emergency admissions, elective admissions and outpatient appointments in secondary care for the specialist assessment and treatment of continence problems.

It is anticipated that there may be an increase in the prescription costs for oral medication for constipation, including polyethylene glycol 3350 (Movicol), in primary care. However, it is also anticipated that these costs will be more than offset by a corresponding reduction in the number of inpatient spells and outpatient attendances for children and young people with constipation, as early treatment will prevent the problem from becoming a chronic condition.

There is also the potential to reduce costs further by reducing the demand for continence products such as nappies or pads. These cost savings may be possible through investment in a paediatric continence service using a primary or community care model.
The potential for cost savings is examined further in the commissioning and benchmarking tool.

**Identify future change in capacity required**

Using the indicative benchmark provided, or your own local benchmark, you can use the commissioning and benchmarking tool to compare the activity that you might need to commission against your current commissioned activity. This will help you to identify the future change in capacity required. Depending on your assessment, your future provision may need to be increased or decreased.

**Model future commissioning intentions and associated costs**

You can use the commissioning and benchmarking tool to calculate the capacity and resources needed to move towards the benchmark level, and to model the required changes over a period of 4 years.

Use the tool to calculate any potential savings that may be associated with a reduction in secondary care activity over a 4-year period, and to model the appropriate investment that may be needed in a paediatric continence service to allow these savings to be realised. You may need to consider the settings in which the paediatric continence service may be provided. The tool is pre-populated with data on the potential recurrent and non-recurrent cost elements that may need to be considered in future service planning, which can be reviewed and amended to better reflect your local circumstances.

Commissioning decisions should consider both the clinical and economic viability of the service, and take into account the views of local people. Commissioning plans should also take into account the costs of monitoring the quality of the services commissioned.
Ensuring corporate and quality assurance

Commissioners should ensure that the services they commission represent value for money and offer the best possible outcomes for patients. Commissioners need to set clear specifications for monitoring and assuring quality and productivity in the service contract.

Commissioners should ensure that they consider both the clinical and cost effectiveness of the service, and any related services, and take into account the views of clinicians and of children and young people and their parents or carers, and those of other stakeholders, when making commissioning decisions.

A paediatric continence service needs to:

- be effective and efficient
- be responsive to the needs of children and young people, and their parents or carers
- provide treatment and care based on best practice, as defined in NICE clinical guidelines CG99 on constipation in children and young people and CG111 on nocturnal enuresis
- deliver the required capacity and outcomes
- be integrated with other elements of care for children and young people with continence problems
- ensure a coordinated approach is taken to promoting the quality of care across all pathways spanning more than one provider
- define agreed criteria for referral, local protocols and the care pathway for children and young people with continence problems
- be patient-centred and provide equitable access, ensuring that children and young people, and their parents or carers, are treated with dignity and respect, are fully informed about care and are able to make decisions about care in partnership with healthcare professionals
- consider and respond to recommendations arising from any audit, serious untoward incidents or patient safety incidents
- demonstrate how it meets requirements under equalities legislation
- demonstrate value for money.

Local quality assurance

Any mechanisms for quality assurance at a local level are likely to refer to the following.
• **Service and performance targets**, including estimated activity levels and case mix, waiting and referral-to-treatment times (ensuring that children and young people, and their parents or carers, do not experience unnecessary delays), complaints procedures.

• **Clinical governance arrangements**, including incident reporting.

• **Clinical quality criteria**: appropriateness of referral, consenting procedures, clinical protocols.

• **Audit arrangements**: frequency of reporting, reporting route and format, and dissemination mechanisms, including: prescribing practices, outpatient referrals to paediatrics or gastroenterology, hospital admissions for urinary tract infections or constipation, numbers of children and young people using continence products, inappropriate referrals to CAMHS, referrals to safeguarding services, and monitoring of patient outcomes (see audit support for NICE clinical guidelines [CG99 on constipation in children and young people](/content) and [CG111 on nocturnal enuresis](/content) for further information).

• **Health, safety and security**: infection prevention, waste management, confidentiality procedures, legislative requirements.

• **Equipment**: testing and calibration.

• **Accreditation requirements**: for some or all elements of the service, the premises and/or staff.

• **Patient and service user experience**: using the national patient survey; taking into account perspectives and perception of service provision to help shape services; engagement to inform commissioning decisions; complaints.

• **Outcomes**: length of time children and young people are clean and dry; improvement during treatment and after discharge; improved quality of life for children and young people and their parents or carers.

• **Staff competencies**: individual and team baseline requirements, monitoring and performance.

• **Information requirements**, including both patient-specific information (NHS number, referring GP, provision of high-quality information to children and young people and their parents or carers) and service-specific information (referral-to-treatment times, workload trends, number of complaints).

• **The process for reviewing the service with stakeholders**, including decisions on changes necessary to improve or to decommission the service.

• **Compliments and complaints**.
• Achieving targets associated with equalities legislation.

Further information

General information on quality and corporate assurance can be obtained from the following sources:

• NHS Alliance online resources. NHS Alliance is the representational organisation of primary care and primary care trusts, and provides them with an opportunity to network and exchange best practice. The alliance supports its members with an open-access helpline, in-house and joint publications and briefings, internal newsletters and a website.

• The DH commissioning framework provides guidance on the commissioning process in the context of the NHS reform agenda.

• NHS Institute for Innovation and Improvement support for commissioners: includes Commissioning for Health Improvement products to accelerate the achievement of world class commissioning; The Productive Leader programme to enable leadership teams to reduce waste and variation in personal work processes, and Better care, better value indicators to help inform planning, to inform views on the scale of potential efficiency savings in different aspects of care, and to generate ideas on how to achieve these savings.

Specific information on quality and corporate assurance for a paediatric continence service can be obtained from the following sources:

• Skills for health works with employers and other stakeholders to ensure that those working in the sector are equipped with the right skills to support the development and delivery of healthcare services. See details of the continence care competence framework.

• BMJ Learning is an online service provided to support continuing professional development requirements and to develop knowledge in key areas. See modules on nocturnal enuresis in children and functional recurrent abdominal pain in children.
Topic-specific Advisory Group: paediatric continence service

A topic-specific advisory group was established to review and advise on the content of the commissioning guide. This group met once, with additional interaction taking place via email.

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