Continence Needs Assessment

Selection: North Lincolnshire Geographies: Top level local authority

Developed in conjunction with the Paediatric Continence Forum

- Using this report
- Introduction and background
- Prevalence of urinary continence problems in children
- Constipation and faecal incontinence
- Children with special needs
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Using this report

Health and social needs are inherently complex; it is unlikely that there will be a single factor which is responsible for the particular situation in your local area. For this reason, it is important that no single item of information is treated in isolation. Instead the various pieces of data and evidence should be used as pieces of a jigsaw which when linked together give you a picture of the needs of your local community.

As with all health data and intelligence, it is important to ‘sense check’ the findings with colleagues and compare it with your own local knowledge. Is the picture given by the data what you would expect? There can sometimes be anomalies in data which have been submitted for central collection or one-off events or changes, for example a new housing development, in a local area which have resulted in atypical results. The data may not be wrong but you should be sure that you understand the reasons why something is not as you might expect. Contact the Child and Maternal Health Intelligence Network local specialist in your area if you need further advice - www.chimat.org.uk/default.aspx?QN=CHIMAT_LOCAL

Where prevalences have been used to calculate estimates of the approximate numbers affected, these estimates have been rounded up to the nearest five.

This report is intended for you to cut and paste text, tables and charts and include them in your own local documents. Please acknowledge the Child and Maternal Health Intelligence Network as the source and state the date on which you accessed the report.

Introduction and background

Introduction

It is intended that this needs assessment is used in conjunction with the commissioning guidance published by the Paediatric Continence Forum available at www.paediatriccontinenceforum.org/wp-content/uploads/2013/09/PCF-Commissioning-Guidance-for-NICE-11-August-2014-Final.pdf

Background

NICE estimate that about 900,000 children and young people (5-19 years) have bladder or bowel dysfunction (or a continence problem)\(^1\). This may consist of bedwetting, daytime urinary incontinence, or constipation and faecal incontinence, or a combination of these. However, these figures may be an underestimate, as recording prevalence accurately is difficult, because of the related stigma attached to these conditions. There is a greater prevalence among children and young people with physical disabilities, such as spina bifida or cerebral palsy - and children and young people with learning difficulties, such as Down’s syndrome or autistic spectrum disorders, may take longer to achieve continence.

Continence problems can have a significant emotional impact and increase the risk of bullying and behavioural problems in children and young people\(^2\). Managing the problem can be stressful for parents and carers and can strain family relationships.

While it is not the case for most parents, there is evidence of a link between wetting and soiling accidents and child punishment, including physical abuse by parents or carers\(^3,4\).
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. Failure to intervene early often results in the condition becoming chronic, requiring referral, treatment and possibly surgery in hospital2.

Services are currently fragmented and often made up of a collection of professionals providing different levels of intervention in both the community and hospital. This currently results in gaps in service provision, inappropriate hospital or specialist referrals and a waste of money in providing incontinence products (pads and nappies) instead of expertise8.

An integrated paediatric continence service is community-based and treats all bladder and bowel issues for children and young people aged 0-19 years (this includes children under five years who have bladder and bowel dysfunction due to a physical difficulty and children who are late to toilet train). It should be integrated across primary, secondary and tertiary services, with strong working links with education and social care. A specialist paediatric continence nurse should lead the multidisciplinary team and effective referral and care pathways should be in place.

In addition, an integrated, community-based paediatric continence service ensures that accessible, high quality assessment and treatment is provided to children and their parents and carers in any setting, including, for example, children looked after and children at boarding schools7. Children and young people with special needs and/or disabilities should have equal access to investigation and treatment programmes.

Commissioning an integrated paediatric continence service will lower costs dramatically, by preventing acute care admissions (NICE estimates up to 80%), reducing inappropriate referrals to paediatricians and reducing the need for incontinence products (including a reduction in children transferring to adult services requiring products). It also improves clinical outcomes and quality of life for children and their families8.

**Compliance with NICE guidance**

The Paediatric Continence Forum issued freedom of information (FOI) requests to all primary care trusts in England in 2011 to find out about local paediatric continence services for bedwetting, daytime urinary incontinence, toilet training and constipation/faecal incontinence and how well they complied with NICE guidance. This was repeated with a similar set of questions in 2014, and results will be described here shortly. In 2011, three quarters of PCTs did not operate a dedicated paediatric continence service. 49% of PCTs that offered paediatric services did not class their services as ‘joined-up’. Overall, 68% of PCTs commissioned services in four areas but provision varied in quality and type. Although all PCTs pointed out that they did not know of any plans to cut back services as a result of commissioning reforms, two thirds of PCTs already limited products to four or five a day per individual. The following information on services in or near North Lincolnshire may be of interest.

North Lincolnshire PCT provided evidence that it ensures the provision of all four main paediatric continence services. It provided no clear evidence that it had a standalone paediatric continence service led by a paediatric continence advisor. From their response it is clear that the service offers a choice of disposable and washable continence products. They offer three disposable products in each 24 hour period.

The Paediatric Continence Forum welcomes any more complete or up-to-date information you may have about paediatric continence services in your area. Please send any relevant information to paediatriccontinenceforum@whitehouseconsulting.co.uk. Please be aware that your comments are not automatically shown on this report but will be considered for inclusion in a future revision. NOTE: This email account is managed by The Whitehouse Consultancy which is undertaking this research and is not part of the Child and Maternal Health Intelligence Network or Public Health England.

**Prevalence of urinary continence problems in children**

**Bedwetting**

The term bedwetting (sometimes called nocturnal enuresis) is used to describe the symptom of involuntary wetting during sleep without any inherent suggestion of frequency or pathophysiology9. It is estimated that about 600,000 children in the UK suffer from nocturnal enuresis (persistent bedwetting). The prevalence decreases with age as follows:
Children with nocturnal enuresis, estimates by age

<table>
<thead>
<tr>
<th>Children with nocturnal enuresis, aged 4-5 (21.3% prevalence) (2011)</th>
<th>North Lincolnshire</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>870</td>
</tr>
<tr>
<td>Children with nocturnal enuresis, aged 7.5 (15.5% prevalence) (2011)</td>
<td>295</td>
</tr>
<tr>
<td>Children with nocturnal enuresis, aged 9.5 (8% prevalence) (2011)</td>
<td>145</td>
</tr>
<tr>
<td>Children with nocturnal enuresis, aged 11-14 (2.5% prevalence) (2011)</td>
<td>195</td>
</tr>
<tr>
<td>Children with nocturnal enuresis, aged 15-19 (1.5% prevalence) (2011)</td>
<td>155</td>
</tr>
</tbody>
</table>


The Avon Longitudinal Study of Parents and Children (ALSPAC) survey identified that at 7.5 years old the prevalence of bedwetting is high but only 2.4% of this large population-based sample wet at a frequency that meets the definition of nocturnal enuresis (wetting at least twice a week) as defined by the Diagnostic and Statistical Manual of Mental Disorders (fourth edition)\textsuperscript{12}.

Swithinbank et al identified that there is a decrease in the prevalence of urinary symptoms with age. Nocturnal enuresis was reported by 4.7% of children at 11-12 years and 1.1% at 15-16 years\textsuperscript{1}.

Daytime urinary incontinence (DUI)

The term "daytime urinary incontinence" (DUI) is the current term accepted by the International Children’s Continence Society to describe wetting during the day in children (to replace the terms daytime wetting or diurnal enuresis). DUI can be described qualitatively by the amount of distress it causes to the child or family, or quantitatively based on the frequency of its occurrence i.e at least twice a week in children over the age of five years in the absence of congenital or acquired defects of the central nervous system\textsuperscript{13}.

As with bedwetting, the prevalence of DUI decreases with age. Unlike bedwetting, the prevalence is generally greater among girls than boys.

The table below shows the estimates, by age, of children in North Lincolnshire with (mostly infrequent) DUI. More frequent daytime 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

<table>
<thead>
<tr>
<th>Children with daytime wetting, aged 4.5 (15.5% prevalence) (2011)</th>
<th>North Lincolnshire</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>320</td>
</tr>
<tr>
<td>Children with daytime wetting, aged 9.5 (4.9% prevalence) (2011)</td>
<td>90</td>
</tr>
<tr>
<td>Children with daytime wetting, aged 11-12 (12.5% prevalence) (2011)</td>
<td>475</td>
</tr>
<tr>
<td>Children with daytime wetting, aged 15-16 (3% prevalence) (2011)</td>
<td>130</td>
</tr>
</tbody>
</table>


Urinary tract infection

Urinary tract infection (UTI) has been identified as a common bacterial infection causing illness in children\textsuperscript{17}. UTIs are associated with both bowel and bladder dysfunction in children such as constipation, overactive bladders and dysfunctional voiding.

In 2011/12 126.3 children and young people per 100,000 population aged 0 to 24 were admitted to hospital in North Lincolnshire with urinary tract infection compared with the national average of 108.3 per 100,000.

The graph below shows the trend of emergency admissions.
Constipation and faecal incontinence

Definitions

In 2006 the Rome Committee revised the standardised working definitions\(^{18}\) to help health professionals be consistent in their terminology when discussing common defecation problems in children. Terms such as soiling and encopresis had previously been used interchangeably, and with some confusion. Both of these terms have now been replaced by the general term "faecal incontinence" to describe the passage of stools in an inappropriate place.

The term "functional constipation" describes all children in whom constipation does not have an organic cause (due to neurological damage caused by trauma or congenital conditions). Because functional constipation and functional faecal retention often overlap, the two disorders have been merged into the "functional constipation" category.

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

Non-retentive faecal incontinence, which is often termed 'encopresis' in the UK, is much less common than constipation-associated faecal incontinence. This is defined as the repeated, inappropriate passage of stool in a place other than the toilet in a child older than 4 years, with no evidence of faecal retention\(^{19}\). 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 recognised learning disability.

The NICE guideline Constipation in Children and Young People\(^{20}\) provides practitioners with further definitions:

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic constipation</td>
<td>Constipation lasting longer than 8 weeks.</td>
</tr>
<tr>
<td>Idiopathic constipation</td>
<td>Constipation that cannot (currently) be explained by any anatomical, physiological, radiological or histological abnormalities.</td>
</tr>
<tr>
<td>Intractable constipation</td>
<td>Constipation that does not respond to sustained, optimum medical management.</td>
</tr>
</tbody>
</table>

Prevalence

There is a wide variation in the reported prevalence figures for faecal incontinence due to the use of varying definitions with little relative data on the sub - groups. One population-based study reports soiling in 4.1% of children aged 5-6 years and 1.6% of children aged 11-12 years\(^{21}\). Data analysed from 8,000 parents and children aged 7½ 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\(^{22}\). This study also confirms earlier research that the problem is more common in boys than in girls.

Estimates suggest prevalence of faecal incontinence in children is as follows:
- 1 in 30 of children aged four to five
- 1 in 50 of children aged five to six
- 1 in 75 of children aged seven to ten
- 1 in 100 of children aged 11 to 12

The following table shows the estimates and prevalence, by age, of children with faecal incontinence in North Lincolnshire:

**Children with faecal incontinence, estimates by age**

<table>
<thead>
<tr>
<th>Boys with faecal incontinence aged 4.5 (6% prevalence) (2011)</th>
<th>North Lincolnshire</th>
</tr>
</thead>
<tbody>
<tr>
<td>Girls with faecal incontinence aged 4.5 (3.9% prevalence) (2011)</td>
<td>40</td>
</tr>
<tr>
<td>Boys with faecal incontinence aged 5.5 (4.8% prevalence) (2011)</td>
<td>50</td>
</tr>
<tr>
<td>Girls with faecal incontinence aged 5.5 (3.1% prevalence) (2011)</td>
<td>35</td>
</tr>
<tr>
<td>Boys with faecal incontinence aged 6.5 (5.9% prevalence) (2011)</td>
<td>55</td>
</tr>
<tr>
<td>Girls with faecal incontinence aged 6.5 (3.5% prevalence) (2011)</td>
<td>35</td>
</tr>
<tr>
<td>Boys with faecal incontinence aged 7.5 (5.1% prevalence) (2011)</td>
<td>50</td>
</tr>
<tr>
<td>Girls with faecal incontinence aged 7.5 (2.9% prevalence) (2011)</td>
<td>30</td>
</tr>
<tr>
<td>Boys with faecal incontinence aged 9.5 (3.6% prevalence) (2011)</td>
<td>35</td>
</tr>
<tr>
<td>Girls with faecal incontinence aged 9.5 (2.1% prevalence) (2011)</td>
<td>20</td>
</tr>
</tbody>
</table>


**Constipation**

Benninga, M. A et al. report that to date, the worldwide prevalence figures for constipation in children vary widely and is estimated to range between 0.3%-28%.

This large range is likely due to the differing criteria used to define constipation and to differing cultural norms regarding acceptable bowel habits. 34% of British children 4-11 years of age are reported to have had constipation. Of these, 5% had complaints for more than six months.

**Hospital admissions for constipation**

In 2011/12 there were 109.9 admissions per 100,000 children and young people aged 0-24 in North Lincolnshire compared to a national average of 110.1. The mean length of stay was 2.0 days compared to a national average of 1.2 days.

The graph below demonstrates the trend in admissions for North Lincolnshire.
Children with special needs

Children with associated learning and physical disabilities

There are about 770,000 disabled children in the UK (children with learning and physical disabilities); 570,000 of these live in England. (Every Disabled Child Matters 2009)

1 in 33 children between 5-16 years have a physical disability

Half of all children with a physical disability may have continence problems.

The limited research available suggests that between 0.45% and 0.6% of children 0-18 years have a moderate to severe learning disability (between 55,000 and 75,000 children in the UK). It is not known how many of these children are likely to have a continence problem, but clinical practice suggests that it is higher than the average.

Guidelines


You may also find the following documents helpful:

Continence service implementation pack Department of Health(2011)

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


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

Paediatric Continence Service Commissioning Guide NICE (2010)
a href="http://www.nice.org.uk/usingguidance/commissioningguides/paediatric

Specifying a Paediatric Continence Service NICE


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

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

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


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

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

NICE quality standard: Constipation in children and young people (QS62), NICE, 2014
www.nice.org.uk/guidance/index.jsp?action=byID&o=14517

Supporting tools

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

Good practice in continence services
www.continence-foundation.org.uk/campaigns/goodpracticecontinence.pdf

School Information Tool Kit
http://www.eric.org.uk/Campaigns/TheRightToGo

Organisations

1. Paediatric Continence Forum (PCF)

The Paediatric Continence Forum is an independent national campaign group, set up in 2003 to improve political awareness 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 (Education and Resources for Improving Childhood Continence) and PromoCon (Promoting Continence through Product Awareness), 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.

Chair: Dr Penny Dobson MBE
The Whitehouse Consultancy, 222, Southbank House, Black Prince Road, London SE1 7SJ
Tel : 020 7089 2607
Email: paediatriccontinenceforum@whitehouseconsulting.co.uk

2. ERIC (Education and Resources for Improving Childhood Continence)

A national charity that provides information and support to children, their families and the professionals who treat
3. PromoCon (Promoting Continence through Product Awareness)

Working under the umbrella of Disabled Living, PromoCon provides impartial advice and information regarding the whole range of continence products, equipment and services.

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

References

   Available at www.nice.org.uk/usingguidance/commissioningguides/paediatriccontinenceservice/home.jsp

   Abstract available at http://pediatrics.aappublications.org/content/117/5/1575.short

   Available at www.nice.org.uk/guidance/cg111/

   Available at www.nice.org.uk/guidance/cg99

   Available at www.nice.org.uk/usingguidance/commissioningguides/paediatriccontinenceservice/home.jsp


   Available at www.nice.org.uk/usingguidance/commissioningguides/paediatriccontinenceservice/home.jsp

   Available at www.nice.org.uk/guidance/cg111

    Available at www.nice.org.uk/guidance/cg111


17. NICE Guidance, Urinary tract infection in children (CG54) Available at http://guidance.nice.org.uk/CG54


**Acknowledgement**

Public Health England is grateful for the help of Dr Penny Dobson and members of the Paediatric Continence Forum for updating this Needs Assessment.