

Children's Continence Commissioning Guide

A handbook for setting up (commissioning) and running of children's community bladder and bowel services



Sponsoring Organisation: The Paediatric Continence Forum

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Description	Guidance to support the commissioning or setting up of integrated,		
	nurse-led, paediatric community bladder and bowel services in all		
	areas of the UK, so that children and young people who have bladder		
	and bowel issues have access to early assessment and equitable		
	cost-effective treatment. This is not a clinical guideline and does not		
	make clinical recommendations.		
Cross reference	Excellence in Continence Care (NHS England 2018)		
	Minimum Standards for Paediatric Continence Care in the UK (UKCS		
	2016)		
	NICE CG 111 Nocturnal enuresis: the management of bedwetting in		
	children and young (2010)		
	NICE QS 70 Nocturnal enuresis in children and young people (2014)		
	NICE CG 99 Constipation in children and young people (2010)		
	NICE QS 62 Constipation in children and young people (2014)		
	NICE CG 148 Urinary incontinence in neurological disease		
	management (2012)		
	NICE Transition from children's to adults' services for young people		
	using health or social care services (2016)		
	NICE Babies, children and young people's experience of healthcare		
	(2021)		
	Standardization documents from the International Children's		
	Continence Society		
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Disclaimer

The expectation of the Paediatric Continence Forum is that this document forms a guide for the development of community-based children's bladder and bowel specialist services. However, the circumstances, population and geography of different areas of the United Kingdom varies significantly and should be accounted for in decisions about how to implement recommendations contained in this Guide.

The information and recommendations made in this document are in line with the current evidence-base, where this exists and consensus of best practice where there is no or limited quality evidence.

The Paediatric Continence Forum has made every effort to ensure that the links and references included are relevant and appropriate. However, they do not accept any liability for the maintenance of links, the completeness, accuracy, availability, suitability or content of any of the links or references. Any reliance or use of them is undertaken at your own risk.

Introduction

This third edition of the Children's Continence Commissioning Guide (the Guide) provides the information and tools for commissioners, service planners, managers and clinicians across the UK to set up and run effective and appropriately resourced integrated, nurse-led, community-based paediatric bladder and bowel services.

The Guide is based upon the most recent published evidence from:

- The National Institute for Health and Care Excellence (NICE) and their Guidance and Quality Standards
- NHS England's publications: Excellence in Continence Care (2018) and Leading Change Adding Value (2016)
- The principles of NHS RightCare i.e. the right care in the right place at the right time
- The standardization documents from the International Children's Continence Society
- Research on the physical and mental impact of bladder and bowel issues and incontinence and what children, young people and their families want from bladder and bowel services
- Information from the Burdett National Transition Network

This Guide also fulfils the commitments for action within the NHS Long Term Plan by:

- Addressing mental health: there are clear associations between childhood continence problems, and children's mental health
- Increasing family understanding of issues and therefore reducing parental intolerance and child punishment which may escalate to abuse
- Improving the quality of care for children with long term conditions
- Recommending an integrated and collaborative structure to service delivery



- Improving children's involvement in and experiences of care: The Guide has taken
 into account the views of children and young people about the kind of services they
 want
- Reducing emergency department (A&E) attendance: children and young people
 account for 25% of the total and are the most likely age group to attend A&E
 unnecessarily. One major cause of A&E visits is constipation (faecal impaction).
 This could be radically reduced through prevention, early detection and availability
 of appropriate treatment in the community
- Responding to the needs of all children and young people, including those with learning and physical disabilities
- Ensuring good transition to adult care

In England Integrated Care Systems bring together health and care organisations to develop shared plans and join up services. Integrated Care Systems include Integrated Care Boards, which have the general function as commissioners of arranging for the provision of services to meet population health needs. Integrated Care Systems also include health and care providers, such as Primary Care Networks, through which GPs, their teams and community services work together. There is an expectation in the NHS Long Term Plan to improve the quality of care for children and young people with long term conditions.

Northern Ireland has a <u>commissioner for children and young people</u> whose role is to safeguard and promote the rights of children and young people.

In Scotland, <u>Getting it Right for Every Child</u>, which is based on the United Nations Convention on the Rights of the Child, is about making sure that children and young people receive the right help at the right time from the right people. Appropriate children's community bladder and bowel services fit within the wellbeing principles of safe, healthy, achieving, nurtured, active, respected, responsible and included.

The Welsh government formally adopted the <u>United Nations Convention on the Rights of the Child</u> as the basis of their policy making relating to children and young people in 2004. Children's community bladder and bowel services fit with children's rights that the best interests of the child are paramount in decisions and actions affecting children (Article 3); the right to health development, so that children reach their full potential (Article 6); the right to participate in decision making (Article 12); the right to privacy (Article 16); the right to special care, support and access to education for those with a disability (Article 23); the right to good quality healthcare (Article 24); and the right to education (Article 28). The paediatric section of the All Wales Continence Forum advise the Welsh Government on issues related to bladder and bowel care of children in Wales.

Executive Summary

1. The Paediatric Continence Forum estimates that bladder and bowel (continence) problems affect more than 1.5 million children and young people in the UK, with a negative impact on their physical and mental health, wellbeing and emotional, social,



educational and psychological development¹. These children need to be identified and treated at an early stage to improve their health, development and wellbeing, as well as to prevent attendance at accident and emergency departments for faecal impaction or urinary tract infections, hospital admissions and unnecessary referrals to secondary care.

- 2. All children from birth to 18 with bladder and/or bowel issues and/or delayed toilet training, should have access to a fully integrated children's community bladder and bowel service (CCBBS)² that provides individualised evidence-based care in line with national guidance and best practice.
- 3. The CCBBS should consist of an appropriately resourced multidisciplinary team led by a children's bladder and bowel nurse specialist. It should have clear and effective care pathways from universal (Level/Tier 1)³ services and to secondary and tertiary care (Level 3 services), as well as to education, social services, child and adolescent mental health services and other services as required.
- 4. A proper CCBBS will result in considerable savings for the NHS. See Section 1.3
- 5. Key Service Outcomes and their measurement are outlined in Section 2
- 6. Clinical guidance within this document follows:
 - NICE Clinical Guideline: <u>CG111 Nocturnal Enuresis: the management of bedwetting in children and young people 2010</u>
 - NICE Quality Standard <u>QS70 Nocturnal Enuresis</u> (<u>Bedwetting</u>) in children and young people 2014
 - NICE Clinical Guideline: <u>CG99 Constipation in Children and Young People 2010</u>
 - NICE Quality Standards: QS62 Constipation in Children and Young People 2014
 - NICE Clinical Guideline: <u>CG148 Urinary Incontinence in Neurological Disease</u> <u>Management 2012</u>
 - International Children's Continence Society recommendations and standardization documents

1. Best Practice Care Pathway for Children's Continence

1.1. Brief description of childhood bladder and bowel issues

Continence is the ability to maintain bladder and bowel control until a socially appropriate time and place to urinate or defecate has been reached. Full control is normally acquired in early childhood as the result of an active learning process. Introducing children to the skills they will need for toilet training and support with the development of these should start in

¹ See Section 1.2.1 for more information

² See Section 1.5.2 for a full description of a CCBBS, which is the specialist (level/tier 2) service.

³ The terms 'Level' and 'Tier' may be used interchangeably, but the term Level will be used in this document. A full description of the Levels is in Section 1.5



the early months of life, but there is evidence that this is often being delayed until children are at least two years old or more [1]. This has resulted in children not attaining control and independence until later than earlier generations, causes problems at school entry, and an associated increased risk of daytime wetting [2] in primary school children and bedwetting

Common bladder and bowel issues in childhood include constipation, soiling (faecal incontinence), daytime wetting, bedwetting (enuresis) and delay or difficulties with toilet training. The majority of these are functional problems: that is they cannot be explained by anatomical, physiological, radiological or histological abnormalities. Instead, it is believed they are caused by a complex inter-relationship of biological, developmental, genetic, psychological and environmental factors [4]. Structural (anatomical) or neuropathic causes are rare but need to be recognised early. The negative impact for the children and their families of any bladder or bowel difficulty should not be underestimated.

Children and young people of all ages can be affected by bladder and/or bowel difficulties. Those with neurodevelopmental disorders, such as intellectual disability, attention deficit hyperactivity disorder and autism spectrum disorder are affected, but often neglected in the mistaken assumption that incontinence is an inevitable part of their wider condition [5].4

Functional bladder and bowel disorders frequently co-exist and are causally linked. An integrated approach to treatment is therefore essential and cost-effective. For example children and young people who experience bedwetting may also have daytime wetting and/or constipation and children and young people with constipation/soiling may also have bedwetting/daytime wetting. [6, 7]

1.2 Why should commissioners and service planners prioritise integrated childrens bladder and bowel services?

1.2.1 The numbers of children and young people affected

There are about 13.4 million children under 18 years of age living in the UK [8]. Koppen et al [9] found that the pooled prevalence of chronic constipation in children is 9.5% globally and 12.4% for North America and Europe. The prevalence in a large British cohort of children aged 4-9 years was 13.2% [10]. Not all children with bladder or bowel issues have constipation and some will have constipation alongside other conditions. Therefore, the Paediatric Continence Forum estimates that about 1.5 million children in the UK have a bladder and/or bowel problem. This is likely to be an under-estimate due to a lack of recognition of the issues and under-reporting because of stigma, embarrassment, or the mistaken belief that the problem will resolve spontaneously as the child grows and develops. However, children with day and night time wetting at ages 4 - 9 years are twenty-three times more likely to have enuresis at 14 years of age and ten times more likely to have daytime wetting continuing into adolescence [11].

Of the estimated 11% of children who have additional needs [12], a proportionally higher number have continence difficulties, due either to an associated disorder of the bowel/bladder, or to their physical or intellectual impairment [13]. Delayed toilet training is common for these children [14] and constipation can have serious long-term implications for

⁴ See Appendix 1 for more details of definitions and terms



those with learning disability, including death in young adulthood [15]. Therefore, children and young people with additional needs should be offered an appropriate bowel and bladder assessment and early support to achieve their potential. It should be the exception, rather than the rule, that children with additional needs are provided with continence containment products.

1.2.2 The impact of childhood bladder and bowel issues

PHYSICAL IMPACT

Failure to identify and treat continence problems at an early stage can give rise to chronic changes in the kidneys, bladder or bowel. Experiencing hard stools in early childhood is a risk factor for later problems with constipation at school age [10]; unrecognised congenital, structural or neuropathic bladder or bowel dysfunction may result in renal impairment and failure or acute bowel crises, with significant consequences for the child's health. The risks of this and of constipation are greater for those with moderate to severe learning disabilities, cerebral palsy and Down syndrome. Without treatment bladder and/or bowel issues may persist into adolescence and adulthood for any affected child [13,16,17,18].

PSYCHOLOGICAL AND MENTAL HEALTH IMPACT

Continence problems occur at a formative time for children and can have an enduring impact on their mental health [18, 19], Children and adolescents with incontinence have increased levels of psychological problems [20] and prospective cohort studies have found evidence that psychological problems in early childhood are risk factors for incontinence at school age [21]. Furthermore, continence problems in primary school-age children are risk factors for psychological problems in adolescence [22].

It is, however, unclear from these studies whether psychological problems are a cause or a consequence of incontinence. Psychological distress might emerge when children become aware that continence problems are abnormal for their age, or in the face of negative reactions from their parents or peers. There is some evidence for improvements in psychological functioning following successful treatment for continence problems [23, 24, 25].

EDUCATIONAL IMPACT

Children and young people with bladder and/or bowel issues are more likely to underachieve at school [26]. Furthermore, the issues affect peer relationships [27] and cause social isolation and feelings of difference [28]. They are also a cause of reduced self-esteem [27, 28], a sense of social stigma [26, 29], distress and are associated with behavioural disorders [4, 24], which may further impact experiences of education.

IMPACT ON BULLYING

Shoham et al [30], Ching et al [31] and Zhao et al [32] and] found that bullying, is associated with increased lower urinary tract symptoms.

IMPACT ON THE FAMILY / SAFEGUARDING

Most families are concerned and positively involved but describe the stress and reduced social opportunities when their child has a bladder or bowel issue. However, lack of understanding and frustration cause some to respond by punishing their children. This can result in a 'vicious cycle' of increased stress, more incontinence, potentially harsher chastisement and the risk of child abuse [33, 34, 35].



Furthermore, the prevalence of adverse childhood events, including abuse of all types, including neglect, is higher in children with functional defaecation disorders than in healthy children [36].

FINANCIAL IMPACT

Effective treatment reduces the cost of extra washing and purchase of additional clothes and bedding. This is substantial and has a disproportionate impact on low-income families.⁵

ENVIRONMENTAL IMPACT

Continuing to use disposable products to manage delayed toilet training, daytime wetting or soiling has a negative environmental impact due to the processes involved in manufacture and distribution alongside the production of non-biodegradable waste. This could be significantly reduced by effective treatment of bladder and bowel issues.

1.3 Cost savings from developing integrated community children's bladder and bowel services

In areas where there is a well-resourced, integrated community children's bladder and bowel service, the cost to the NHS of treating childhood incontinence is considerably reduced, due to:

- Fewer accident and emergency attendances for urinary tract infection and abdominal pain related to constipation / faecal impaction
- Fewer referrals to secondary care for consultant assessment and/or treatment
- Fewer unnecessary investigations
- Reduced inpatient hospital admissions for disimpaction or treatment of urinary tract infection
- Reduced need for disposable continence containment products, as more children who have the ability to toilet train are identified and become trained with nurse-led support

Optimal versus suboptimal patient journeys demonstrate the above savings, as well as the improvements to the quality of care (Bladder & Bowel UK RightCare patient journeys: Toby's journey (enuresis) Michael's journey (constipation), James journey (intractable constipation)).

Costs of children's bladder and bowel conditions are not restricted to the under 18s. There is evidence that 25% of children treated for functional constipation become adults with symptoms of constipation [37]. Those who are not toilet trained by the age of 18 become adults who require continence containment products throughout their life course. This is in addition to the increased prevalence of issues in adulthood for those who had bladder problems in childhood. [16, 17]

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⁵ See section 1.2 and Appendices 2 and 3 for a fuller description of prevalence, risk factors and impact of continence problems on children and families



1.4 Why current practices and services need to improve

Health visiting and school nurses are specialist public health nurses, who are responsible for early intervention. However, when responsibility for commissioning of school nursing and health visiting services in England transferred from NHS England to Public Health England in 2015, many Level 1 continence services were decommissioned⁶. The subsequent lack of early intervention has continued, in many areas.

In Northern Ireland, despite the lack of commissioning of children's bladder and bowel services, each of the five health and social care trusts have established nurse-led specialist children's continence services, although services delivery formats are variable. The Public Health Agency have supported staff education and the development of service standards across the region.

In Scotland the Universal Health Visiting Pathway has refocused the role of health visitors, resulting in reduced support for skill development for toilet training and early recognition and intervention for bladder and bowel issues. School nurses are no longer mandated to provide support for enuresis. This has increased the pressure on children's bladder and bowel services, where they exist, and compounded referrals to secondary care in areas where there are no Level 2 services [38].

In Wales health visitors and school nurses provide Level 1 healthy bladder and bowel advise in some areas. There are also some established nurse-led specialist community children's bladder and bowel services, but where these services exist the delivery formats and resourcing are variable.

Level 2 specialist community children's bladder and bowel service provision is variable across the UK. Where services exist, many are neither comprehensive nor properly integrated. The Paediatric Continence Forum carried out Freedom of Information surveys of Clinical Commissioning Groups and Health Boards in 2014, 2017 and 2021 to assess the number of community children's bladder and bowel services across the UK and which aspects of bladder and/or bowel support they provide for.

Key questions were:

- For which of the paediatric bladder and bowel issues (bedwetting, daytime wetting, toilet training, constipation/soiling, product supply) are services being commissioned
- Whether a single (integrated) service provided for all five issues
- Whether the service is led by a paediatric continence advisor
- Whether there are plans to commission a new service
- Whether there is awareness, or use of the Paediatric Continence Forum's Continence Commissioning Guide (2019).⁷

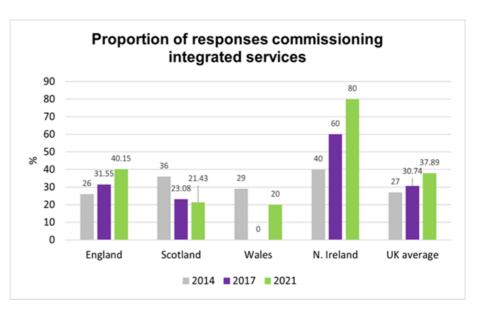
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⁶ See Section 1.5 for descriptions of different Levels of service delivery.

⁷ The full report of the outcome of the Freedom of Information survey 2021 is available at: <u>An Examination of Paediatric Continence Services Across the UK: Results of a Freedom of Information Request June 2022</u>



Graph to show comparison of how many CCGs / Health Boards commission provide a single integrated service for all four common paediatric bladder and bowel issues (constipation and soiling, daytime wetting, night time wetting, difficulties with toilet training) and for product provision in 2014, 2017 and 2021 (PCF 2022)



The results show improvement in England, Northern Ireland and Wales, but only just over a third of areas throughout the UK are able to provide for all issues in one integrated service. Therefore two thirds of the UK are still not working to the model that delivers the most cost-efficient and highest quality care to affected children and families.

1.5 Service descriptions: what 'good' looks like

1.5.1 Level/Tier 1 services8: Universal healthcare

These are universal services that should be provided by health visiting and school nursing teams, who play an important role in the early identification of difficulties with toilet training and bladder and bowel issues. With knowledge of bladder and bowel development and continence milestones, universal services for children and young people are ideally placed to provide general and targeted advice on skill development for toilet training and the promotion of bladder and bowel health. This might include, but not be limited to information on fluid intake, dietary advice, the importance of regular toileting and correct positioning on the toilet.

All children with identified issues, or where these are likely due to additional needs or disabilities, should receive a basic assessment at Level 1. Level 1 services should offer initial lifestyle advice and support and know when it is appropriate to refer on to the CCBBS at Level 2. Health visitors and school nurses may also provide first line treatment if commissioned to do so. If not commissioned to do so, this needs to be reflected in Level 2 service provision.

GPs, who also provide Level 1 services, should understand the role of the CCBBS and know how and when to refer. Mechanisms to enable effective communication and referrals between Levels 1 and 2 and primary care are essential and should be established locally.

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⁸ The terms 'Level' and 'Tier' may be used interchangeably, but the term Level will be used in this document. Level one refers to universal services that include GPs, school nursing and health visiting, level two is provided by the CCBBS and level three by secondary or tertiary services.



Health visitors lead the Healthy Child Programme (HCP) 0 – 5 years in England and have a specific responsibility to support children to be 'ready to learn at two and be ready for school at five' [39]. School nurses lead the HCP for ages 5 – 19 years⁹. Universal access and early identification of additional needs is included in commissioning and service planning. Therefore, health visitors and school nurses should provide support with skill development for toilet training. In Northern Ireland the equivalent is the Healthy Child, Healthy Future (includes Toilet training) and the Family Nurse Partnership Programme.

Refocussing of the health visitor role in Scotland means that support for toilet training is no longer a standard or documented component of mandatory visits. School nursing roles have also been redefined so that physical health conditions are not one of the ten priority areas of their current remit. This has resulted in a gap in service delivery that should be reflected in provision of CCBBS.

Health visitors lead <u>The Healthy Child Wales Programme</u>, and the core contacts provide an opportunity for the health visitor to support the family and assess the child's health and development, and to discuss any concerns or support needed to assist families to help their child reach their full potential, this includes for bladder and bowel health and toilet training.

1.5.2 Level 2: The Children's Community Bladder and Bowel Service (CCBBS)

- Undertakes comprehensive bladder and bowel assessments and treats children and young people from 0 – 19 years with bladder and/or bowel problems and/or delayed toilet training, where universal Level 1 interventions have not resolved the issues
- Consists of an experienced and competent multidisciplinary team led by a children's bladder and bowel nurse specialist.
- Has clear and effective referral and care pathways from Level 1 services to Level 3 (secondary and tertiary care), as well as to other professionals and services e.g. paediatricians, education, allied health professionals, child and adolescent mental health services (CAMHS), social care, the organisation's children's safeguarding team and local voluntary services as the child's health, social or psychological situation warrants
- Has a good understanding of and skills to work with children affected by neurological and developmental diversity: up to one third of children with bladder and bowel issues have developmental or neurological diversity, which may be undiagnosed
- Provides specialist training, education and support to primary and community care staff delivering services at Level 1. This is to ensure that all staff are able to identify bladder and bowel issues early and offer timely intervention or refer appropriately if they are not commissioned to provide assessment and treatment. The CCBBS should also provide training and support to education and social care staff to raise awareness of bladder and bowel issues that may impact at nursery, school or college, in foster care, children's homes, respite placements etc and ensure children and those looking after them are supported appropriately

1.5.3 Level 3: Secondary or tertiary services

There are some situations where children may require referral for a medical assessment to a paediatrician, or to specialist secondary or tertiary care, as per the local pathway. These include children with 'red flag' symptoms indicating a serious underlying disorder, children

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⁹ in Scotland it is the Child Health programme; in Wales it is the Healthy Child Wales programme,



with recurrent febrile urinary tract infections, children who have not responded to optimal interventions and support at Level 2, children where there are neurodevelopmental concerns and some children where there are safeguarding concerns.

1.5.4 The Children's Community Bladder and Bowel Service (Level 2): A 'good' service has:

1.5.4.1 Clinical standards

- Agreed bi-directional care and referral pathways to and from Level 1 and 3 services, with standards and thresholds based on best practice, using available current evidence
- The opportunity for all children and young people referred to have a comprehensive bladder and bowel assessment from an appropriately trained healthcare professional with appropriate individualised treatment. This should include awareness of the impact of bladder and bowel issues on the child's life, mental health and wellbeing
- Commissioners / service planners who are aware that the time required for assessment will vary according to the child's condition and situation and that the amount of follow up required is highly variable; bladder and/or bowel issues may take months or years to resolve and, in some cases, may be lifelong
- Established transition pathways for all young people aged 11 and over in anticipation of moving to the adult bladder and bowel service, at age 16-18 years should this be required (age will vary according to local arrangements). See section 1.5.4.8 also.

1.5.4.2 Waiting times and access

Waiting times for assessment, treatment and review that are reasonable, in line with national guidance and best practice, meet the individual's needs and are not in breach of any nationally or locally agreed targets

- Provides assessment and review in a variety of settings that are age-appropriate and meet the needs of the child or young person [40]. This may include but not be limited to clinics, homes, special schools and telephone reviews
- Has waiting and treatment areas that are appropriate to the age, development and needs of the children and families concerned [40]
- Provides settings that are geographically convenient with adequate parking and are accessible via public transport

1.5.4.3 Appointments and follow-up

- Initial appointments that are face-to-face, with adequate time to complete comprehensive assessments
- The same person to undertake the treatment programme. This person needs to talk to the child or young person directly, using language appropriate to their age, development and cognition, to develop a trusting relationship with them [40]
- Follow-up at appropriate intervals, times and locations to meet individual needs, but
 with sufficient frequency and appointment time to prevent relapse. Follow-up may be
 in clinic, at school, at home, via the telephone or other electronic means, depending
 upon the needs of the individual child and their family. The child or young person
 should always be communicated with directly and involved, unless clearly
 inappropriate



1.5.4.4 Staffing

Staffing should be sufficient to meet the numbers and needs of the children and young people who require the service. It is recommended that a new CCBBS have one whole time clinician post per 100,000 of the total population (all ages) of the area. However, staffing may need to be adjusted according to local need and demand for the service.

Key appointments are:

- The service manager and the lead clinician (a minimum of Band 7). One person may undertake both roles. The lead clinician should be a children's bladder and bowel nurse specialist – a registered children's nurse, with appropriate knowledge and experience in children's bladder and bowel health
- Sufficient administrative staff to support the service and enable timely communication with other professionals
- The clinical team should have a skill mix to include band 6 and 5 children's nurses and band 4 nursery nurses, as well as psychology, occupational therapy and paediatric pelvic health physiotherapy hours

In addition there should be

- Support from educational or behavioural psychologists and/or children's mental health specialists. This is because many children with bladder and/or bowel issues also have psychiatric developmental disabilities. Furthermore, psychiatric comorbidity is especially common in children with secondary enuresis [41]
- A consultant paediatrician who is designated to support the service and review children as required
- Supervision and support from the local safeguarding team as required

1.5.4.5 Resources

- A budget for sufficient equipment and consumables. This should include, but not necessarily be limited to telephones, computers, printers, access to the internet, enuresis alarms, sensors, bladder scanners, uroflow equipment, TENS machines
- Information leaflets, including those directing families to web-based information
- A budget for equipment to promote skill development for toilet training
- A budget for washable and disposable continence containment products for those children unable to attain continence¹⁰

1.5.4.6 It is the responsibility of the service to:

- Recruit skilled, trained and appropriately qualified personnel
- Ensure that the specialist nursing staff have the following qualifications: registered sick children's nurse, or registered nurse child branch, or degree level health visitor, or school nurse
- Provide a competency-based training programme to ensure staff have and maintain the required knowledge and skills to practice safely and effectively, including providing care to children with additional needs.¹¹
- Ensure that staff work empathetically, promote dignity and respect and empower and encourage children and families to self-care

¹⁰ There is national Guidance for the Provision of Continence Containment Products

¹¹ Training is available from <u>The Association for Continence Professionals</u>
<u>Bladder & Bowel UK, British Association of Paediatric Urology and Continence Nurses, ERIC the Children's Bowel and Bladder Charity, The International Children's Continence Society</u>



- Encourage non-medical prescribing
- Enable all clinicians to have access to relevant training, education and supervision
 and attend regular meetings as appropriate, including for peer support to ensure that
 their practice remains in line with evidence and current recommendations. Clinicians
 should be encouraged to engage with multi-professional networks across the health
 economy
- Work to NICE guidance and International Children's Continence Society recommendations and consensus documents and, for conditions where these are not available, to follow high quality, evidence-based practice, within nationally or locally agreed pathways, policies and procedures
- Identify a governance lead with responsibility for operations management and anonymous reporting of all clinical incidents in the appropriate way¹²
- Be compliant with Health and Safety legislation and the Equality Act 2010
- Adhere to local safeguarding policies and procedures

1.5.4.7 Discharge

Discharge should be considered when clinically appropriate. The family should be informed about whom to contact if there is deterioration or if concerns arise after discharge. The service provider should report the patient's clinical progress and discharge management or further treatment plans to the GP within five working days of discharge.

1.5.4.8 Transition to adult services

The Integrated Care Board, Health Board, or Health and Social Care Board should consider best practice with respect to transition for all young people and ensure that any plans for transition to adult bladder and bowel services are in line with these, made in advance and organised in a way that fully meets the young person's individual needs and is positive and seamless (NICE NG 43, 2016)

- The service needs to recognise that some young people will have ongoing bladder and bowel issues beyond their 18th birthday. These young people need a proactive transition to the adult bladder and bowel service. Work towards transition should start for all young people from the age of 11 or 12 years old or as soon as they are accepted into the CCBBS if older than this
- There needs to be a cohesive transition pathway from the children's to the adult service.
- The upper age limits for the CCBBS must at least reflect the lower age limit for the adult service, so that no young person is left without appropriate provision.
- There should be a clearly defined pathway for transition that addresses issues that young people may have with adherence. This is particularly important for those with neuropathic bladder and/or bowel, neurodiversity, physical disabilities or pelvic floor dysfunction
- CCBBS and adult bladder and bowel services should recognise and provide support for issues that young people may have with accessing education and/or employment due to their bladder and/or bowel issues.

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¹² Reporting in England is to NHS Improvement. In Northern Ireland it is to the Northern Ireland Adverse Incidents Centre; in Scotland it is to the Incident Reporting and Investigation Centre; in Wales it is to the National Reporting and Learning System



Information to support services develop their transition pathways are available from Ready Steady Go and Hello and from the Burdett National Transition Nursing Network

1.6 Criteria for referral

All children with bladder and bowel dysfunction from birth – 18 years should be eligible for referral to the CCBBS. Children should not be excluded due to resource restrictions, or their age, additional need, or due to perceived lack of potential to be toilet trained.

Referral would normally be via the patient's GP, health visitor, school nurse, or other local professional for all patients contracted within the Integrated Care Board or Health Board area or living or attending school in the geographical area.

1.6.1 Exclusion criteria

- Those living outside the geographical boundaries of the of the commissioned service
- Those aged over 18 years of age, if there are no identified additional needs
- Those aged over 25 years if there are identified additional needs, but with local transition arrangements in place [42]

1.7 Care pathways

Care pathways should be developed and agreed locally for Level 1 and 2 services to meet the needs of children and young people with any or all bladder and/or bowel issues and include transition to adult services. There should be local agreement on procedures and pathways for seamless referral to other services as required according to individual need. Any contractual relationships should be the responsibility of the service provider.

<u>Care pathways for Level 1 and Level 2 services</u>, together with supporting <u>resources for Level 1 healthcare professionals</u> that includes a Level 1 assessment tool are available from Bladder & Bowel UK.

A <u>Children's continence care pathway</u> and index of resources is available from ERIC that informs parents and professionals about the <u>assessment</u> and intervention for a child with a bowel or bladder problem.

NHS England has produced a <u>national primary care clinical pathway for constipation in</u> England



2. Quality Indicators for Children's Bladder and Bowel Health

2.1 Measuring cost savings

Baseline data on hospital admissions for constipation and urinary tract infections for individual Integrated Care Board areas in England, using Hospital Episodes Statistics (HES Data) enables on-going measurement of some outcome indicators and allows assessment of savings. Costs for provision of continence containment products¹³ should also be measured.

The Department for Health in Northern Ireland Hospital Inpatient system provides data on daycase and inpatient admissions by diagnosis.

Public Health Scotland collects data on clinical diagnoses and inpatient and outpatient hospital activity. However, currently constipation is included with other gastrointestinal conditions and urinary tract infections are included in diseases of the genito-urinary system. This makes measurement of cost savings more complex in Scotland.

The Patient Episode Database for Wales (PEDW) provides information on admissions to hospital in Wales and is loosely aligned with Hospital Episode Statistics Data produced in England.

See Appendix 4 for examples of comparative costs of nurse-led clinics against acute/secondary care.

2.2 Service outcomes and key indicators

The key service outcome for integrated CCBBS is to help children achieve complete bladder and bowel control with resolution of any associated symptoms. If that is assessed as not being clinically possible, the key outcome is that they can manage their condition discreetly and effectively. Key outcomes should cover finance, customers internal business processes, learning and growth as per the NHS England NHS Improvement Balanced Scorecard.

2.2.1 Key outcome indicators

- Rates of A&E attendance and hospitalisation for constipation and urinary tract infection
- Rates of referral to secondary or tertiary services for day and night time wetting, constipation, soiling and delayed toilet training
- Percentage of the children referred to the service who are successfully treated without onward referral
- Reduction in costs to the NHS of washable and disposable products to contain incontinence

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¹³ Refer to <u>Guidance on the provision of continence containment products to children and young people</u>



- Quality of Life assessment from the perspective of the child and/or family¹⁴
- Number of children starting full time education with bladder and / or bowel incontinence

2.2.2 Supporting outcomes

- Children and their families have improved perception and understanding of bladder and bowel issues and have gained knowledge about how to effectively self-manage
- Effective use of care pathways and skill development programmes for toilet training

2.3 Measuring clinical outcomes

2.3.1 Enuresis and daytime wetting

There is international consensus on outcome measures for enuresis and daytime wetting available from the International Children's Continence Society [6]:

Initial success measures

- No response: < 50 % reduction in symptoms
- Partial response: 50 99% reduction in symptoms
- Complete response: 100% reduction in symptoms

Long-term success measures

- Relapse: More than one symptom recurrence per month
- Continued success: No relapse in six months after interruption of treatment
- Complete success: No relapse in two years after interruption of treatment

However, Austin et al [6] recognise that in the clinical setting, the child and their family should decide the criteria for treatment success.

Clinical Indicator

Treatment response

2.3.2 Constipation/soiling/faecal impaction

An improvement in the number of children achieving the passage of regular sized, soft, painfree stools at least three times a week with no soiling or withholding behaviours, including those on medication and after the final withdrawal of medication.

Clinical indicator

Treatment response

2.3.3 Toilet training

- A reduction in the proportion of children referred to the service with difficulties in toilet training who then receive disposable products for continence containment
- The annual cost of washable and disposable products provided to children in the geographical area covered by the CCBBS

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¹⁴ 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 five.



2.3.4 Patient satisfaction

The service should gather opinions from a cross-section of children with bladder and/or bowel difficulties and their families via a self-completion questionnaire. Baseline and end-point data should be collected for comparison. See Appendix five.

2.3.5 Quality of life

The service should make use of validated, reliable and reproducible quality-of-life (QoL) measures developed for children with bladder dysfunction. See Appendix five.

3. Audit

Clinical audit allows services to establish whether the care provided meets standards or could be improved. It allows focus on improvement that will be most beneficial. [43] Audits may be undertaken against:

- The service and clinical outcome indicators outlined in 2.1 and 2.2.
- NICE Quality Standards for Bedwetting (QS 70) and Constipation (QS 62).
- Waiting times for the service
- Waiting times for investigations such as bladder scans or urodynamics
- Waiting time for provision of treatment e.g. enuresis alarm or medication provision
- Child and family satisfaction with the CCBBS one year after first contact and at discharge
- Time taken for written communications to be sent to appropriate professionals and the family
- Referral efficiency between Level 1, 2 and 3 services
- Clinical professional development and study to ensure that staff maintain and update their skills appropriately and in line with professional regulatory requirements

4. Further information

4.1 Children's Continence Commissioning Guide development

This current guideline is a later iteration of the original that was NICE accredited in 2014 under their 'single guideline' category. The 2019 update went through the same regulatory process, including a full literature review, although NICE no longer had the resources to accredit this category of guideline. This review has followed a similar process.

4.2 Barriers to implementation

- Lack of understanding of the impact of bladder and bowel issues on individual children and young people and the effect on their mental health and wellbeing
- Lack of understanding that bladder and bowel issues may affect any child, at any age, including before they might reasonably be expected to attain bladder and bowel control



- Lack of awareness of the cost implications to the NHS and Local Authorities of failing to provide a properly resourced integrated nurse-led community children's bladder and bowel service for all ages from 0 – 18 years
- Lack of awareness that young people with bladder and bowel health issues may continue to require support and interventions into adulthood, so need to transition to adult services.
- Lack of adequate funding for sufficient personnel with the appropriate skills and training, alongside lack of investment in professional development for staff
- Lack of funding for equipment
- Lack of professional training courses for a post registration qualification of a paediatric bladder and bowel nurse specialist
- Adequate time to persuade local agencies of the benefit of integrated working
- Poor signposting of services

4.3 Acknowledgements:

This version of the Children's Continence Commissiong Guide is based on work done by the Paediatric Continence Forum Guideline development group in 2014. These were: Dr Penny Dobson MBE (then chair of the PCF), Dr Carol Joinson (reader in developmental psychology), Mr Nicholas Madden (paediatric surgeon/urologist), Davina Richardson (children's specialist nurse) and Dr Anne Wright (consultant paediatrician). The PCF remains grateful to them and to those who peer reviewed the original and previous versions.

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Appendix one

Summary of definitions and terms

The definitions of continence conditions below are based, where possible, upon the International Children's Continence Society (ICCS) 'Standardization of Terminology of Lower Urinary tract Function in Children and Adolescents' [6].



Bedwetting Also known as enuresis, or nocturnal enuresis. It is defined as a symptom and condition of intermittent incontinence that occurs during periods of sleep. It relates to children over five years of age, where it occurs more than once a month for more than three months. Enuresis is further classified as 'frequent' if it happens four or more times a week or 'infrequent' if it is happening less than four times a week [6]. The term bedwetting is suitable for all children, but the term 'enuresis' is applicable to children from their fifth birthday [6].

Children and young people Any person from birth to the age of 18 years. This document relates to all children and young people and does not exclude those children and young people who have learning or physical difficulties or disabilities or sensory or processing differences, or chronic illnesses. For simplicity all children and young people aged 0-18 years are referred to as children.

Children's Community Bladder and Bowel Service (CCBBS) A service provided in the community for children and young people (aged 0 - 18 years) that provides care for all bladder and/or bowel conditions as well as difficulties with toilet training (see section 1.5.2).

Constipation: one month of at least two of the following in infants up to 4 years of age: two or fewer defecations per week; history of excessive stool retention; history of painful or hard bowel movements; history of large-diameter stools; presence of a large faecal mass in the rectum. In toilet-trained children, the following additional criteria may be used: at least 1 episode/week of faecal incontinence; history of large-diameter stools that may obstruct the toilet.

Continence The ability to control bladder and bowels until a socially acceptable time and place is reached to pass urine and/or faeces. The term continence is often used interchangeably with bladder and bowel difficulties, issues, problems or dysfunction.

Continence difficulties Any problem(s) maintaining bladder or bowel continence, or any bladder or bowel symptom, or issue with toileting that affects day-to-day living.

Daytime wetting Incontinence of urine during waking hours. Diurnal enuresis was previously used to describe daytime wetting, but is now obsolete.

Disability A long term impairment of physical functioning (physical disability) or intellectual functioning (learning disability / intellectual disability).

Encopresis *This term is obsolete*. It was used to describe the passage of normal stools in inappropriate places, and described children who were soiling due to mental health, behavioural or psychological problems, as distinct from those who were soiling due to chronic constipation. It has been replaced by the term non-retentive faecal incontinence.

Enuresis Intermittent urinary incontinence during periods of sleep (see bedwetting above)

Faecal incontinence (Soiling) Passage of stools in an inappropriate place. It may be due to neurological damage or congenital abnormality but is most often functional or idiopathic in origin and is usually associated with chronic constipation.

Faecal impaction A quantity of faeces in the rectum or colon that is so large that the child is unlikely to be able to pass it spontaneously without treatment.



Incontinence The loss of control of bladder or bowels resulting in uncontrolled wetting or soiling in a child who is old enough to have been toilet trained.

Integrated In this document refers to a CCBBS (see above) that provides assessment and treatment for all bladder and bowel symptoms in the same clinic (see section 1.5.2).

Intractable Constipation Chronic constipation that does not respond to optimum medical management.

Learning difficulty Someone who has a problem with a specific area of learning e.g. dyslexia.

Learning disability / intellectual disability Someone who has an IQ of lower than 70 and is intellectually delayed in every aspect of their life. Learning disabilities can be mild, moderate, severe or profound.

Level/Tier 1 services All universal healthcare services. This includes general practitioners, practice nurses, children's community nurses, health visitors and school nurses.

Level/Tier 2 services Specialist services in the community. Within this Guide Level 2 services refer to the integrated community children's bladder and bowel service. Level/Tier 3 services Services provided by secondary or tertiary care. These include paediatricians, paediatric gastroenterologists, paediatric urologists and paediatric surgeons, as well as inpatient facilities and accident and emergency departments.

Lower urinary tract symptoms Includes both storage and voiding symptoms, such as incontinence, increased or decreased voiding frequency (having to go to the toilet more or less often than normal to pass urine), urgency (sudden, unexpected and immediate need to pass urine), hesitancy (difficulty starting to pass urine when there is a need to do so), straining (having to make an effort to start or continue passing urine), weak stream, intermittency (stopping and starting when passing urine), and dysuria (pain when passing urine). Other symptoms include holding manoeuvres to prevent urine being passed, feeling of incomplete bladder emptying, urinary retention (being unable to completely empty the bladder), post-micturition dribbling (incontinence of urine immediately after finishing passing urine on the toilet) and splitting of the urinary stream (urine is passed as a spray or split stream, rather than a single discrete stream) [6].

Nocturnal enuresis Synonymous with enuresis or bedwetting. The word nocturnal is no longer required as enuresis always refers to incontinence during sleep. See bedwetting above.

Non-retentive faecal incontinence The passage of normal stools in inappropriate places, due to mental health, behavioural or psychological problems

Physical disabilities A long-term impairment of a person's physical functioning, affecting any aspect of daily living. Physical disabilities include conditions that limit stamina, mobility, dexterity as well as problems such as respiratory disorders, blindness and epilepsy.

Soiling Incontinence of faeces in a child who is old enough to have been toilet trained, or who has previously toilet trained. It is usually associated with constipation and in the presence of constipation may also be called retentive faecal incontinence.



Urinary tract infection A bacterial infection of the upper or lower urinary tract (kidneys, ureter, bladder and/or urethra) that causes illness in children. It can be associated with lower urinary tract symptoms, urinary and/or faecal incontinence.

Appendix two

Prevalence of continence issues in children and young people

Numerous studies have been conducted to estimate the prevalence of childhood incontinence but there is variation in prevalence estimates, because the studies use different definitions of incontinence. Furthermore, many have small sample sizes, and many are conducted in non-UK (and non-European samples) and, therefore, may not generalise to British children.

The prevalence estimates below are based on studies undertaken in the UK, using data collected in the Avon Longitudinal Study of Parents and Children (https://www.bristol.ac.uk/alspac/), which uses data collected from 14,820 children born in Avon in the early 1990s. The figures from these studies are the most likely to generalise to British children.

Prevalence of bedwetting at least two nights a week in British children [44]				
Age in months	Percentage affected			
54 (4 years 6 months)	8.4%			
65 (5 years 5 months)	6.0%			
78 (6 years 6 months)	4.0%			
91 (7 years 7 months)	2.6%			
115 (9 years 7 months)	1.5%			

NB significantly higher numbers of children experience bedwetting less than two nights a week. 2.5% of 14 year olds experience any frequency of bedwetting (from less than once a week to more than once a night) Heron J et al 2017

Prevalence of daytime urinary incontinence in British children				
Age in years	Percentage affected	Reference		
7	8%	Joinson C et al 2006 [20]		
14	2.9%	Heron J et al 2017 [11]		

At age 14, 9.2% of children reported experiencing nocturia, 4.8% had urinary urgency (having to get to the toilet quickly), 2.7% had frequency (having to void more than seven times a day, and 13.7% had voiding postponement (delaying voiding until the last minute).

Prevalence of constipation:



Koppen et al [9] undertook a systematic review and meta-analysis of constipation in children aged 0-18 years. They found a pooled prevalence 9.5% globally and of 12.4% for studies that included populations in Europe and North America alone. They found that age was not associated with prevalence of functional constipation.

Prevalence of faecal incontinence (soiling)

Joinson et al [20] found that 6.8% of children aged 7 had some soiling. 1.4% were soiling once a week or more frequently.

Those wishing further information may refer to International Continence Society: Incontinence 7th Edition (2023) editors Linda Cardozo, Eric Rovner, Adrian Wagg, Alan Wein, Paul Abrams Chapter 1: Epidemiology of urinary incontinence (UI) and other lower urinary tract symptoms (LUTS), pelvic organ prolapse(PO) and anal incontinence (AI).

Appendix three

Comparative costs

- The average cost of a community paediatric first appointment is £487 and a follow-up appointment is £391 if the child has not been admitted to hospital
- The average cost of a consultant-led outpatient paediatric gastroenterology surgical appointment is £166 and a consultant-led paediatric gastroenterology outpatient appointment (not surgical) is £255
- The average cost of a consultant-led outpatient paediatric urology appointment is £151
- The average cost of a first appointment with an occupational therapist is £168
- The average cost of an A&E first attendance is £140.83
- The cost of a specialist continence nurse face-to-face appointment is £87 and non-face-to-face is £69

Source: National schedule of NHS costs – 2021/22 https://www.england.nhs.uk/costing-in-the-nhs/national-cost-collection/ accessed 3.8.2022

Appendix four

Surveys and proformas for service audit

There are a number of questionnaires which have been used in children with continence conditions and are available on-line and/or in published papers.



Quality of Life

The PedsQL is a more general questionnaire, which is commercially available on-line (http://www.pedsql.org/) and has been used in relation to childhood continence in a study of faecal incontinence [45] and one of school children with constipation [46].

A similar, slightly simpler 12-question assessment, the DCGM -10 has been used for children with continence and other chronic health problems [47].

Detailed questionnaires relating to bowel problems are the FIC QOL. These are available online using the link: https://www.ucdmc.ucdavis.edu/urology/specialties/pediatric_urology where they can be found under 'pediatric urology information handouts', with the titles 'Bowel care survey for caregiver' (the 'Caregiver' referring to the fact that the questionnaire is to be administered by adults) and 'Bowel care survey for patients (adolescents). They include useful questions regarding symptoms in addition to the quality of life elements [48].

The CINCY-FIS is a reliable and valid assessment for paediatric faecal incontinencespecific quality of life and parenting stress [49]. The QQVCFCA is a validated quality of life questionnaire for children and adolescents with faecal incontinence, Hirschsprung's disease or anorectal malformation [50].

The PinQ included children aged 6 - 17 years old with daytime urinary incontinence and enuresis in its development [51].

Symptom Scores

The Dysfunctional Voiding Scoring System [52] and Dysfunctional Voiding and Incontinence Symptom Scoring System [53], 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. The Child Bladder and Bowel Dysfunction Questionnaire (CBBDQ) [54] is a self- administered tool, developed with children aged 5-12 years and is suitable to use prior to seeing a health care professional.

PROM / FROM

Patient and family reported outcomes can be assessed using the Experience of Service Questionnaire (ESQ) produced by the Commission for Health Improvement (now the Healthcare Commission) and available on the Child Outcomes Research Consortium website. ESQ (formerly CHI-ESQ;) is available in three versions: one for parents/carers, one for young people aged 12 – 18 years and one for children aged 9 – 11 years.



Appendix Five

RESOURCES

The Paediatric Continence Forum (PCF)

The Paediatric Continence Forum is an independent national campaign group which was set up in 2003 to improve awareness amongst policy makers of the needs of children and young people with bladder and bowel issues and to improve NHS services in this often neglected area of child health. It has strong links with the charities Bladder & Bowel UK and ERIC, The Children's Bowel and Bladder Charity as well as formal representation from the All Wales Continence Forum, the British Association of Paediatric Urologists, the British Association of Paediatric Surgeons, the Community Practitioners' and Health Visitors' Association, the Royal College of Nursing, the Royal College of Paediatrics and Child Health, the School and Public Health Nurses' Association, the Royal College of Nursing, Northern Ireland and Paediatric Continence Scotland.

The companies Coloplast Ltd., Ferring Pharmaceuticals Ltd. and Kimberly-Clark Europe Ltd actively support the work of the PCF but they have had no input into the contents of this document. The PCF employs the services of The Whitehouse Consultancy, which acts as advisers and provides a secretariat service.

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Patient information

Bladder & Bowel UK

Working under the umbrella of the national charity Disabled Living, Bladder & Bowel UK offers advice and information on all bladder and bowel issues for all age groups, including children and people with additional needs. Staffed by specialist nurses they have a free confidential helpline to support families and professionals. They provide a range of webbased resources, information leaflets and newsletters for professionals and for children and families, as well as training to help children, their parents, carers and professionals to understand bladder and bowel difficulties, promote continence and manage incontinence. They offer education events and, symposia both online and in person for professionals.

Address: Burrow's House, Priestley Road, Worsley, Manchester M28 2LY Helpline: https://www.bbuk.org.uk/enquiries/ or telephone 0161 214 4591

Email: bbuk@disabledliving.co.uk
Website: https://www.bbuk.org.uk

ERIC, The Children's Bowel & Bladder Charity

ERIC is dedicated to helping all children and teenagers manage and overcome distressing continence conditions. Whether it is a toilet-training issue, bedwetting, constipation or

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soiling problem, ERIC provides expert support, information and understanding to children and young people and enables parents, carers and professionals to help them establish good bowel and bladder health. ERIC family support includes a free confidential helpline, parent and family workshops, online resources and information. Support for professionals includes training targeted at the needs of health, education, early years and social care professionals working with children and families and policies, such as for toilet training. Professionals can also access ERIC's free helpline, online tools, resources and information.

Address: 36 Old School House, Britannia Road, Kingswood, Bristol BS15 8DB

Helpline: 0808 801 0343 Email: info@eric.org.uk Website: www.eric.org.uk

International Children's Continence Society (ICCS)

An international professional membership organisation, that focuses on progression of research and healthcare. **Website:** http://i-c-c-s.org/

Stopbedwetting.org

<u>www.stopbedwetting.org</u> is a national website sponsored by Ferring Pharmaceuticals that provides information and resources to families affected by enuresis.

Professional information and education

Association for Continence Professionals

Tel: +44 (0) 1506 811077 Email: admin@acpcontinence.co.uk website: https://acpcontinence.co.uk/

BAPU (British Association of Paediatric Urologists)

Website: http://www.bapu.org.uk

BAPU-CN (British Association of Paediatric Urology and Continence Nurses)

Operating under the umbrella of BAPU. www.bapu.org.uk/bapu-cn Contact via email: Claire.lindsay@nhs.net

Bladder & Bowel UK

Email: bbuk@disabledliving.co.uk webform: https://www.bbuk.org.uk/enquiries/

Website: https://www.bbuk.org.uk

ERIC, The Children's Bowel & Bladder Charity

Email: info@eric.org.uk Website: www.eric.org.uk

International Children's Continence Society

Website http://i-c-c-s.org Paediatric continence care e-learning course is available from http://i-c-c-s.org/e-learning/

NHS Health Education England Mind-Ed e-learning for health. Modules on paediatric continence wetting and soiling problems – Available from:

https://www.minded.org.uk/Catalogue/Index?HierarchyId=0_36391_36845_36857&program_meld=36391_



Paediatric Continence Scotland Paediatric Bladder and Bowel Health in Children elearning course is available from https://www.paediatriccontinence.scot.nhs.uk/

Royal College of general Practitioners CPD library: Bladder and Bowel Problems in Children is available from

https://elearning.rcgp.org.uk/course/info.php?id=471#:~:text=May%202021,daytime%20wet ting%2C%20constipation%20and%20soiling.

United Kingdom Continence Society

Website http://www.ukcs.uk.net

Additional information, guidelines and practical guidance for commissioners and service planners

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

NICE Quality Standard: <u>QS70 Nocturnal Enuresis</u> (bedwetting) in Children and Young People (September 2014, reviewed 2017)

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

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

NICE Clinical Guidance <u>CG43 Transition to adult's services for young people using health</u> and social care services (2016)

NICE Clinical Guidance <u>CG148 Urinary incontinence in neurological disease: assessment and management</u> (August 2012)

NICE Assessing the resource impact of implementing NICE guidance

NHS England: Excellence in Continence Care: practical guidance for commissioners and leaders in health and social care (2018)

NHS England: NHS Long Term Plan

NHS England: National primary care clinical pathway for constipation in children (2023)

Department of Health <u>Improving Children and Young People's Health Outcomes: A System Wide Response</u> (2013)

United Kingdom Continence Society (UKCS) <u>Minimum Standards for Paediatric Continence</u> <u>Care in the UK</u> (2016)

Bladder & Bowel UK <u>Guidance for the Provision of Continence Containment Products to Children and Young People</u> (2016 reviewed 2019, Updated 2021)

Bladder & Bowel UK Best practice guidelines for professionals, supporting skill development for toilet training in all children, including those with learning disabilities and developmental differences (2023)



Appendix Six

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