

Guidance for the provision of continence containment products to children and young people

A consensus document

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Disclaimer

The expectation is that healthcare staff and services will use clinical judgement, medical, nursing, and clinical knowledge in applying the general principles and recommendations contained in this document. Recommendations may not be appropriate in all circumstances and the decision to adopt specific recommendations should be made by the practitioner, based on individualised assessment of the child or young person (CYP), considering their unique circumstances, as well as the available resources. Therapeutic options should be discussed with the family, child, and clinicians on a case-by-case basis, as appropriate.

It is essential that the health care professionals (HCP) undertaking the assessment of the ability of the CYP to learn the skills required for toilet training and for provision of appropriate containment products to children and young people who are unable to become continent, have sufficient knowledge and expertise to do so.

Without sufficient knowledge and expertise in children's bladder and bowel health and continence, as well as the factors that influence this, there is the risk that child/young person's ability and potential to toilet train will be underestimated, so reducing the likelihood of them attaining the level of independence of which they are capable, in a skill normally acquired in early childhood.

The information and recommendations in this document are based on evidence, where currently available and on current agreed best practice. Efforts have been made to ensure that all links and references in this document are relevant and appropriate. However, they do not accept any liability for maintenance of links, or to the completeness, accuracy, reliability, suitability, availability or content of the links or references. Any reliance or use of them is undertaken at your own risk.

Glossary of Terms

The generic term incontinence is interchangeable with the terms bladder and bowel difficulties, bladder and bowel issues, bladder and bowel dysfunction, or wetting and soiling problems. For this document, the term incontinence or bladder and bowel dysfunction will be used.

Similarly, the terms continence containment products, products, nappies and pads are all used to denote the same thing. This document will refer to containment products. Containment products may be washable or disposable.

Disposable pant-style products (commonly referred to as 'pull ups' or 'pull up pants') will be referred to as disposable pants.

Disposable containment products are available in one piece, (nappy-style pads) or two pieces (a disposable pad with a washable close-fitting underwear or a fixation pant). The latter is referred to in this document as a 'two-piece system'.

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For the purposes of this document, child or young person (CYP) refers to anyone up to their 19th birthday.

The term carers is used in this document and normally refers to the person or persons who provide most of the child or young person's (CYP's) day-to-day care. However, it may also refer to anyone who has care of the CYP for all or part of a day. This includes school, nursery and respite centre staff, as well as carers employed to assist with the CYP's care in the home. It may also include nursing staff if the child or young person is admitted to hospital.

Executive Summary

Background

There is no statutory requirement for the NHS to prescribe or provide containment products. All children and young people (CYP) should receive support to achieve their potential for the attainment of continence, regardless of their age, culture, ability, medical condition or diagnosis. Containment products will only be supplied following a full individualised assessment by a healthcare professional with the appropriate knowledge and expertise, and only when toilet training is not achievable within a minimum six-month period of a supported, individualised toilet skill development programme, or where there is an underlying anatomical or neurological issue that means bladder and/or bowel control is not achievable. Traditionally each NHS organisation developed their own policy and guidelines. The aim of this guidance is to provide consistency and transparency of approach across the UK and to meet the needs of CYP who have been assessed as unable to attain continence.

All CYP should be supported to attain their potential for continence, including those children who have additional needs or disabilities. Assumptions about a child's potential should not be made based solely on diagnosis of a condition that causes developmental delay, learning or physical disability, or a processing difference. Continence should be promoted at all times and, as stated by NHS England (2015), *'…the provision of continence products to this group of children should be the exception rather than the rule'.* Any bladder and/or bowel issues should be assessed and treated. This prevents discrimination, ensures that potential underlying conditions are not missed, as well as ensuring cost-effective care with appropriate use of resources.

This document aims to facilitate a consistent, equitable approach to continence care for all CYP aged 0 - 19. It also aims to facilitate a consistent and equitable approach to the provision of containment products from the age of 5 years old, to CYP who are not able to make progress towards continence within a minimum six months of engagement with appropriate support, interventions, and/or toilet skill development programmes, by bringing together a consensus of agreement, combining the available evidence from the literature and clinical expertise.

Toilet skill development should start early in life with prospective parents educated about what to expect in terms of infant bladder and bowel health and with midwives, GPs, health visitors and early years professionals providing information about early skill development. This should be in line with the <u>Best practice guidelines for professionals, supporting skill development for toilet training in all children, including those with learning disabilities and developmental differences.</u> Assumptions should not be made regarding the ability, or lack of ability of CYP with additional needs to be toilet trained. Furthermore, it is not appropriate to wait for readiness signs to commence support for toilet skill development programmes, as readiness signs are not evidence based.

Key Recommendations:

- Children's bladder and bowel services should not have an arbitrarily assigned minimum age limit for CYP with disabilities or additional needs to access specialist assessment and treatment or support.
- All CYP who are struggling to develop the skills required for toilet training or who have a bladder or bowel issue, must have a comprehensive assessment of their bladder and bowel, with interventions appropriate to the individual undertaken
- All CYP must be supported with a toilet training programme for at a minimum of six months, prior to containment products being provided to them, unless this is inappropriate e.g. for children with a neuropathic bladder and bowel.
- Products will not be supplied before a child has reached their fifth birthday. Products will
 only be supplied from age five so long as the CYP has undergone a comprehensive bladder
 and bowel assessment and there is no evidence of progress towards continence despite
 appropriate engagement with a targeted individualised toilet skill development programme
 for at least six months. This programme must have been undertaken in all settings where
 the child spends their time.
- Children where it is known or anticipated there may be difficulties with toilet training, e.g. those who have identified physical, learning or processing differences, should have the opportunity for early assessment and support from the first year of life to facilitate the development of the skills necessary for toileting.
- Any assessment should be undertaken by a healthcare professional with the necessary knowledge and expertise.
- The practice of automatically providing products to CYP with an acknowledged disability once they have reached a particular age e.g. their fifth birthday, is not appropriate and could be considered discriminatory.
- The number of products issued per 24 hours is calculated by the HCP following an individualised clinical assessment of need. Typically, provision would not exceed four products per day. If the product provision is based on correct assessment and the product is used according to manufacturer's instructions a maximum of four per day should meet containment needs. This is because the products are highly absorbent and do not need changing until they reach capacity or are soiled.

- The use of two-piece system (pad and pants) should be considered wherever possible instead of an all-in-one (nappy)
- Consideration should always be made regarding the provision of washable products rather than disposable, as clinical experience and feedback from families demonstrates that they are effective in supporting toilet training.
- Containment products will not be supplied for treatable medical conditions, such as bedwetting, constipation, or soiling. CYP with these conditions should be offered assessment and treatment.
- Clear plans and pathways need to be in place to ensure the smooth transition from paediatric to adult continence services for those young people requiring ongoing support and product provision.

Section 1: Background

1.1 Need for a National Guidance Document

All children and young people (CYP) should receive support to achieve their maximum continence potential, regardless of their age, culture, or ability. Some CYP may require targeted bladder and bowel assessments and interventions to support this and others, due to medical need or the nature of their disability, may never be able to attain independence with toileting and may require help throughout their life. However, with the right support and interventions, most CYP will be able to attain continence. For these children providing disposable containment products may delay toilet training (Tarbox et al 2004, Greer 2016 cited in Cagliani 2021) and is therefore not appropriate. A small study by Turpin et al (2024) suggested that nappy removal alone may increase continence for some. Individual assessment aimed at ensuring potential is reached is crucial. The aim of this document is to bring together a consensus of agreement, combining research-based evidence from literature (where available) and clinical experience.

Currently there is no statutory requirement to provide containment products, resulting in each NHS trust, ICS, health board or health and social care board developing their own policy and guidelines. Furthermore, not all areas provide a children and young people's bladder and bowel (continence) service. This has led to inequity in provision and may result in delays in CYP attaining their potential for continence, as well as increasing the likelihood of underlying conditions, such as neuropathic bladder and/or bowel, congenital anomalies, or chronic constipation being missed (Rogers and Patricolo 2014). Provision of containment products and promotion of their use, without comprehensive assessment of ability to develop the skills required for toilet training, may suggest to a family or inappropriately reinforce that their CYP is not ready or able to learn the skills required to be toilet trained. Prolonged use of containment products is also potentially detrimental to the CYP (Kroeger and Sorensen-Burnworth 2009).

For CYP with additional needs it is too frequently assumed that delayed acquisition of bladder and bowel control is inevitable. Work on skill development for toilet training is often not tried in the

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mistaken belief that the CYP needs to be showing signs of readiness to toilet train and that delaying until these are present will make toilet training quicker and easier (Richardson 2016). However, while Kaerts et al (2012) found no research base for the so called 'readiness signs' a study by Wyndaele et al (2020) found that children who had started or completed toilet training were more likely to exhibit readiness signs than children who had not started toilet training and that signs specific to toileting were likely to appear during toilet training. It is reasonable to consider that the longer that toilet training is postponed, the longer it is reinforced to the CYP that the nappy is the place where they should pass urine and defecate.

The majority of CYP who struggle with the acquisition of bladder and bowel control, including those with additional needs or disabilities, have the ability to be toilet trained and as stated by NHS England (2018) '*It must be the exception rather than the rule that children and young people are provided with containment products.*'

1.2 Clinical impact of incontinence in children and young people

Bladder and bowel problems are believed to be caused by biological, developmental, genetic, environmental, or emotional factors. Structural or anatomical causes are rare. Issues occur at a formative time for CYP and influence their health, their wellbeing, and their emotional development. There is evidence that they are associated with emotional, behavioural and mental health problems (Joinson et al 2018, von Gontard et al 2011. Gordon et al 2023), including a strong association with bullying, both as recipients and perpetrators (Ching et al 2015, Zhao et al 2015). Incontinence in children and young people is associated with child abuse (Dayan et al 2022, Sa et al 2016).

Bladder and bowel issues can reduce self-esteem and cause feelings of shame and difference. They have a negative impact on learning and academic performance and increase the likelihood of exclusion from normal social interaction (Whale et al 2017). The absence of pro-active toilet skill development programmes results in many CYP not reaching their full potential and being inappropriately labelled as incontinent. In addition, there is evidence that having a CYP who is incontinent is more stressful for parents and carers (Kroeger and Sorensen, 2010), although a study by Mattheus et al (2021) found that, in children aged 3 – 6 years old, parental stress was likely to be related to the psychological symptoms and externalising problems that were manifest more frequently in children who were incontinent. Furthermore, having a child who is incontinent may take more time for changing than supporting toileting does and has a financial impact in terms of provision of containment products and laundry.

1.3 Overview of epidemiology of incontinence in children and young people

There are about 13.4 million children under 18 years of age living in the UK (Office for National Statistics 2022). About 11% of these are disabled (House of Commons Library 2023). There is evidence that CYP with physical disabilities and/or learning difficulties have a higher incidence of continence problems (Eke et al 2024, von Gontard et al 2016). This may be due to an associated disorder of the bladder and or bowel, to limited mobility, to processing difference or to intellectual impairment (Duel BP et al 2003; van Laecke et al 2001; Roijen LE et al 2001; Ersoz M et al 2009).

It may also be due to economic, social or environmental factors as well as issues intrinsic to parenting or the child's behaviour (Eke et al 2024). It may also be due to reduced expectations of a child with disabilities.

1.4 Aim of a national guidance document for provision of continence containment products for children and young people

The purpose of this guidance is to:

- Facilitate a consistent approach to the provision of containment products to CYP by providing up-to-date evidence based clinical guidance.
- Facilitate an appropriate pathway to ensure the continence needs of all CYP with bladder and bowel dysfunction are met.
- Ensure that every CYP who struggles to acquire the skills required for toilet training, or has a bladder or bowel issue, irrespective of age or additional need is able to access a comprehensive bladder and bowel assessment by a competent HCP followed by appropriate treatment or support. It is important that the assessing health care professionals have sufficient knowledge and expertise in CYP's bladder and bowel health and continence acquisition as well as the factors that influence this. Otherwise, there are the risks that any underlying problems may be missed, and that the CYP's ability and potential will be underestimated, so reducing the likelihood of them attaining the level of independence of which they are capable.
- Ensure that bladder and bowel services do not have an arbitrarily assigned minimum age limit for CYP with disabilities or additional needs to access specialist assessment and treatment or support.

To achieve this, all professionals working with CYP should:

Identify all CYP with incontinence by using trigger questions opportunistically during contacts with families. Questions should be phrased using terminology and language that all parents/carers can understand, such as: 'Does your child always use the potty or toilet when they have a wee or poo?', 'Does your child have any bladder or bowel problems?', 'Do your child's pants ever get damp, or soiled?'. Any positive response should trigger an initial bladder and bowel assessment, or a referral to the appropriate HCP for this, with the required action taken as outlined in appendix 2.

All healthcare professionals should:

- Ensure that families and carers know what is typical for bladder and bowel from infancy and throughout childhood and adolescence
- Help families and carers to understand bladder and bowel symptoms and incontinence and the treatment options that are available

 Offer appropriate individualized treatment and then offer onward referral to specialist services, in line with locally agreed pathways and national best practice guidance, if progress towards acquiring the skills for toilet training or improvement in bladder and bowel health is delayed or there are any concerns.

Specialist children's bladder and bowel services should:

- Offer and complete a comprehensive paediatric bladder and bowel assessment, if CYP are not toilet trained (see appendices), or if there are bladder and bowel problems and an assessment has not already been done, or it is more than twelve months since the last assessment
- Promote the skills required for toilet training as outlined in the document <u>Supporting Skill</u> <u>Development for Toilet Training: Best Practice Guidelines for Professionals</u>
- Consider issuing containment products:
 - o once the CYP has undergone a comprehensive bladder and bowel assessment **and**
 - the family and carers have undertaken a toilet skill development programme, with support from a HCP with the appropriate knowledge and experience for a minimum of six months (see appendices 1 and 2 and <u>Supporting Skill Development for Toilet</u> <u>Training: Best Practice Guidelines for Professionals</u>), unless a toilet skill development programme is inappropriate because there are clear underlying anatomical or neurological reasons for lack of bladder/bowel control **and**
 - $\circ~$ the CYP is over five years of age

1.5 Scope of this national guidance, target population and target audience

This policy relates to all children and young people (CYP) and all professionals involved in their care. Reference should be made to the '<u>Guidance for the provision of containment products for</u> adult incontinence A consensus document 2023 (ACP 2023) for those over the age of 19 years.

1.6 Methodology and literature review

A literature search was carried out using PubMed and NICE Health Care databases using the following terms: product provision, toilet training, continence and children, children with disabilities. Existing policies regarding product policy provision were also identified and reviewed.

The guidance document was widely reviewed by clinicians, including those from Scotland, Northern Ireland, and Wales. It was also offered to a small number of parents for review. It was amended several times until a consensus was agreed. The 2021 review followed the same process, as did the 2024 review.

1.7 Original Guideline Development Group (2016 version)

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1.8 Author and reviewers of 2024 update

The following agreed to be listed as reviewers of the 2024 document:

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Michelle Newton, children's specialist bladder and bowel nurse, on behalf of the Bladder and Bowel Service, Gateshead NHS Foundation Trust

Shirley Richards, specialist bladder and bowel nurse for children and young people, on behalf of the Bladder and Bowel Specialist Service, Cornwall Foundation Trust

June Rogers MBE, independent practitioner (Retired Children's Specialist Bladder & Bowel Nurse) Down Syndrome UK

Kate Triscott, School Nursing, NHS Lothian

1.9 Guidance Exclusion

This guidance covers all children and young people (CYP). It does not cover those who have passed their 19th birthday or the assessment and management of specific bladder or bowel problems that occur after daytime continence has been achieved and for which treatment is

available, such as bedwetting or constipation. Competency and training around these activities will need to be managed locally by relevant services.

1.10 Audit criteria

To ensure that this guideline positively impacts on care of CYP, it is important that implementation is audited. Audit is recommended to support continuous quality improvement in relation to the implementation of the National Policy.

Suggested audit topics:

- Number of CYP with disabilities or additional needs accessing the bladder and bowel (continence) service each year, or percentage of CYP with disabilities or additional needs of total number referred
- Age of CYP with disabilities who are referred to the bladder and bowel service for assessment for their ability to toilet train or for provision of containment products
- Number of CYP with disabilities referred for containment products who are subsequently diagnosed with, or referred for further assessment of bladder or bowel conditions, that were previously not recognised in that individual
- Number of CYP with disabilities or medical conditions being provided with containment products or percentage of the total caseload who are receiving products
- Number of CYP with disabilities, or percentage of those who are referred to the bladder and bowel service who have disabilities and have not been provided with products, but have developed the skills for toilet training and achieved continence
- Cost of products provided to CYP in the ICS/Health Board/Health and Social Care Board area
- Parent/carer satisfaction with the service and where appropriate CYP satisfaction with the service
- Benchmarking against another local service

SECTION 2. National Guidance recommendations

2.1 Product provision

The provision of containment products to children and young people (CYP) would not be considered before the child's fifth birthday.

Referral to the health visitor, school nurse, children's bladder and bowel service or other HCP with the appropriate knowledge and expertise in children's bladder and bowel health, according to locally agreed pathways and health commissioning, should be made as soon as any bowel/bladder problems are identified, or they are anticipated (for example children with diagnosed or suspected conditions, such as cerebral palsy, Down syndrome, or developmental disabilities, including autism). Where it is anticipated that CYP may have problems with

continence or developing the skills required for toilet training they should undergo assessment and be supported with a toilet skill development programme, appropriate to their individual needs. This should begin as soon as possible, ideally in the first year of life, and should be reviewed as appropriate and adapted according to the CYP's learning and progress (see appendices). Those who have bladder or bowel problems would, therefore, be identified early and be offered investigations and treatment according to need and best practice.

Delaying toilet training until the child has reached an arbitrarily decided age, such as 4 or 5 years old, or until they appear to be showing readiness signs (e.g. awareness of passing urine or stools, able to sit on the toilet, understand language for toileting, wanting to imitate others), is not appropriate and may even be detrimental. There is evidence to suggest that leaving a child in disposable products will delay acquisition of bladder and/or bowel control and lead to constipation, nappy dependence, urinary dysfunction and urge incontinence (Smith and Thompson 2006; Taubman, Blum and Nemeth 2003; Bakker and Wyndaele 2000; Barone, Jasutkar and Schneider 2009, Joinson 2009), although this is contested by Brienbjerg et al (2021) who state that '...a robust correlation between diaper use and continence containment cannot be established...'. However, there is also evidence that early toilet training promotes bladder maturity (Joinson et al 2009, Li et al 2021) .

CYP who have achieved day-time continence should not be considered for provision of night-time products only, even if they have a disability or additional needs. Provision of night-time products should be discontinued when daytime continence has been attained. To offer products for night-time wetting to CYP who have a disability, or additional needs could be considered discriminatory, as CYP who do not have additional needs are not provided with containment products for bedwetting: they are offered assessment and interventions for enuresis. Therefore, all CYP who have reached their fifth birthday and are dry during the day but wet at night should be offered assessment and treatment, unless there are clear reasons for night-time wetting other than nocturnal enuresis. CYP who have medical reasons for night-time wetting, such as overnight feeds or epileptic seizures with associated incontinence, should be considered for products to contain this, on an individually assessed basis.

2.2 Assessment of bladder and bowel health and ability to toilet train

All CYP who are struggling to acquire the skills for toilet training and to attain continence must have a documented assessment. Their families must be offered support to help their children learn the skills required for toilet training, with appropriate adjustments to the programme, according to progress. They must proactively undertake this individualised and healthcare professional supported skill development programme for a minimum of six months, prior to having a further individualised assessment for eligibility for provision of containment products¹. The exception would be where there is a clear anatomical, neurological, or congenital problem with a CYP's bladder or bowel that makes them unable to become continent.

¹ Documentation to support assessment for toilet training and assessment for product provision is provided in appendices two and three

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Containment products should not be provided without assessment and trial of skill development for toilet training simply because a CYP has not presented until after their fifth birthday. It could be considered as active discrimination in relation to a CYP's disability if they are not offered the same continence promotion service as any other CYP who presents with a wetting or soiling problem.

When continence is not achievable, due to the extent of the CYP's disability or medical needs, then bladder and bowel health must be promoted. If, they have reached their fifth birthday and followed a minimum six month individualised and supported skill development programme for toilet training, without any success, they should be provided with suitable containment products as appropriate, to maintain their dignity, comfort and safety (appendix 5). The exception to this would be, as stated above, CYP where such a skill development programme is inappropriate due to an anatomical, neurological, or congenital issue that means they are assessed as unable to become continent.

All CYP provided with containment products must be kept under regular review to ensure bladder and bowel health is promoted and there is regular reassessment about whether a skill development programme has become an appropriate option.

As part of the assessment process each CYP must have their fluid intake documented, alongside their pattern of passing urine and opening their bowels, every waking hour for at least three full days (or as long as the parent or carers can manage) when they are with their family for all or most of the day – school should not be expected to undertake this. The containment product must be checked hourly during waking hours to confirm whether the CYP has passed any urine or remained dry, as outlined in appendix 1a. A toileting chart, such as that in appendix 1b, should be used to facilitate this. Bowel motions should also be monitored and recorded for two weeks.

Once the toileting chart is completed it should be reviewed by the HCP and any identified problems, such as issues around fluid intake (appendix 6) or possible underlying constipation, addressed. If there are any other concerns the CYP should undergo further assessment, as necessary, or be referred on as appropriate.

If the CYP has been identified as having the potential to learn the skills required to be toilet trained this must be discussed with their family and a full toilet skills assessment must be completed, such as one indicated by the chart in appendix 2b. The CYP must then commence on an appropriate, individualised programme of skill development. The assessment in appendix 2b indicates how to support the CYP, family and carers in developing the skills required to toilet train as well as the actions that may be appropriate to address any skill deficits so that the CYP attains their potential for continence and maximum bladder and bowel health².

If the assessment indicates that the CYP has no potential for toilet training at this time due to an underlying anatomical, neurological, or congenital problem, such as neuropathic bladder or bowel and they have passed their fifth birthday and provision of containment products is appropriate,

² Additional information to support toilet training is provided in <u>Best practice guidelines for professionals, supporting skill</u> development for toilet training in all children, including those with learning disabilities and developmental differences: A consensus document

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then an assessment tool for issuing of containment products (such as that in appendix 3b) must be completed.

CYP with physical difficulties, sensory differences, or balance problems should have an occupational therapy assessment to ensure they are provided with the appropriate equipment to facilitate toileting.

Further information regarding toilet training can be found in the children and professional's information libraries on the Bladder & Bowel UK web site <u>http://www.bbuk.org.uk³</u>

2.3 Containment product provision

CYP who have an underlying medical reason for not being able to attain continence may be assessed for an appropriate containment product from their fifth birthday. CYP who have passed their fifth birthday and have recently engaged with toilet skills development programme for a minimum of six months, with the support of an appropriately knowledgeable and experienced healthcare professional and have subsequently been assessed as unable to become continent, may also be assessed for product provision.

Containment products may not be provided to CYP whose families do not engage in the assessment process or a subsequent toilet skill development programme. However, HCPs should endeavour to engage and work with families as well as the multidisciplinary team to regularly reassess and update the skill development programme in line with the individualised needs of the CYP and their family. Those providing services should ensure that there are no undue delays in assessment and support for a toilet skill development programme and assessment and follow up are adjusted in line with the CYP's needs.

For CYP who meet the criteria for containment product provision, consideration must be given to the type of containment product that will be most suitable for them, either washable or disposable. It is not anticipated that ICS, NHS Trusts, Health Boards, or Health and Social Care Boards would supply both washable and disposable containment products to the same CYP at the same time, as the former do support toilet training, where the latter do not. Consideration should be given to the use of pads with close fitting underwear or fixation pants wherever possible and sheaths should be considered for older boys, as these may offer more discretion and comfort. (See appendix 8 for more information.)

There are a wide variety of washable and disposable containment products available, which vary according to design and fit, as well as absorbency. The most appropriate product for the individual CYP's individual clinically assessed needs should be provided. The tools in appendices 2b and 3b may be helpful for the assessment process. The maximum number of disposable containment products that would be sufficient for most CYP is four per 24 hours and the maximum number of washable products that would typically be provided at any one time is eight.

³ Further information on toilet training can be found in the <u>Bladder & Bowel UK Information Library</u> This includes a <u>troubleshooting guide</u> and information on the <u>impact of sensory issues on toileting</u>

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It is important to ensure that CYP and all their carers know how to use the containment products correctly. This includes instructions for washable containment products, such as temperature of the water to be used for laundering and whether fabric conditioners should be avoided.

Instructions for use of disposable containment products will include showing families and carers how to cup and fold the product, how to ensure it is applied and fastened correctly and to avoid talc and creams (unless the latter are required to maintain skin integrity), as these affect absorbency and leakage. They should also be shown how to use wetness indicators (when present) to ascertain the appropriate time to change the CYP⁴. Educational establishments, respite facilities and other carers will also need to be provided with appropriate information on how to use and when to change the products³.

2.4 Provision of washable containment products

CYP provided with washable containment products

- would usually be undergoing a toilet skill development programme, supported by a HCP
- should have a measurement taken of their hips and waist, to guide sizing. However, as products fit differently, the following action should be taken:
 - The family should be provided with a sample product, appropriate to the CYP's needs, to try. If the product is suitable, further pairs of the same product should be supplied. If it is not suitable then a different sample should be provided
 - Once agreement is reached about which product is suitable for the CYP then, up to a total eight washable pants should be provided for each CYP
 - If the CYP grows their hips and waist should be measured, and a new sample provided. If the sample is suitable then a further seven products should be provided (total eight pants that fit)
- A CYP would not receive more than eight washable pants at a time and not more than a maximum of two sets in a chronological year.

2.5 Provision of disposable containment products

CYP provided with disposable containment products

- Will be over five years old, have recently been assessed as unable to toilet train within a minimum of six months of the date of assessment, due to the extent or nature of their disability or medical need (appendix 5)
- Should have samples of disposable containment products tried on them by their HCP to assess for fit and suitability

⁴ There is information on how to use containment products for families in the Bladder & Bowel UK leaflet at <u>Getting the best out</u> <u>of continence products</u>

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- Once samples have been tried by the HCP, the parents and carers should be shown how to apply the containment product and then be provided with at least two further samples and information about how to contact the HCP
- Once the parent or carer has tried the samples, they must let the HCP know whether they felt the samples fit well and offer good containment, or not. If the fit and containment are good, then the CYP should be provided with that containment product
- The number of containment products to be provided is calculated by the HCP following an individualised clinical assessment. Typically provision would not exceed four per 24 hours
- Some CYP may require a different containment product for use at night, to those needed during the day e.g. they may require a containment product with more absorbency at night, particularly if they have an overnight feed; some may require a different style of containment product for the night
- If a CYP has frequent bowel actions, they should be assessed for constipation or other bowel disorder and appropriate intervention given
- If a CYP is passing high volumes of urine, then consideration should be given to assessment for polyuria with appropriate onward referral to a paediatrician if there are concerns
- Disposable pants are not typically supplied. They are only provided in exceptional circumstances and where these are the only product that meets the child's clinically assessed needs. Studies (Simon et al 2006, Tarbox et al 2004) and clinical experience have shown they do not support toilet training. Alternative products offer similar discretion and containment and are easier to change. Disposable pants are not provided as an alternative product for children who shred or remove the disposable product.
- The parents and carers should be made aware of how to obtain more containment products and when and how to contact the HCP if the child's needs change e.g. if they grow and need a larger size containment product
- Swimming nappies are not provided by the NHS. HCPs may signpost parents/carers to where these and other items can be purchased as well as ensuring affected CYP are in receipt of any financial support to which they are entitled, such as Disability Living Allowance
- Sanitary towels are not provided for girls who are menstruating, nor are extra containment products provided for this. Parents and carers who wish to use a sanitary towel inside the containment products during days of the heaviest menstrual flow should be advised to purchase a product with a breathable (non-waterproof) back sheet. These will not negatively affect the ability of the containment product to absorb urine and can be changed as often as required without impacting on the containment product⁵. However, care should be taken to ensure that if a sanitary towel is used it does not affect the fit of the product, causing leakage, that it does not cause moisture to remain against the skin or cause pressure, all of which may result in skin damage.

⁵ More information is available in the Bladder & Bowel UK leaflet <u>Using continence products during your period</u>

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- Disposable products are not provided for children who refuse to open their bowels on the toilet⁶.
- If a CYP has an acute illness or requires disimpaction, that results in a temporary increase in the number of products required, parents/carers should provide the extra products, but may require information on where/how to purchase these. This is equitable with provision for children who do not normally have products provided but may develop incontinence for a short period of time, such as when having disimpaction treatment or during a bout of gastroenteritis

For more information regarding the range of products available email Bladder & Bowel UK at <u>bbuk@disabledliving.co.uk</u>. Information leaflets for families on <u>Getting the best out of continence</u> <u>products</u> is available.

2.6 Reassessment of need, changes in need and transfer to different area

- Parents and carers should be advised about how much notice should be given to the HCP, prior to a containment product delivery being due, if the CYP's needs have changed. This will allow reassessment prior to the next order being requested. It is not unreasonable to ask parents or carers to give six to eight weeks notice that the CYP's needs are changing, to ensure there is time for samples to be ordered, trialled and for further specialist input to be arranged, should this be necessary. This is to ensure that the CYP's comfort and containment is maintained, without having to change the containment products part way through a delivery cycle.
- Changing containment products part way through a delivery cycle has resource implications, including the environmental impact of extra deliveries and collections, as well as financial implications for services. For the reasons above, a containment product would not be changed part way through a delivery cycle
- Every CYP receiving disposable containment products should have a full reassessment of need, of bladder and bowel health and, where appropriate, of their ability to develop the skills required to toilet train at least once every twelve months
- Families need to be informed of the importance of having their child's needs reviewed at least annually, as children's needs and bladder and bowel health may change. The product order may be suspended until the review has been carried out. However, it would not be appropriate for a product order to be suspended if delay in review was caused by problems within the service undertaking the review
- When a CYP has toilet trained, the supply of disposable containment products would be terminated immediately
- Families should be advised that any unused products remain the property of the NHS. If their CYP has been provided with containment products that they do not need or are no longer suitable for them, the service who provided them must be contacted and

⁶ Information on how to approach this is available in the Bladder & Bowel UK leaflet <u>Understanding toilet refusal</u>

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arrangements made to cancel the order and for any unused products to be returned as per local policy

- If a CYP has toilet trained in the day but is still wet at night six months later and the CYP has reached their fifth birthday, they should be offered assessment for nighttime wetting. Containment products are not provided for night-time wetting, unless this is medically indicated e.g. in the case of a CYP with epilepsy who has seizures at night and is incontinent as a result. To provide containment products for night-time wetting in children who are toilet trained in the day could be discriminatory and in breach of the Equality Act 2010, as containment products are not provided for night-time wetting to CYP who do not have additional needs. They should be provided with assessment and treatment for enuresis. Parents or carers may choose to purchase their own containment products to manage enuresis and may decline, or delay treatment if they so wish
- CYP who have achieved urinary continence will not be provided with a containment product if they refuse to open their bowels on the toilet. This normally occurs because of a behavioural, emotional, or sensory issue and the CYP and their family should be offered appropriate support with toilet training for bowels. If the CYP has frequent soiling, they should be offered an assessment and treatment for their bowel condition in the same way as a CYP who does not have additional needs
- CYP should not be discriminated against if they move from one Health Trust, ICS (England), Health Board (Scotland and Wales) or Health and Social Care Board (Northern Ireland) area to another. They should be provided with at least three months supply of product prior to their transfer. They should also be referred to the appropriate service in the new area on transfer. This will allow time for the CYP to have an assessment of their bladder and bowel health and potential to toilet train in their new area and appropriate intervention to meet their clinical need undertaken.

2.7 Manufacturer, style and provision of containment product

There are different styles and manufacturers of containment products.

Most NHS Trusts, ICS (England), Health Boards (Scotland and Wales) or Health and Social Care Boards (Northern Ireland) will have contracts with a specific containment product company and will have an agreed basic formulary from that company's range that will meet the needs of most CYP. This will normally include washable containment products; one piece disposable containment products (nappy style products); or two-piece products (fixation pants and a disposable pad).

For many CYP, particularly those who can stand or walk, a two-piece containment product is the most appropriate option: it facilitates easy changing and allows the CYP to be involved, when they have the ability to do so. These containment products are often more discrete and comfortable to wear. However, the fixation pants need to be a snug fit and available in small enough sizes for smaller CYP. Often basic ranges of fixation pants are not adequate to hold the pad securely in position on CYP. Therefore, consideration of the type of fixation pant provided on the basic formulary is important. See appendix 8 for more information on types of products available.

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HCPs assessing CYP's continence containment needs should give due credence to the overarching need for the safety of both the CYP and of their carer as well as for good containment. Each CYP is an individual with a unique set of circumstances. Therefore, the overriding principle, once the CYP has been assessed as needing a containment product, should be of meeting individually assessed need.

It would be expected that for all CYP who have not previously received a containment product, assessment would be undertaken by level one (also known as Tier 1) services e.g. health visiting or school nursing, provided that the HCPs in these services have undergone appropriate education and they have the necessary knowledge and expertise. In addition, the CYP should have been supported in a trial of toilet training for a minimum of six months, unless that is not clinically appropriate e.g. where the CYP has a neuropathic bladder or bowel. Normally, following the assessment, authorisation for the containment product for CYP assessed as unable to toilet train within six months would be given by the level two service i.e., the children's bladder and bowel (continence) service, once the child was five years old. It is reasonable for the children's bladder and bowel nurse to expect to be provided with copies of all the assessment information before authorising delivery of containment products.

Not all CYP requiring containment products will need direct contact with the children's bladder and bowel (continence) nurse. However, this will depend on local pathways and arrangements. If there are any concerns about the assessment, the CYPs ability to toilet train, or difficulty finding a containment product to meet an individual's need, then the children's bladder and bowel service may need to become directly involved. In the absence of a children's bladder and bowel service, pathways for toilet training and for provision of continence containment products should be decided locally, with information disseminated to all healthcare professionals who work with CYP.

When an NHS Trust, ICS (England), Health Board (Scotland and Wales), or Health and Social Care Board (Northern Ireland) changes its contract with a containment product manufacturer, families of all CYP should be informed by letter prior to the change date. They should all be offered the opportunity to attend a clinic to have their containment product reassessed and fitted. They should also be provided with at least two samples of the containment product that is being recommend for them, from the proposed manufacturer, to try at home. This will ensure smooth transition when the contract changes and that the CYP will continue to be provided with containment products that meet their needs. It will also reduce the inconvenience, stress, and expense of having to change containment products that are not working effectively, following a contract change. Clinics should be held in locations convenient to CYP and their families, including at special schools.

2.8 Safeguarding

All HCPs have a duty to safeguard the wellbeing of CYP. If they become aware of any concerns, they should seek advice and take appropriate action according to their employer and Local Safeguarding Children Partnership policies and procedures.

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Children that are looked after by social care under Section 20 or 31 of the Children Act 1989 should not be discriminated against if they move from one Health Trust, ICS (England), Health Board (Scotland and Wales) or Health and Social Care Board (Northern Ireland) area to another⁷. They should be provided with at least three months' supply of product prior to their transfer. They should also be referred to the appropriate service in the new area on transfer. This will allow time for the child to have an assessment of their bladder and bowel health and potential to toilet train, in their new area and appropriate intervention to meet their clinical need undertaken.

Section 10 of the Children Act 2004 provides that the local authority must promote co-operation between the authority and relevant partners, with a view to improving the wellbeing of CYP, including their physical and mental health, protection from harm and neglect, and education. Relevant partners, including children's bladder and bowel services, are under a duty to co-operate in the making of these arrangements.

Parents or carers who do not, cannot, or find it difficult to fill in charts should be offered support by their HCP, school, or family support workers, to ensure their CYP gets the same assessment as any other CYP. However, it is not in the CYP's best interest to refuse assessment, treatment, or appropriate containment product provision because charts have not been completed. The HCP can gain some relevant information in clinic, at home, or in school, and gather verbal information from the parents/carers, or the child. If there are concerns, the HCP should request guidance from their safeguarding supervisor(s).

CYP with additional needs who are referred for product provision due to a regression in continence or toilet training, should be treated in the same way as any other child with a regression of continence symptoms, but HCPs should be mindful that neglect, physical, emotional, or sexual abuse can be an underlying cause for this.

2.9 Transition

It is important to ensure a smooth transition from paediatric to adult bladder and bowel services, particularly as there may be different criteria for containment product provision, including both the type and number of products provided. NICE Guidance 43 'Transition from children's to adults' services for young people using health or social care services' (2016) outlines the characteristics of good transition services, including an agreed process for joint strategic planning between children's and adult health services and a clear transition pathway. There is also information on transition for families and for professionals on the Bladder & Bowel UK website⁸.

⁷ Similar legislation for the devolved nations includes the 1995 that the Children (Northern Ireland) Order and the 1995 Children (Scotland) Act

⁸ Information for families and CYP is at Starting to think about adult services and the process of transition. Information for professionals is at Supporting transition from child to adult services and at Getting started with transition - How to develop your transition process as a health care team

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Risk management procedures need to be in place, including effective follow-up for vulnerable young people transferring to adult services. There also needs to be a joint planning and funding process between the ICS (England), Health Board (Scotland and Wales) or Health and Social Care Board (Northern Ireland) and the local authority to ensure ongoing needs, which may require specialist commissioning, are met.

Section 3: References, additional information, and appendices

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3.3 Further information

<u>Bladder & Bowel UK</u> provides impartial information and advice regarding all aspects of bladder and bowel care for all age groups, including about products, equipment and services. Email: <u>bbuk@disabledliving.co.uk</u> for further information.

Bladder & Bowel UK have produced <u>children's continence care pathway</u> for level one and level two (tier one and tier two) services, including for toilet training and containment product provision. These are available at <u>https://www.bbuk.org.uk/professionals/professionals-resources/</u>. They have also produced a resource pack to support level one services with continence promotion, available from the same source.

3.4 Conflict of interest

No conflicts of interest have been declared.

3.5 Copyright owner

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Appendix 1a: Sample baseline bladder /bowel (toileting) chart – instructions on how to complete chart at 1b

To help plan a toileting skills development programme and to identify if there are any underlying problems, such as constipation, a baseline bladder chart should be completed, for at least three full days or longer if the family can manage, and a bowel chart for two weeks. The days for the bladder chart do not need to be consecutive, but the CYP needs to be home for most of the time. Schools and nurseries do not usually have the resources to help. The more days that are completed the easier it is to see if there are any patterns to the CYP's elimination. Knowing the pattern, if there is one, can be helpful for skill development for toilet training.

Modern disposable nappies have 'super absorbency' which locks away urine, so the top layer of the nappy stays dry next to the CYP's skin. While this maintains skin health, it reduces the likelihood of the CYP feeling wet and makes it difficult to know when a CYP passes urine.

When completing the chart, it may be easier to see if the CYP has been wet if a clean, folded piece of kitchen roll (one that does not disintegrate when wet) is placed inside the nappy. The parent must check the nappy every hour their CYP is awake and note on the chart whether the pad was wet (W), or dry (D), or if their CYP has had their bowels opened (B). If a kitchen roll has been used and is wet it should be changed, but the nappy can stay on until it cannot hold any more urine or is soiled i.e., when it would normally be changed.

If the CYP sits on the toilet or potty, the parents should write T in the pad column and if they pass urine while there the parent should write TU to show this or TB for poo, as per the key on the chart. Drinks or tube feeds must be recorded in the drink's column, with the volume in mls and type of drink if possible. The HCP will evaluate the chart with the parent and provide appropriate advice.

Bladder capacity in mls can be calculated up to the age of 14 using the formula age in years $+ 1 \times 30$. CYP of 4 years or more should be voiding frequency of about 4 - 7 times per day (Austin et al 2016). A frequency of eight or more voids per day may indicate an overactive bladder. However, for many children frequency, if present, will reduce with toilet training. Persistent frequency after 5 years of age and a few weeks after toilet training would warrant further assessment and appropriate treatment, as would any other bladder issues.

Typical bowel development follows a pattern of cessation of bowel movements at night at around one year of age, with awareness and control at around 12 - 24 months. Soiling at night after the first birthday may indicate an underlying problem, such as constipation, which should be assessed and treated.

The family should be supported to help their child learn the skills for toilet training, with the nappy being removed during the day when the child is both able to sit happily on the potty or toilet (with support or adaptations if needed) and is passing about half of their voids there⁹.

⁹ For more information on toilet training refer to the national guidance: <u>Best practice guidelines for professionals, supporting skill</u> development for toilet training in all children, including those with learning disabilities and developmental differences

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Appendix 1b sample baseline bladder/bowel (toileting) chart

Child's Name:		
onna s Nanie.	Pad:	Toilet/potty:
NHS Number:	W = wet	TU = wee
Date of birth:	D = dry	TB = poo
	P = poo/soiled	
Date chart started:		

DAY	1	DAY 2		DAY	DAY 3		DAY 4		
Pad/ toilet	Drink - Type and amount	Pad/ toilet	Drink - Type and amount	Pad/ toilet	Drink – Type and amount	Pad/ toilet	Drink – Type and amount		
	Pad/	DAY 1 Pad/ toilet Drink - Type and amount I I	Pad/ Drink - Pad/	Pad/ Drink - Pad/ Drink -	Pad/ Drink - Pad/ Drink - Pad/	Pad/ Drink - Pad/ Drink - Pad/ Drink –	Pad/ Drink - Pad/ Drink - Pad/		

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Appendix 2a: Toilet skills (re)assessment checklist – instructions for how to complete assessment in appendix 2b)

Professionals must always maintain high expectations for the ability of all children, including those with learning disabilities, to acquire the skills for toileting. For those children with a condition or disability that may delay achievement of the skills for toilet training, early assessment must be offered.

The assessment is a continuous dynamic process that commences in the first year of life, or as soon as it is identified that the child has, or may have, a disability that impact on toilet training, or there is concern about how they are developing the required skills for toileting. There is more than one element to a holistic bladder and bowel assessment.

The bladder and bowel health assessment will allow early identification of any underlying issues, and either onward referral following local pathways, or commencement of appropriate treatment with the support of an HCP with sufficient knowledge and experience. Treatment for conditions such as constipation may be undertaken whilst also working on the skills for toilet training. Urinary frequency may improve with toilet training.

A bladder and bowel health assessment will include a baseline record of the CYP's bowel habits for two weeks (Bauer et al 2015) and bladder habits for at least three days. A sample chart is available at appendix 1b, with information and instructions for completing it at appendix 1a. This is the minimum time required for an adequate picture of bladder and bowel habits and any patterns in elimination to emerge.

The CYP should also be assessed for their ability to develop the skills required for toilet training. The Toilet Skill Assessment Tool appendix 2b may be used as a tool for this. The outcome of this will help inform an individualised toilet skill development programme that addresses any area where the CYP has not manged to achieve the highest level for each skill. The assessment tool in appendix 2b may be used to support this, as it indicates the highest level for each skill (coloured green) and actions that could be taken to reach this at each level. However, the HCP must suggest interventions appropriate to the child and family's capacity and circumstances. The HCP must avoid making assumptions based on a CYP's diagnosis or their experience of other children in similar circumstances.

At the assessment, the box on the toilet training skills checklist that is closest to where the CYP is in relation to each skill, will be ticked. The individualised programme will advise the family how to work on helping their child develop the required skills, with focus on the areas where the greatest skill development is needed. The programme will last different lengths of time, according to the CYP's progress. How often reviews should be undertaken and any additional support that may be required will be based on progress and how much support the family need.

If progress is being made the family should continue with the steps to toilet training as outlined in the <u>Best practice guidelines for professionals</u>, supporting skill development for toilet training in all

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children, including those with learning disabilities and developmental differences, with support from the HCP.

If there is no progress in skill development reported, discussion with the family should indicate modifications to the programme that are likely to be beneficial in troubleshooting the issues. For each item on the assessment there is a suggestion of what may be an appropriate intervention if further skill development is needed in that area.

For example, if the CYP will not sit on the potty or toilet, the family should be taught strategies to use that they and their child can manage, such as gradually increasing time on the potty from a few seconds, using distraction or engaging the CYP in a pleasurable activity while sitting. Parents can also be advised about appropriate rewards or motivators for the child and be supported and encouraged by the HCP during this process. The programme continues until the CYP can sit for long enough to complete a void or evacuate their bowels. If the CYP was unable or unwilling to sit, due to an issue such as lack of balance or sensory need, referral to an Occupational Therapist (OT) should be made for further assessment and intervention.

The most important skills for a child to learn to be successful with toilet training are being able to sit happily on the potty or toilet, and being able to pass about half of their wees onto the potty or toilet when put they are put there at regular times, informed by their baseline toileting chart. At this point the nappy can be removed.

The key to success is consistency and perseverance from the family and all those caring for the child. However, the assessment may indicate that it is not appropriate to continue with a toilet skill development programme at the current time. Furthermore, the family may be unwilling to engage with the toilet skill development programme or may refuse any recommended referrals to other members of the MDT, but this does not mean that the child is entitled to containment product provision. This must be assessed on a case-by-case basis.

If the family consent, an education professional who knows and supports the CYP in nursery or school should be asked for their perspective. They may be able to provide information around toileting, changing, effective communication etc. Nursery or school, home and the MDT should work together with HCP to devise an appropriate skill development and care plan with agreed review dates appropriate to the family's needs. The family should be advised about how to contact their HCP if they have concerns or require extra support before the agreed review.

The assessment tool (appendix 2b)

The assessment tool is designed to be SMART in that it should be:

- Specific to each CYP and their family
- Measurable, as the measurement numbers on the far left of each element and the colours help to indicate where the child is, the progress they have made between assessments and their current ability. The measurement numbers may also be used to direct current and future care plans. The highest level of skill for each section is colour coded in green to

indicate the skill has been achieved; some progress towards reaching the skills is colour coded yellow and the lowest level of skill attainment is coloured blue.

- Achievable as each section can be broken into smaller steps as indicated in the document: <u>Supporting Skill Development for Toilet Training: Best Practice Guidelines for</u> <u>Professionals</u>.
- Reasonable as it should be in line with what the family should be able to manage, nursery or school expectations and capacity, as well as the child's developing abilities.
- Timebound: it is expected that the HCP who is undertaking the assessment / reassessment will agree expectations with the CYP and family of the skill development work to be done. As an individualised assessment it is recognised that time between reviews will vary depending on circumstances and differing needs for support. Appropriate time scales for review also provide the opportunity for the HCP to reinforce what is going well and make timely adjustments to the programme so the family continue to feel supported.

It is anticipated that reassessment will take place at a maximum of three-monthly intervals, although many families will need more frequent contact and reviews. Small steps with ongoing guidance, rather than being given large amounts of information at once, is often more manageable for the CYP and their family.

Verbal information should be supported with written information. Families should be asked for consent for any onward referrals but should be made aware that products will not be provided until all avenues for toilet training skill development have been considered and undertaken, unless there is a clear reason why they are inappropriate.

Appendix 2b TOILET SKILLS (RE)ASSESSME assessment must be completed with appropriate action taken before considering pro reassessment is required.	NT TO oduct provisi	DL It is expected that an initial assessment and at least two subsequent assessments will be completed on as per the <u>Supporting Skill Development for Toilet Training: Best Practice Guidelines for Professionals</u>	l on the same This form ca	form. The to n be used wh	oilet skills enever		
Child's Name:		What are the parent's goals and expectations:					
NHS Number:		What are the strengths of the child and what are their needs:	What are the strengths of the child and what are their needs:				
Date of Birth:							
Key: 1 – lowest level of skill (shaded in blue) 2 – developing skills (shaded in yellow) 3 – skill developed (shaded in green)		Voice of the child:					
BLADDER /BOWEL MATURITY			Assess	Assess 2	Assess 3		
(a) Bladder function – bladder emptied		Date of assessment:	1	2	Ŭ		
1 More than once per hour	Check fluid intake – adjust if necessary. Toilet training is likely to help and is advised. If frequency persists after 5 th birthday, consider assessment for constipation and/or bladder issues e.g. overactive bladder						
2 Between 1-2 hourly	Indicat	Indication of developing bladder maturity. Toilet training skill development advised					
3 More than 2 hourly	Maturing bladder. Start / continue toilet training skill development						
(b) Bowel function							
1 Opens bowels more than three times a day or less than once every three days		e / treat any underlying constipation or bowel pathology and work on toilet velopment					
2 Does not always have normally formed bowel movements i.e. is subjected to constipation or diarrhoea	Address underlying bowel problem while starting/continuing work on toilet skill development programme						
3 Has regular normally formed bowel movements	Mature	bowel – start/continue work on toilet skill development					
(c) Night-time wetting							
1. Wet most nights or every night	To be expected in a child who has not toilet trained						
2 Has occasional or some dry nights	Indication of developing bladder maturity: start / continue work on toilet skills						
3 Is usually or always dry at night	Mature bladder: start / continue work on toilet skill development						
(d) Night-time bowel movements							
1 Occur more than once per week Assess for constipation, treat as appropriate while working on toilet skills							
2 Occurs less than once a week	Consider constipation, treat as appropriate while working on toilet skills						
3 Never occurs	Start / continue work on toilet skill development programme						

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INDEPENDENCE		Assess	Assess 2	Assess 3
(e) Sitting on the toilet / potty			2	
1 Afraid, refuses or unable to sit even with help	Refer to OT and physio for assessment, advice and appropriate equipment			
2 Needs additional support to sit on toilet / potty	Liaise with OT if necessary, re toilet adaptation / equipment			
3 Sits without help	Start / continue work on toilet skill development			
(f) Going to the toilet / potty	· · · · · · · · · · · · · · · · · · ·		•	
1 Gives no indication of need to go to the toilet / potty	Consider introducing strategies to raise awareness of wet/dry/soiled as part of skill development for toileting			
2 Gives some indication of need to go to the toilet / potty	Introduce positive reinforcement for target behaviour			
3 Sometimes goes to or asks for toilet / potty of own accord	Continue to use strategies such as motivators to reinforce this behaviour			
(g) Handling clothes at toilet / potty	·		•	•
1 Cannot handle clothes at all	If child physically able, introduce programme to encourage child to dress / undress			
2 Attempts or helps to pull pants up / down	Introduce positive reinforcement for this behaviour			
3 Pulls clothes up and down without help	Reinforce this behaviour as part of toilet skill development programme			
BEHAVIOUR				
(h) Bladder control				
1 Never or rarely passes urine on toilet / potty	Complete baseline bladder chart to identify voiding interval and then start toilet / potty sitting at times when bladder most likely to be full			
2 Passes urine on toilet / potty sometimes	Reinforce behaviour; remove nappies when about half voids on the toilet / potty			
3 Can initiate a void on request	Remove nappies and continue to work on skill development			
(i) Bowel control				
1 Never or rarely opens bowels on toilet/potty	Complete baseline bowel chart to identify frequency of bowel movements and then start toilet / potty sitting at a time when bowel more likely to be emptied			
2 Opens bowels on toilet/potty sometimes	Start / continue work on toilet skill development programme			
3 Opens bowels on toilet every time	Evidence of bowel control consider removing nappies if doing well with voids see section (h) above			
(j) Behaviour problems, that interfere with toileting problems	rocess e.g. potty / toilet refusal			
1 Occurs frequently, i.e. once a day or more	Consider causes, modification to environment and individualised strategies			
2 Occurs occasionally, i.e. less than once a day	Consider assessment to identify trigger factors for behaviour e.g. sensory issues			
3 Never occurs	Start / continue work on toilet skill development programme			
(k) Response to basic commands, e.g. 'come here'	· · · · ·		•	
1 Never/unable to respond to commands	Discuss with MDT to see explore strategies that may help			
2 Occasionally responds to commands	Consider routines, using or adapting child's communication strategies			1
3 Usually responds	Start/continue work on toilet skill development programme			

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Appendix 3a: Instructions for paediatric assessment tool for issuing of containment products

This tool should only be used when assessing for product provision and only after:

- A bladder and bowel assessment has been undertaken including a minimum three-day bladder diary and two-week bowel diary, to indicate volume of urine passed, frequency and type of bowel actions etc, which will help determine the most appropriate absorbency of product
- A full supported individualised toileting skills development programme has been undertaken and assessed and modified as required, as outlined in <u>Supporting Skill Development for</u> <u>Toilet Training: Best Practice Guidelines for Professionals</u>, using an assessment tool such as the one in 2b for at least six months, unless a trial of toilet training is clearly inappropriate e.g., neuropathic bladder or bowel.

Throughout the assessment tool (appendix 3b), suggestions are made about actions that may help resolve some of CYP's presenting problems. Highlighted problems should not be ignored but treated where possible and the CYP then reassessed their ability to acquire the skills required for successful toilet training. It is highly recommended that these suggestions are used. In this way, more CYP will be supported to achieve their potential for toilet training, rather than remaining reliant on containment products.

SCORING

Mainly blue indicates a **HIGH** clinical need. However, the CYP may have potential for acquiring skills to support toilet training. They may require disposable containment products but should be supported with skill development and should be reviewed regularly (at least every 12 months).

Mainly yellow indicates **MEDIUM** clinical need. The CYP may have potential for acquiring the skills for toilet training and should commence or continue a toilet skill development programme. Provision of washable containment products, which support toilet training are likely to be most appropriate, but disposable may be appropriate in the short term. However, services would not provide products for use while the child is developing the skills for toilet training, unless there is a clear clinical indication to do so. These CYP will need regular review (at least every 3 months).

Mainly green indicates a **LOW** clinical need. These CYP may respond positively to a toilet skill development programme with regular review according to individual need. When they are passing half of their voids in the potty or toilet the containment products should be removed during the day. It is unlikely to be appropriate to supply containment products, as prolonged use of disposable containment products in this group has been found to delay toilet training.

Any recommended products should be reviewed with the CYP and their family as outlined in sections 2.3, 2.4 and 2.5 of this document, to ensure appropriate fit and that the family understand instructions for use.

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Exceptions

There will always be exceptions within the scoring system. HCPs need to understand that this tool is designed as an aid to decision making. It does not override clinical expertise and specific issues relating to individual CYP.

For example, there may be some CYP with congenital anomalies and ongoing wetting or soiling as well as those who have a vesicostomy or neuropathic bladder or bowel, whose assessment indicates they are mainly in the green areas but may be eligible for disposable containment products. This should be assessed on an individual basis.

There may be other CYP who assessment indicates they are mainly in the blue areas, because they have not been offered support to develop the skills needed for toileting, from a professional with the appropriate knowledge and expertise. Many of these CYP progress well on a toilet skill development programme and, therefore, it would be detrimental to them to provide disposable containment products, which would further delay skill development for toilet training. It is important to use sound clinical judgement.

Each area on the chart indicates care that may be required and can be used as the basis of a care plan, alongside those indicated in the toilet assessment at appendix 2b.

The assessment tool (appendix 3b)

The assessment tool is designed to be SMART in that it should be:

- Specific to each CYP
- Measurable, as the colour coding of each element helps to indicate where the child is in terms of their bladder and bowel function, awareness of and level of independence with the skills required for toilet training as well as their behaviour around toileting. The highest level of skill for each section is colour coded in green to indicate the skill has been achieved; some progress towards reaching the skills is colour coded yellow and the lowest level of skill attainment is coloured blue.
- Achievable as each section indicates a skill level that corresponds with the assessment tool for toilet skill development, but also indicates the likelihood that the child needs product provision, as outlined in the key on the chart in section 3b.
- Reasonable as, when used in conjunction with a toileting chart and bowel chart, it should indicate the type of product provision and the quantity of products that are likely to meet the child's needs.
- Timebound: it is expected that the HCP who is undertaking the assessment / reassessment will explain the outcome of the assessment to the family and will agree the products to be tried first. They will also agree a date to review the samples provided and whether the level of containment provided was sufficient to meet the child's needs. A timescale for the products to be provided or an alternative to be trialled will also be agreed. The child will then be reviewed at least annually, or sooner if the family contact to say that the child needs reassessment due to growth or changing needs.

Appendix 3b PAEDIATRIC ASSESSMENT TOOL FOR ISSUING OF CONTAINMENT PRODUCTS

There is an expectation that this form will only be completed when assessment and support for toilet training has been offered as per the national guidance, or when this is clearly inappropriate

	NHS No:	Кеу	
Child's Name:	Date of Birth:	Mainly blue – Continue bladder and bowel health promotion and work on toilet skills as appropriate. A disposable	
		containment product may be required if already undertaken six months of supported skill development training according to local policy	
Assessment completed by:	Date of assessment: new chart required for each assessment	Mainly yellow – making progress with skills for toilet training. Continue work on these with appropriate MDT support.	
		Consider a product for short term if appropriate and regular reviews ongoing, according to local policy Mainly green – commence or continue a toilet skill development as per toilet training guidance unless this is clearly inappropriate e.g. neuropathic bladder.	

BLADDER /BOWEL MATURITY				
Bladder function – bladder emptied				
1 More than once per hour,	Check fluid intake – adjust if necessary. Toilet training may help. If frequency persists > aged 5 years and toilet trained consider assessment for OAB or other bladder storage issue			
2 Between 1-2 hourly	Indication of developing bladder maturity. Consider continuing with toilet training			
3 More than 2 hourly	Maturing bladder			
(b) Bowel function				
1 Opens bowels more than three times a day	Exclude underlying constipation and introduce potty / toilet sits to promote emptying			
2 Does not always have normally formed bowel movements i.e.is subjected to constipation or diarrhoea	Address underlying bowel problem while commencing toilet skill development progamme (check Bristol Stool Form score)			
3 Has regular normally formed bowel movements	Mature bowel – consider a toilet skill development			
(c) Night-time wetting				
1 Usually i.e. most or every night	If over the age of 5 years and dry in the day, consider referral to the enuresis service			
2 Frequently i.e. has occasional dry nights	Indication of developing bladder maturity			
3 Rarely/Never i.e. is usually dry at night	Mature bladder – consider a toilet skill development programme			

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(d) Night-time bowel movements				
1 Occur more than once per week	Assess for underlying constipation – treat as appropriate			
2 Occurs less than once a week	Assess for underlying constipation – treat as appropriate			
3 Never occurs	Mature bowel			
INDEPENDENCE / AWARENESS				
(e) Sitting on the toilet				
1 Afraid, refuses or unable to sit	Try to work out causes. Consider behaviour modification programme and OT referral			
2 Sits with or without help	Liaise with OT if necessary, re toilet adaptation/equipment			
3 Sits without help for long enough to complete voiding	Check for bladder / bowel maturity and consider toilet training readiness			
(f) Going to the toilet				
1 Gives no indication of need to go to the toilet	Consider introducing strategies to improve communication: picture cues, words, signs, songs, object of reference etc			
2 Gives some indication of need to go to the toilet	Introduce positive reinforcement for target behaviour and continue comms strategies			
3 Sometimes goes to or asks for toilet of own accord Consider timed toileting and visits when requested with removal of containment product				
(g) Handling clothes at toilet				
1 Cannot handle clothes at all	If child physically able introduce programme to encourage child to pull pants up/down independently			
2 Attempts or helps to pull pants up/down	Introduce positive reinforcement for target behaviour			
3 Pulls clothes up and down without help	Continue to work on other required skills			
BEHAVIOUR				
(h) Bladder control				
1 Never or rarely passes urine on toilet/potty	Complete baseline wetting/soiling chart to identify voiding interval and then start toilet sitting at times when bladder most likely to be full			
2 Passes urine on toilet sometimes most days	Consider removal of product and timed toileting when half of voids are on the potty / toilet			
3 Can initiate a void on request	Consider removal of products			

(i) Bowel control				
1 Never or rarely opens bowels on toilet/potty	Complete assessment charts. Introduce toilet sitting at a time when bowel more likely to be emptied e.g. after meals			
2 Opens bowels on toilet sometimes	Use timed toileting when child most likely to need bowel motion			
3 Opens bowels on toilet every time	Evidence of bowel control continue with skill development in other areas			
(j) Behaviour problems, that interfere with toileting process e.g. screams when toileted				
1 Occurs frequently, i.e. once a day or more	Consider cause of issues and make appropriate adaptations. Liaise with MDT			
2 Occurs occasionally, i.e. less than once a day	Consider cause of issues and make appropriate adaptations. Liaise with MDT e.g hand dryer			
3 Never occurs	Continue to work on other toileting skills			
(k) Demonstrates understanding by responding to basic instructions using correct communication, e.g. 'Jo, come here'				
1 Never/ Rarely responds to commands	Consider appropriate motivational reward systems and work with MDT to build co-operation			
2 Often responds	Consider motivational reward systems for toileting			
3 Usually or always responds	Consider how to make toilet time fun for the child to sustain progress			

Samples supplied: No / Yes If yes, date ordered

If samples supplied: type of product: Washable / Disposable Name, make and size of product

Date of review:

Outcome of review:

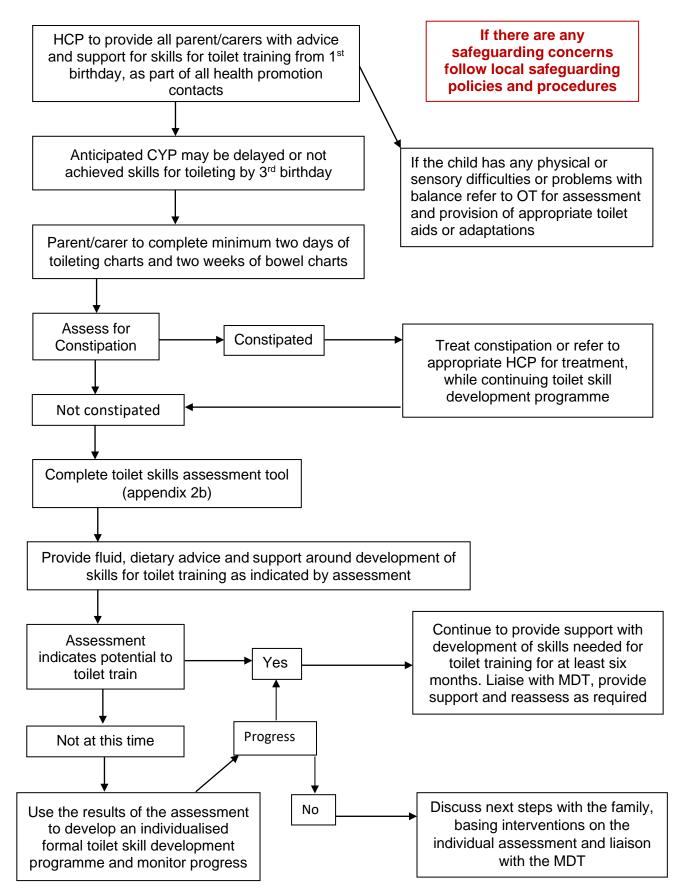
Appendix 4: DOCUMENTING AN ASSESSMENT

The assessments should be documented and filed in the CYP's clinical record, using the forms at appendix 1b, 2b and 3b (or similar). It is also important that any assessment for provision of products to contain incontinence to a CYP should include the following elements:

- The child's mobility: e.g are they able to walk independently or with aids, stand independently or with aids, crawl or bottom shuffle or do they use a wheelchair
- What level of cognition does the child have
- Behaviours that may impact on product choice e.g. behaviour when being changed that may impact their or their carer's safety; shredding the products if they are able to access them; do they cooperate when being changed
- The child's anatomy: e.g. do they have hip dysplasia or scoliosis or other anatomical differences that may affect how the product fits
- Comorbidities or health issues that may impact on volume and frequency of voiding or bowel motions and hence the number of products a day that may be required to meet individual needs
- Any other issue that may influence the number and type of products provided

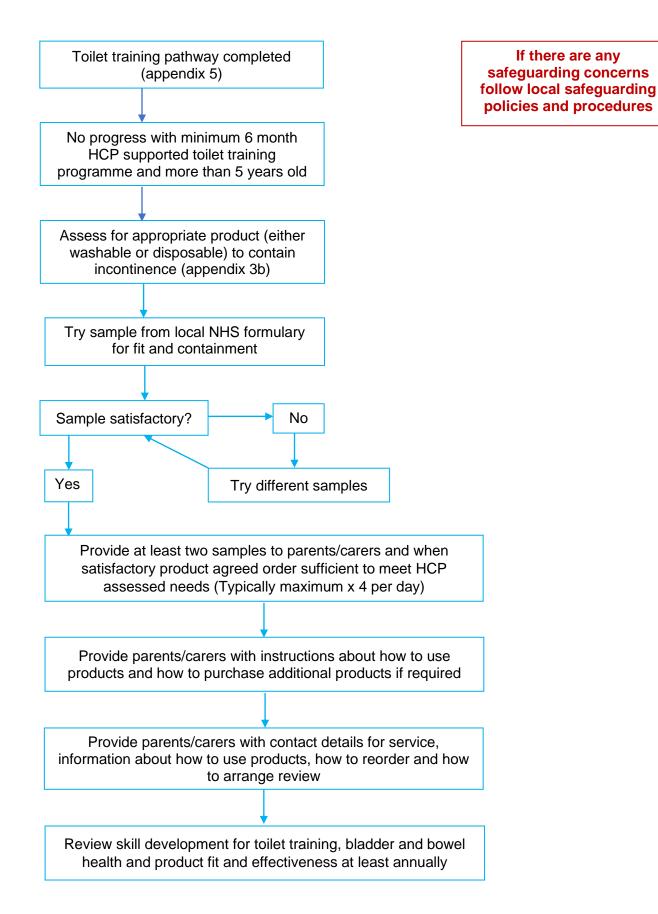
The outcome of the assessment should be discussed with the family and any differences of opinion are resolved. The family must be provided with details about how and when to order the products and how to contact the service if the child's needs change. Details of the discussion and information provided to the family should also be documented along with arrangements for reassessment.

Appendix 5 TOILET TRAINING PATHWAY



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Appendix 6: PROVISION OF CONTAINMENT PRODUCTS PATHWAY



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Appendix 7: FLUID ADVICE

Adequate fluid intake is important for maintaining bladder, bowel and general health and is important in toilet training. Maintaining a good fluid intake is difficult for some CYP with disabilities. However:

- Caffeinated drinks, including tea, coffee, hot chocolate, and cola should be avoided as they may have a diuretic effect and can contribute to bladder overactivity.
- Fizzy drinks should be avoided as they can contribute to bladder overactivity
- CYP need to increase their fluid intake if doing lots of exercise (including sports, playing out and school playtimes), or if the weather or environment is hot
- Milk is healthy but is used by the body as a food. It should not be encouraged instead of or as part of total water-based drinks
- Excessive milk intake can cause excessive weight gain and for some CYP may contribute to constipation
- CYP who are of school age should have about half of the fluid requirement during the school day. CYP who do not drink well during the school day are more likely to drink large volumes in the evening which may contribute to or cause bedwetting.
- Overweight CYP may need more water than indicated in the table below.

Age	Sex	Total drinks per day
7-12 months		600 – 900ml
1-3 years	Female Male	900 – 1000ml 900 – 1000ml
4-8 years	Female Male	1200 – 1400ml 1200 – 1400ml
9-13 years	Female Male	1200 – 2100ml 1400 – 2300ml
14-19 years	Female Male	1400 – 2500ml 2100 – 3200ml

Suggested intake of water-based drinks per 24 hours according to age and sex (NICE 2010)

N.B. Dieticians or medical advice about fluid intake, where provided for individual CYP should be followed.

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Appendix 8: STRATEGIES TO MANAGE INCONTINENCE

When assessing a CYP who is unable to acquire sufficient skills for successful toilet training, HCPs should consider all options available to ensure the most appropriate containment is provided for the individual. Consideration for the safety of the CYP and their carer is paramount. However, promotion of CYP independence as far as possible and of comfort are also important. Parents and carers should be introduced early to options other than a one-piece nappy-style product. The following are all available and may be successfully used in CYP:

- Washable pants
 - Washable pants with varying amounts of absorbency and/or waterproofing are available from a range of manufacturers. Not only does this help to promote toilet training, but it can be used to manage occasional incontinence or family concerns about getting wet when away from home e.g., when on public or school transport. Washable pants come in a variety of styles including those with poppers at the side seams for wheelchair users
- Washable pads/chair/mattress protectors
 - Washable pads with varying amounts of absorbency can be used to protect bedding, chairs etc. during toilet training programs or for children who continue to have occasional wetting after toilet training. These are not supplied by the NHS, but families should be advised about options to purchase them.
- Urinals
 - Urinals are available in a variety of designs including male, female and unisex. They
 may be used in combination with powders that convert urine to a gel-like consistency, to
 avoid splashes and spills. Urinals combined with adapted clothing (hook and loop
 fastening or popper side seams on trousers and underwear) facilitate toileting in children
 who use wheelchairs. These can avoid more time-consuming hoisting onto toilets.
- Sheaths may be appropriate for urinary incontinence in boys
- Two-piece disposable products
 - Disposable pads of differing sizes and absorbencies. These need to be combined with a close-fitting fixation pant or close-fitting underwear. Fixation pants are available from disposable containment product companies, but the smallest sizes may be too large for smaller children. CYP may require the 'premium' designs as these offer enhanced fixation, and these should be considered for CYP who are more active. Pants with elastic throughout the fabric are also appropriate for use in children. Comfizz produce small sizes that are available on prescription (FP10) or parents may choose to purchase cycling shorts or tight fitting swimwear.
- One piece disposable products
 - One-piece products are available in a range of designs and sizes, including traditional shaped products (nappy-style), belted products and pant shaped products. The needs of most CYP who require a one-piece disposable product will be met by the traditional shaped product.

- Disposable pads/bed mats
 - Disposable pads or bed mats can be used to protect bedding, but also chairs, school bus seats etc. for children who are toilet training. These are not supplied with disposable or washable products but are available for families to purchase. To reduce the risk of slipping consideration should be given to purchasing pads or mats that can be secured.

Appendix 9: ABBREVIATIONS

- CE Chief executive
- CYP Children and young people
- DOH Department of Health
- GP General practitioner
- HCP Health care professional(s)
- ICB Integrated care board
- ICS Integrated Care System
- NHS National Health Service
- NICE National Institute for Health and Care Excellence
- OT Occupational therapist

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