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

A consensus document



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	continence containment products to children and young
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	a comprehensive assessment and have access to an
	equitable service
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	Excellence in Continence Care (NHS England 2018)
	Minimum Standards for Paediatric Continence Care in the UK
	(UKCS 2016)
	NICE CG54 Urinary tract infection in under 16s: diagnosis and
	management (2007)
	NICE CG99 Constipation in children and young people:
	diagnosis and management (2010) NICE CG111 Bedwetting in under 19s (2010)
	NICE QS36 Urinary tract infection in children and young
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	NICE QS62 Constipation in children and young people (2014)
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Contact details for further	June Rogers
Information/feedback	Bladder and Bowel UK
	Specialist Children's Nurse
	Disabled Living, Burrows House
	Priestly Road, Wardley Ind Est
	Worsley M28 2LY
Review Date	2021

Disclaimer

The Guidance Development Group's expectation is that health care staff 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, taking into account the individual circumstances presented by each child and young person, as well as the available resources. Therapeutic options should be discussed with the family and clinicians on a case-by-case basis, as appropriate.

It is essential that the health care professionals undertaking the assessment of both toilet training ability and for provision of appropriate containment products to children and young people who are not able to toilet train, or have faecal and/or urinary incontinence, are sufficiently trained, experienced and competent to do so. The United Kingdom Continence Society (UKCS) have produced 'Minimum Standards for Paediatric Continence Care in the U.K.' that may be used alongside this document and is available from http://www.paediatriccontinenceforum.org/wp-content/uploads/2016/07/MINIMUM-STANDARDS-FOR-PAEDIATRIC-CONTINENCE-CARE.pdf.

Without sufficient training and expertise in children's continence and factors that influence this, there is the risk that children'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 consensus of good practice. The authors have made efforts 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 dysfunction', or 'wetting and soiling problems'. For the purpose of this specification, 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 fixation pant). The latter is referred to in this document as a 'two-piece system'

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 day-to-day care. However, it may also refer to anyone who has care of the child or young person for all or part of a day. This includes school, nursery and respite centre staff, as well as carers employed to assist with the child or young persons care in the home. It may also include nursing staff, if the child or young person is admitted to hospital.

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

Foreword

Enabling children and young people to achieve continence is crucially important. It is estimated that approximately 750,000 children and young people across the UK experience continence problems on a day to day basis. There are many different strategies recommended to help parents and children and young people cope, while enabling them to participate in educational and leisure activities relevant to their age and abilities. Ensuring that they have access to a comprehensive assessment, the right products, advice and guidance is crucially important. Unfortunately there is generally a lack of expertise about children's continence care in many parts of the country, resulting in inappropriate provision of products, as well as a post code lottery in terms of access to resources. This welcomed guidance aims to achieve a consistent approach to the provision of containment products for children and young people by providing clear guidance for commissioners, providers and clinicians, as well parents/families and children and young people themselves. Getting this right for children and young people can make a significant difference to the quality of their lives, and also those of their families.

Fiona Smith Professional Lead for Children and Young People's Nursing Royal College of Nursing

Executive Summary

Background

All children and young people should receive support to achieve their maximum continence potential, regardless of their age, culture or ability. Containment products should only be supplied following a full assessment and only when toilet training is not achievable. Currently there is no statutory requirement to provide containment products, resulting in each NHS health care trust, CCG (England), Health Board (Scotland and Wales) or Health and Social Care Board (Northern Ireland) developing their own policy and guidelines. This has resulted in an ad hoc approach to care and a post code lottery in terms of containment product provision, with some areas providing very little more than a 'free nappy' service. This is not only a potential waste of resources, but is discriminatory in that children with disabilities are not supported to attain continence in the same way as children who do not have disabilities.

Additionally, failure to ensure affected children and young people undergo a comprehensive bladder and bowel assessment may result in serious underlying problems, such as neuropathic bladder or bowel, or chronic constipation going undiagnosed and untreated.

This document aims to facilitate a consistent and equitable approach to the provision of containment products to children and young people aged 0 - 19 by bringing together a consensus of agreement, combining available evidence from the literature and clinicial expertise.

Assumptions should not be made regarding the ability, or lack of ability of children and young people with additional needs to be toilet trained. 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'

Key Recommendations

- All children and young people must have a comprehensive assessment of their bladder and bowel, with appropriate identified interventions undertaken
- All children and young people must be supported with a toilet training programme for at least three months, prior to providing containment products, unless it is clear that this is inappropriate e.g. in children with a neuropathic bladder and/or bowel
- Products would not normally be supplied before a child has reached their fourth birthday and then only after the child or young person has undergone a comprehensive bladder and bowel assessment and, where appropriate, a trial of toilet training for at least three months
- Children where it is known or anticipated there may be difficulties with toilet training e.g. learning disabilities or autism, should have the opportunity for early intervention (at around 2 years of age) to facilitate the development of the necessary toileting skills
- Any assessment should only be undertaken by a healthcare professional with the necessary skills and expertise
- The 'custom and practice' of automatically providing products to children with an acknowledged disability once they have reached their fourth birthday is not appropriate and could be considered discriminatory
- The number of products issued per 24 hours would normally not exceed four, but provision should meet clinically assessed need

- The use of two-piece system (pad and pants) should be considered wherever possible instead of an all-in-one (nappy) or disposable pant style product
- Disposable pant style products should not be provided as part of toilet training programmes for children with additional needs
- Consideration should always be made regarding the provision of washable products rather than disposable clinical experience has shown that they are effective in supporting toilet training and help 'normalise' the process
- Containment products should not be supplied for treatable medical conditions, such as bedwetting and constipation with overflow. Children 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

June Rogers MBE Bladder and Bowel UK Specialist Children's Nurse Davina Richardson Bladder and Bowel UK Specialist Children's Nurse

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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 continence provision to support this and others, due to medical need or nature of their disability, may never be able to attain continence. However, with the right support and interventions, many CYP will be able to attain continence. For these children providing disposable containment products may delay toilet training (Tarbox et al 2004) and is therefore not appropriate. 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 the literature (where available) and clinical experience.

Currently there is no statutory requirement to provide containment products, resulting in each health care trust, CCG, health board or health and social care board developing their own policy and guidelines. This has led to a postcode lottery, with where the CYP lives determining what and how many products are supplied, rather than provision being based on an individualized assessment of need. Also in many areas there is no paediatric continence service, so provision of containment products to CYP in these places is often no more than a 'free nappy' service. When health care professionals (HCP) promote the provision of containment products, this reinforces to the family that their CYP is not ready or able to be toilet trained.

For CYP with additional needs it is too frequently assumed that delayed acquisition of bladder and bowel control is a result of the CYP's disability. Formal toilet training is often not tried in the 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, there is no research base for the so called 'readiness signs' (Kaerts et al 2012) and 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. In addition, consideration is not always given to whether there may be an underlying problem, or even whether the CYP has the potential to toilet train. As a result, many CYP are provided with containment products as a matter of 'routine', rather than as part of a proactive continence management programme. This is not only a waste of resources but, more importantly, means that many affected CYP do not undergo a comprehensive bladder and bowel assessment, which has potentially dangerous consequences, with a high risk of any underlying co-morbidities being missed (Rogers & Patricolo 2014).

It has been recogised that current bladder and bowel (continence) services for CYP are inequitable with very patchy service provision. The NHS England document Excellence in Continence Care (2018) refers to an audit by the Healthcare Quality Improvement Partnership (HQIP, 2010) which revealed that '...many services were not providing services in line with NICE guidance...'. In 2017 the Paediatric Continence Forum undertook a Freedom of Information survey of Clinical Commissioning Groups (CCGs) and health boards. This showed that less than 31% of CCGs and health boards across the UK commissioned fully integrated children's continence services with only 23% being led by a specialist paediatric continence advisor (PCF 2017).

However, the majority of CYP with straightforward delayed 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

Continence problems are believed to be caused by biological, developmental, genetic, environmental or emotional factors. Structural or anatomical causes are rare. They 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 and behavioural problems (Joinson et al 2018, von Gontard et al 2011), including a strong association with bullying, both as recipients and perpetrators and CYP who are incontinent are more at risk of abuse.

Continence problems can reduce self-esteem at a crucial time for a CYP's emotional development, cause feelings of shame and difference, have a negative impact on learning and academic performance and increase the liklihood of exclusion from normal social interaction (Whale et al 2017). The absence of pro-active toilet training programmes results in many CYP not reaching their full potential and being innapropriately 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), takes more time for changing than toileting does and has a financial impact in terms of containment products and laundry (Hyams et al 1992; Stenson and Danher 2005; Brown and Peace, 2011).

1.3 Overview of epidemiology of incontinence in children and young people

The National Institute for Health and Care Excellence (NICE) estimates that bladder and bowel dysfunction affects about 900,000 CYP, out of a population of 8,500,000 in the UK (NICE Paediatric Continence Commissioning Guide, 2010: 21). Of the latter, approximately 800,000 have a physical or learning difficulty (Dept for Work and Pensions, 2013). There is evidence that CYP with physical disabilities and/or learning difficulties have a higher incidence of continence problems. This may be due to either an associated disorder of the bladder/bowel, or to limited mobility or intellectual impairment (Duel BP et al 2003; vanLaecke et al 2001; Roijen LE et al 2001; Ersoz M et al 2009), or a combination of these, or reduced expectations of them by professionals and/or their parents or carers.

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 provison of containment products to CYP by providing up-to-date evidence based research and clinical guidance.

To facilitate an appropriate pathway (appendix 4 and 5), to ensure the continence needs of all CYP with bladder and bowel dysfunction are met.

To ensure that all CYP undergo a comprehensive bladder and bowel assessment (appendix 4), by a competent healthcare professional with the necessary knowledge and expertise. It is important that the assessing health care professionals have sufficient training and expertise in children's continence and the factors that influence this. Otherwise, there is the risk that any underlying problems may be missed and CYP's ability and potential 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. To ensure that continence services do not have an arbitrarily assigned minimum age limit for CYP with disabilities to access specialist assessment and treatment or support.

To achieve this all HCPs should use this continence provision guidance to:

- Identify all CYP with incontinence, through an initial clinical assessment process and by using trigger questions opportunistically in all services for CYP. Questions should be phrased using terminology and language that all parents/carers can understand, such as: "Is your child toilet trained?", "Does your child have any bladder or bowel problems?", "Do your child's pants ever get damp?", and "How often do they poo?"
- Offer and complete a comprehensive paediatric continence assessment, if CYP are not toilet trained (appendix 4), or 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
- Help parents and/or carers to understand incontinence and the treatment options that are available
- Offer individualized treatment in relation to the outcome of the assessment, in keeping with treatment care pathways and best practice guidance
- Consider issuing containment products, only after the CYP has undergone a comprehensive continence assessment and has undergone a toilet skill development programme for a minimum of 12 weeks (see appendices 4 and 5), unless there are clear underlying medical or neurological reasons for lack of bladder/bowel control
- Work within their scope of practice and refer to the appropriate services/professionals, without delay, as identified through the assessment process

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

This policy relates to all children and young people (CYP) from 0 -19 years and all those healthcare professionals involved in their care. Reference should be made to the 'Guidance for provision of containment products for adult incontinence: A consensus document (2017)' for those over the age of 19 years.

1.6 Guideline Development Group

June Rogers MBE (Lead Author) Specialist Children's Nurse, Bladder and Bowel UK, Disabled Living, Manchester

Davina Richardson (Lead Author) Specialist Children's Nurse Bladder and Bowel UK, Disabled Living, Manchester

Sheena Kennedy Paediatric Clinical Nurse Specialist / Continence Lead Nurse. Paediatric Continence Service Halton and St Helens Division Bridgewater Community Healthcare NHS Foundation Trust Julie Bardsley Team Leader - Children's Continence Service, Children's Community Services,

Central Manchester University Hospitals NHS Foundation Trust Hospital

Members of Bladder and Bowel UK Paediatric Continence Special Interest Group

1.7 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 developed and reviewed by clinicians, including those from Scotland, Northern Ireland and Wales, and by parents. It was amended a number of times until a concensus was agreed.

1.8 External reviewers

Dr. Anne Wright, Consultant Paediatrician in charge of Children's Bladder Clinic, Evelina Children's Hospital London All Wales Continence Forum Association for Continence Advice (ACA) Community Practitioners and Health Visitors Association (CPHVA) British Association Paediatric Urology & Continence Nurses (BAPUCN) ERIC (the Children's Bowel and Bladder Charity) Profesional Advisory Group NHS England Excellence in Continence Care (EICC) Programme Board NHS Scotland Continence Clinical Leads Northern Ireland Childrens Nursing Forum Paediatric Continence Forum (PCF) Bladder and Bowel UK Paediatric Special Interest Group Royal College of Nursing (RCN) represented by: **RCN** Continence Forum RCN CYP Staying Healthy Forum RCN Continuing and Community Care Forum RCN CYP Acute Care Forum **RCN CYP Specialist Care Forum RCN CYP Professional Issues Forum** School and Public Health Nurses Association (SAPHNA)

The document was also reviewed by parents of children in receipt of products, with some of their comments below:

I think this is fine, everything seems to have been covered and explained.

I think it's a good idea as well, these things need to be picked up earlier, by the right people.

Interesting and much needed document as there is such variation between what GP surgeries will provide within(parent's area) ... never mind nationally

1.9 Guidance Exclusion

This guidance covers children and young people aged 0 - 19 years. It does not cover those who have passed their 19th birthday or the assessment and management of specific continence problems that occur after daytime toilet training 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 patient care, 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 accessing the continence service each year
- Age of CYP with disabilities who are referred to the continence service for assessment for toilet training/provision of containment products
- Number of CYP with disabilities referred for containment products who are 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
- Number of CYP with disabilities referred to the continence service who have not been provided with products, but have toilet trained
- Cost of products provided to CYP in the CCG /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 Guideline recommendations

2.1 National recommendations.

The provision of containment products to children and young people (CYP) would not normally be considered before the child's fourth birthday (DOH 2000).

However, referral to the health visitor, school nurse, paediatric continence service or other health care professional trained and competent in children's continence, 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's syndrome, or developmental disabilities, including autism). Where it is anticipated that CYP may have problems with continence or 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 around the child's second birthday . This is in anticipation of a formal structured toilet training programme commencing as soon as the necessary skills are in place (see appendix 4). Those who have bladder or bowel problems would, therefore, be identified early and offered investigations and treatment according

to need and best practice.

Delaying toilet training until the child has reached an arbitarily decided age, such as 4 or 5 years, 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. There is good 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) and that toilet training promotes bladder maturity (Joinson et al 2009).

CYP who have achieved day-time continence should not normally be considered for provision of night time products only, even if they have a special need or disability. To offer products for night time wetting to CYP who have a special need or disability could be considered discriminatory, as CYP who do not have additional needs are not provided with containment products for bedwetting. All CYP who have reached their fifth birthday and are dry during the day, but wet at night should be offered treatment, unless it is clear that there are 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.

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

All CYP who are delayed or struggling with toilet training should have a documented assessment and trial of toilet training (unless it is clear that they will be unable to toilet train e.g. children with a neuropathic bladder and/or bowel) prior being issued with any containment product. 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 full continence is not achievable, due to the extent of the CYP's disability or medical needs, then bladder and bowel health should be promoted at all times. The CYP should be kept under review and provided with suitable containment products as appropriate, to mantain their dignity, comfort and safety (appendix 5).

As part of the assessment process each CYP should 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 carer can manage). The containment product should be checked hourly to confirm whether the CYP has passed any urine or remained dry. Cotton pants or folded kitchen towel inside the containment product, will help to ensure that any small dribbles of urine are detected. A toileting chart, (such as that in appendix 1b) should be used to facilitate this.

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.

If the CYP has been identified as having the potential to be toilet trained this should be discussed and the toilet skills assessment chart (appendix 2b) should be completed and the CYP commenced on an appropriate programme of skill development.

If the CYP is over the age of 4 years and the assessment indicates that the CYP has no potential for toilet training at this time or has an underlying neurological or congential problem, such as spina bifida or anorectal malformation, and would be suitable for provision of containment products then the paediatric assessment tool for issuing of containment products (appendix 3b) should be completed. The paediatric assessment tool for issuing of containment products will indicate the type of containment product, if any, that should be supplied. It also indicates how to support the CYP and family in developing the skills required to toilet train. Where the CYP has a high score in any area, appropriate action should be taken to help reduce the score, and therefore work towards the CYP reaching their potential, with respect to attaining continence.

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 and assessment can be found on the Bladder and Bowel UK web site <u>http://www.bbuk.org.uk</u> and on the ERIC website at: <u>www.eric.org.uk</u>

2.12 Containment product provision

If an assessment for product provision has been completed and indicates that a containment product should be provided, then consideration should then be given to the type of containment product that best meets the CYP's needs, either washable or disposable. It is not anticipated that CCGs, NHS Trusts, Health Boards, or Health and Social Care Boards would normally 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. Products provided should be age appropriate and meet the CYP's needs, rather than just using nappy style products. Consideration should be given to the use of pads with close fitting underwear or fixation pants; sheaths should be considered for older boys, as these may offer more discretion and comfort. (See appendix 7 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 CYP's individual needs should be provided. There should not be a blanket approach to the type or number of containment products provided. However, this guidance will recommend the maximum number of containment products that would normally be sufficient for most CYP (i.e. four per 24 hours).

It is important for environmental and resource reasons to use the minimum number of containment products to meet needs. It is also 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 parents and carers how to cup and fold the product, how to ensure it is applied and fastened correctly and to avoid talc and creams, as these all affect absorbency and leakage. They should also be shown how to use wetness indicators (when present) to ascertain the appropriate time to change the CYP.

2.121 Washable containment products

For washable containment products,

- Normally CYP provided with washable containment products would be undergoing a toilet training programme, supported by a HCP
- CYP 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, normally, six pairs of washable pants should be provided for each CYP, as this is usually sufficient to meet needs
 - If the CYP was assessed as needing more than this, they should be provided. A further six pairs should be provided annually if required
 - If the CYP grows then the CYP's hips and waist should be measured and a new sample provided. If the sample is suitable then further products should be provided
- It is not anticipated that any CYP would receive more than six pairs of washable pants at a time and not more than two sets in a chronological year. However, there should not be a blanket approach. Provision should be based on individualized needs assessment

2.122 Disposable containment products

For disposable containment products

- Normally CYP provided with disposable containment products would have been assessed as unable to toilet train within six months of the date of assessment, due to the extent or nature of their disability or medical need (appendix 5)
- The HCP should try samples of disposable containment products on the CYP for fit and suitability
- Once samples have been tried by the HCP, the parents and carers should be shown how to apply the containment product and then 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 should let the HCP know whether they
 felt the samples offered good containment, or not. If the containment offered is good, then
 the CYP should be provided with that containment product

- An appropriate number of containment products to meet assessed need should be supplied. However, it is recognised that for most CYP four products per twenty-four hours is sufficient to meet containment needs
- 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 is requiring more than four containment products per day due to frequent bowel actions, they should be assessed for constipation or other bowel disorder and appropriate intervention given
- If a CYP is requiring more than four containment products per day due to volume of urine produced, then consideration should be given to assessment for polyuria with appropriate onward referral if there are concerns and to supplying a more absorbent containment product
- Disposable pants should not be supplied for toilet training. They are more expensive than
 alternative products. In addition, studies (Simon et al 2006, Tarbox et al 2004) and clinical
 experience have shown they do not support toilet training. However, there will be very rare
 circumstances where disposable pants allow independence that is not attainable with any
 other product or where disposable pants maintain parent/carer and CYP safety more
 effectively than other containment products. If there is an assessed need for these
 products in these circumstances, they should be provided
- 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
- On occasion parents or carers may ask NHS providers to supply swimming nappies, but these are not something the NHS can provide. Health care professionals should instead signpost parents/carers to where these and other items can be purchased as well as ensuring affected children are in receipt of any financial support to which they are entitled (such as Disability Living Allowance)
- If a child or young person has an acute illness 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 e.g as a result of disimpaction treatment or gastroenteritis
- If a child or young person has an ongoing bladder or bowel problem that increases their need for products then they should have their needs reassessed and products provided according to assessed clinical need

For more information regarding the range of products available email Bladder and Bowel UK at bbuk@disabledliving.co.uk

2.123 Reassessment of, or changes in need

 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 the services

- For the reasons above, it is not anticipated that a containment product would be changed part way through a delivery cycle, other than in exceptional circumstances
- Every CYP receiving disposable containment products should have a full reassessment of need, of bladder and bowel health and, where appropriate, of ability 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, it would be anticipated that 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 should be contacted and 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 night time wetting. They should not continue to be provided with containment products 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 more than five years old and have been dry for six months in the day could be considered to 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 nocturnal enuresis. Parents or carers may chose to purchase their own containment products and refuse, or delay treatment if they so wish
- CYP who have achieved urinary continence should not normally be provided with a containment product if they refuse to open their bowels on the toilet. This normally occurs as a result 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

2.2 Manufacturer, style and provision of containment product

There are different styles and manufacturers of containment products.

Most NHS Trusts, CCGs, 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 i.e nappy style products; or two-piece products i.e fixation pants and a disposable pad. For many CYP, particularly those who are able to 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 younger 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.

Each company provides containment products that may fit slightly differently from others and therefore there may be occasions when the contracted company's products will not be able to meet the needs of an individual CYP with incontinence. Therefore, in addition to the basic formulary, the service responsible for the budget for containment products (usually the Children and Young People's Bladder & Bowel or Continence Service) should be able to prescribe containment products from all of those available via the NHS, to ensure that the needs of all CYP are appropriately met. See appendix 7 for more information on types of products available. 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. 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 services (also known as Tier 1) (e.g. health visiting or school nursing), provided that the HCPs in these services have undergone appropriate training and they have the necessary skills and expertise. In addition, the CYP should have been supported in a trial of toilet training for at least three months, unless that is not 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. It is reasonable for the Children's Continence 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 Continence Nurse. However, 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 Continence Service may need to become directly involved. In the absence of a Children's Continence 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, CCGs, Health Boards (Scotland and Wales) or Health and Social Care Boards (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 and provided with samples of containment products from the proposed manufacturer. 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. 3 Safeguarding

All healthcare professionals 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 Board policies and procedures.

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, CCG, Health Board (Scotland and Wales) or Health and Social Care Board (Northern Ireland) area to another. The health authority, CCG, Health Board, Health and Social Care Board should honour the pad prescription until the child has been reassessed by the new area, to ensure continuity of care.

Section 10 of the Children Act 2004 provides that the local authority must make arrangements to promote co-operation between the authority and relevant partners, with a view to improving the wellbeing of children, including their physical and mental health, protection from harm and neglect, and education. Relevant partners, including continence 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 child gets the same assessment as any other child. However it is not in the child'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).

Children and young people being 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.

2.4 Transition

It is important to ensure a smooth transition from paediatric to adult continence services, particularly as there may be different criteria for product provision, including both the type and number of products provided. The Department of Health's good practice guide 'Transition: moving on well' (2008) and NICE Guidance 43 'Transition from children's to adults' services for young people using health or social care services' (2016) outline 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. 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 CCG, 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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3.2 Suggested further reading

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Understanding bladder and bowel comorbidities in children with additional needs – the importance of assessment https://www.bbuk.org.uk/wp-content/uploads/2018/08/Understanding-bladder-and-bowel-comorbidities-in-children-with-additional-needs.pdf

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3.3 Further information

<u>www.bbuk.org.uk</u> – Bladder and Bowel UK provides impartial information and advice regarding all aspects of bladder & bowel care including products, equipment and services. EMail <u>bbuk@disabledliving.co.uk</u> for further information

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

ERIC's Children's Continence Pathway aims to inform parents and professionals about the assessment and intervention a child needs using a series of flowcharts. It is available from <u>www.eric.org.uk</u>. Contact <u>info@eric.org.uk</u> for further information.

The United Kingdom Continence Society have produced minimum standards for continence care, which are available from: <u>http://www.paediatriccontinenceforum.org/wp-</u> content/uploads/2016/07/MINIMUM-STANDARDS-FOR-PAEDIATRIC-CONTINENCE-CARE.pdf

3.4 Conflict of interest

No conflicts of interest have been declared.

3.5 Copyright owner

'Guidance for the provision of continence containment products to children and young people: A consensus document' Copyright © 2016 and 2019 Bladder and Bowel UK

Appendix 1a: Sample baseline bladder /bowel (toileting) chart - instructions

In order to help plan a toileting programme and also to identify if there are any underlying problems, such as constipation, a baseline bladder and bowel chart should be completed.

Modern disposable nappies have what is called 'super absorbency' inside the nappy 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. It also makes it very difficult to know exactly how many times a day a CYP passes urine and whether they are dry after a nap, for example.

To complete the chart, therefore something is needed inside the nappy to make it easy to identify if the CYP has passed urine. This could be folded pieces of kitchen roll (one that does not disintegrate when wet).

The chart should be completed for at least three full days, or as long as the parent or carer can manage. These days 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, so charts should be done at weekends or during school holidays. The more days that are completed the greater the likelihood of any patterns to bowel actions and voids being identified, which can be helpful for toilet training.

At the first nappy change of the day the kitchen roll liner is put inside the nappy. The nappy must then be checked hourly and a record made on the chart whether the pad was wet (W), or dry (D) or if the CYP has had their bowels opened (B). If the kitchen roll is wet then 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 uses the toilet or potty at any time then indicate in the pad column if the CYP has a wee (TU) or a poo (TB) on the toilet

Every time the CYP has a drink then that should be recorded in the drinks column, with the volume and type of drink if possible. If the CYP has a tube feed that should be recorded in the drinks column, with the volume. If the CYP is not having an appropriate amount to drink each day suggestions for addressing this should be made. However, it is recognised that many CYP with additional needs may have inadequate or excessive fluid intake as part of their behaviour or condition and adjusting this is not always easy or possible.

Children would normally be expected to void between four and seven times a day. Voiding frequency different from this and any other issues, such as urinary tract infections or continuous dribbling of urine, may warrant investigation or treatment.

Many CYP with special needs are prone to developing constipation for a variety of reasons. The bowel assessment should help to identify underlying issues such as constipation or 'toddler diarrhoea'. The family should identify the type and consistency of stool produced by using the Bristol Stool Form chart. They should also record the timing and frequency of bowel actions. Normal bowel development follows a pattern of cessation of bowel movements at night at around one year of age, with awareness and control at around 18 months to 2½ years. Therefore a CYP who is still soiling at night after their first birthday may have an underlying problem, such as constipation. Any such CYP should be investigated and treated as appropriate.

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

Pad:	Toilet/potty:
W = wet	TU = wee
D = dry	TB = poo
P = poo/soiled	

CHILD'S NAME:_____

DOB: _____

DATE BEGUN:

	DAY 1		DAY 2		DAY 3		Y 4	DAY 5		
Pad	Drink - type and amount	Pad	Drink - Type and amount	Pad	Drink – type and amount	Pad	Drink – Type and amount	Pad	Drink – type and amount	
	Pad									

Appendix 2a: Toilet training skills check list

Prior to commencing a toilet training programme it is important to assess if the CYP has all the skills required in order to be trained. By carrying out the assessment not only can skill deficits be identified, but also any underlying pathology, such as constipation/overactive bladder can be identified. Using the Toilet Skill assessment chart (appendix 2b), the CYP is assessed and the chart completed as directed, so that any skill deficits or problems are identified which will help inform an individualised toilet skill development programme. Once the CYP achieves each skill e.g. will happily sit on a potty or toilet, tick the relevant box. The more boxes that are ticked 'yes' the more likely the CYP is ready to be formally toilet trained.

The assessment should commence in the child's second year, or as soon as it is identified that there is a delay in toilet training, and should be a continuous dynamic process. That is, following assessment a programme is put in place to address any issues that are identified. For example, if the CYP will not sit on the potty or toilet, the family are advised regarding strategies to use, such as engaging the CYP in a pleasurable activity, which will encourage the CYP to sit for an increasing length of time. This programme would then continue until the CYP is able to sit for long enough to complete a void or evacuate their bowels. If the CYP was unable to sit, because of lack of balance etc, referral to an Occupational Therapist (O/T) should be made for assessment for a potty chair/toileting aid.

The CYP would be reassessed every 1-3 months, with the family given an individualized programme to follow in the meantime. The amount of support required for each CYP will depend upon the individual CYP's needs and the family dynamics, with some families needing frequent review and support and others minimal intervention.

Prior to undertaking the assessment a baseline record needs to be taken of the CYP's bowel and bladder habits which will help inform the assessment. The main aim of the bowel and bladder assessment is to identify a maturing bladder that can hold urine for increasing periods of time. In order for this to be identified the frequency of voids needs to be recorded. See appendix one a for information on how to complete a bladder/bowel (toielting chart). A sample chart is available at appendix 1b, with information and instruction for completing it at appendix 1a.

A formal toilet training programme should be put in place once the CYP is achieving the skills to enable training to take place.

These include:

- A maturing bladder that can hold urine for increasing lengths of time
- A bowel that is not constipated
- An ability to sit on toilet/potty for sufficient time (with or without support or toilet adaptations)

This toilet skills assessment checklist will form part of a holistic continence assessment, undertaken by a competent health care professional, which may also need to include urinalysis if indicated, and a physical examination to exclude any underlying pathology, if suspected.

Any identified problems such as constipation / overactive bladder / nocturnal enuresis should be addressed using the normal appropriate care pathway.

TOILET SKILLS ASSESSMENT	
Child's Name:	Date of Birth:
Initial Assessment completed by:	Date of 1 st assessment: Date of 2 nd assessment: Date of 3 rd assessment:

		Assess 1	Assess 2	Assess 3
(a) Bladder function –bladder emptied		\checkmark		
1 More than once per hour				
2 Between 1-2 hourly				
3 More than 2 hourly	\mathbb{R}^{5}			

(b) Bowel function			
1 Has more than three bowel actions per day			
2 Does not always have normally formed bowel movements ie is subject to constipation or diarrhoea			
movements le is subject to constipation of diarnoea	Ļι	_	
3 Has regular normally formed bowel movements	\searrow	1	

(c) If night-time wetting occurs	
1 Frequently, ie every night	
2 Occasionally ie has odd dry night	
3 Never, then shade in areas	

(d) Night-time bowel movements	
1 Occur frequently ie every night	
2 Occur occasionally ie has some clean nights	
3 Never occurs	RA I I

IN	DEPENDENCE				
(e) Sitting on the toilet				
1	Afraid or refuses to sit		ו		
2	Sits with distraction or encouragement				
3	Sits briefly with or without toilet adaptation				
4	Sits long enough to complete voiding or bowel action	\mathbb{R}	7		

(f)	Going to the toilet				
1	Gives no indication of need to go to the toilet				
2	Gives some indication of need to go to the toilet	Π			
3	Sometimes goes to or indicates need for toilet of own	R,	5		
	accord				

		Date	Date	Date
		Date	Duit	Duio
(g) Handling clothes at toilet				
1 Cannot handle clothes at all				
2 Attempts or helps to pull pants down				
3 Pulls pants down by self (if physically able)				
4 Pulls clothes up and down without help		1		
Other components				
(h) Bladder control				
1 Never or rarely passes urine on toilet/potty				
2 Passes urine on toilet sometimes				
3 Passes urine on toilet every time		ļ		
4 Can initiate a void on request	\sim			
(i) Bowel control		1		
1 Never or rarely opens bowels on toilet/potty				
2 Opens bowels on toilet sometimes				
3 Opens bowels on toilet every time	\sim	1		
(j) Behaviour problem, that interferes with toileting proc faecal smears	ess eg	g screan	ns when t	toileted,
1 Occurs frequently				
2 Occurs occasionally, ie less than once a day				
3 Never occurs		1		
(k) Wears nappies, disposable pants or similar				
1 Yes				
2 No		1		
(I) Toilet				
1 Requires toileting aids or adaptations				
2 Uses normal toilet/potty	⊢Į Į	*		
(m) Response to basic commands, eg "come here"				
1 Never responds to commands				
2 Occasionally responds				
3 Always responds	R	1		
	• •	-		
(n) Diet				
1 Refuses/unable to eat any fruit/veg				
2 Will occasionally eat fruit/veg each day				
3 Eats adequate amount (age+5 = grams fibre)		1		
(a) Eluid intoko				
(o) Fluid intake	-+-			
1 Drinks little (much less than expected for age/size)	╷┤╛└	<u> </u>		
2 Drinks moderate amount (close to expected for age/size)) ~			
3 Drinks good amount (as expected for age/size)				

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 full continence assessment and a trial of toilet training has been carried out unless a trial of toilet training is clearly inappropriate e.g. neuropathic bladder.

It is not possible to properly assess bladder and bowel function unless the parents/carers complete a toileting diary for at least three days if possible (or as many days as they can manage) as described in appendix 2a.

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

SCORING

30 and above: Indicates a **HIGH** clinical need but the CYP may have potential for toilet training in the future. They will probably require disposable containment products, but should be supported with skill development and should have a regular (6 -12 month) review.

17 – 30: Indicates **MEDIUM** clinical need. The CYP may have potential for toilet training and should commence or continue a toilet skill development programme. Although they may need a short term supply of disposable containment products, until they have acquired the appropriate skills for formal toilet training, it may be more appropriate to provide washable containment products, which better support toilet training. These CYP will need regular (3 - 6 month) review.

Up to 16: Indicates a **LOW** clinical need. These CYP may respond positively to a toilet training programme with regular review (at least monthly). It may not be appropriate to supply containment products, as prolonged use of disposable containment products in this group has been found to delay toilet training. In some circumstances it may be appropriate to provide washable products

Exceptions

There will always be exceptions within the scoring system and 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 cogenital ano-rectal anomalies and ongoing soiling (such as those with imperforate anus, or Hirschsprung's disease), who may score LOW but may be eligible for disposable containment products, while they are waiting for corrective surgery or treatment intervention.

There may be other CYP who score HIGH, because they have not been exposed to a toileting routine previously and therefore lack awareness of their bowel or bladder. Many of these CYP progress well on a toilet training programme and therefore it would be detrimental to them to provide disposable containment products, which would further delay toilet training. It is important to use sound clinical judgement.

Appendix 3b PAEDIATRIC ASSESSMENT TOOL FOR ISSUING OF CONTAINMENT PRODUCTS

Child's Name:	Date of Birth:		SCORE			
				> 30	HIGH – consider a disposable product local policy)	(according to
Assessment completed by:	Date of assessment:		17 – 29	MEDIUM – may be able to be toilet transformed to consider 2 piece disposable of product short term (according to local	r washable	
			< 16	LOW - consider toilet training programme and try removal of disposable product (if worn)		
						Score
BLADDER /BOWEL MATURITY						
(a) Bladder function – bladder emptied						
1 More than once per hour,		3	Check fluid intake – adjust if necessary If frequency persists > aged 5 yrs consider assessment for OAB			
2 Between 1-2 hourly		2	Indication of developing bladder maturity			
3 More than 2 hourly		0	Maturing bladder – consider toilet training readiness			
(b) Bowel function						
1 Opens bowels more than three times a day		3	Exclude underlying constipation			
2 Does not always have normally formed bowel movements i.e.		2	Address underlying bowel problem before commencing toilet training			
is subjected to constipation or diarrhoea			(check Bristol Stool Form score)			
3 Has regular normally formed bowel movements		0	Mature bowel – consider toilet training readiness			
(c) Night-time wetting						
1 Usually i.e. most or every night		3	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		2	Indication of developing bladder maturity			
3 Rarely/Never i.e. is usually dry at night		0	Mature bladder – consider toilet training			
(d) Night-time bowel movements						
1 Occur more than once per week		3	Assess for underlying constipation – treat as appropriate			
2 Never occurs		0	Mature bowel			

INDEPENDENCE / AWARENESS			SCORE
(e) Sitting on the toilet			
1 Afraid or refuses to sit	4	Consider behaviour modification programme	
2 Sits with or without help	2	Liaise with O.T if necessary re toilet adaptation/equipment	
4 Sits without help for long enough to complete voiding	0	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	4	Consider introducing strategies to raise awareness of wet/dry/soiled	
2 Gives some indication of need to go to the toilet	2	Introduce positive reinforcement for target behaviour	
3 Sometimes goes to or asks for toilet of own accord	0	Consider formal toilet training programme	
(g) Handling clothes at toilet			
1 Cannot handle clothes at all	3	If child physically able introduce programme to encourage child to pull pants up/down independently	
2 Attempts or helps to pull pants up/down	2	Introduce positive reinforcement for target behaviour	
3 Pulls clothes up and down without help	0	Consider toilet training readiness	
BEHAVIOUR			
(h) Bladder control			
1 Never or rarely passes urine on toilet/potty	3	Complete baseline wetting/soiling chart to identify voiding interval and then start toilet sitting at time when bladder more likely to be full	
2 Passes urine on toilet sometimes	2	Consider removal of nappy (if worn) and introduction of formal toilet training programme	
3 Can initiate a void on request	0	Good evidence of bladder maturity commence on toilet training	
(i) Bowel control		programme	
1 Never or rarely opens bowels on toilet/potty	3	Complete baseline wetting/soiling chart to identify frequency of bowel movements and then start toilet sitting at a time when bowel more likely to be emptied e.g. after meals	
2 Opens bowels on toilet sometimes	2	Consider toilet training readiness	
3 Opens bowels on toilet every time	0	Evidence of bowel control consider formal toilet training	
(j) Behaviour problems, that interfere with toileting process	e.g. screa		
1 Occurs frequently, i.e. once a day or more	4	Consider liaison with LD team/CAHMS re behaviour modification programme	
2 Occurs occasionally, i.e. less than once a day	2	Consider assessment to identify 'trigger' factors for behaviour e.g. sound of hand dryer	
3 Never occurs	0	Check bladder/bowel maturity and consider toilet training readiness	1
(k) Response to basic commands, e.g. "come here",	I	· · · · · · · · · · · · · · · · · · ·	4
1 Never/ Occasionally responds to commands	4	Consider introducing 'routine/social stories' to gain co-operation	
2 Usually responds	0	Consider toilet training readiness	1

APPENDIX 4: TOILET TRAINING PATHWAY



APPENDIX 5: PROVISION OF CONTAINMENT PRODUCTS PATHWAY



Appendix 6: Fluid advice

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

- Caffeinated drinks, including tea, coffee, hot chocolate and coke 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 will need to increase their fluid intake if doing lots of exercise (including sports, playing out and school playtimes), or if the weather 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.
- CYP need more water when they are very active, or if the weather or environment is hot.
- Overweight CYP may also need more water.

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

Appendix 7: Strategies to manage incontinence

When assessing a CYP who is unable to toilet train for products, clinicians should consider all options available to ensure the most appropriate contaiment 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 to the possibility of options other than a one piece nappy-style product early. The following are all available and may be successfully used in CYP:

- Two piece disposable products
 - Disposable pads of differing sizes and absorbencies. These need to be combined with a closely fitting fixation pant. Fixation pants are available from disposable containment product companies, but the smallest sizes may be too large for smaller children. Children may require the 'premium' designs as these offer enhanced fixation and should be considered for children 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)
- 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 product provided should meet assessed clinical need. It is anticipated that the needs of most CYP who require a one piece disposable product will be met by the traditional shaped product.
- Sheaths may be appropriate for urinary incontinence in boys.
- 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 (velcro or popper side seams on trousers and underwear) facilitate toielting in children who use wheelchairs. These can avoid more time consuming hoisting onto toilets
- Washable pants
 - Washable pants with varying amounts of absorbency and/or waterproofing are available from a range of manufacturers. Not only do these help to promote toilet training, but they can be used to manage occasional incontinence or family concerns about wetting when away from home e.g. when on public transport
 - Washable pants come in a variety of styles including those with popper at the side seams for wheelchair users
- Disposable pads/bedmats
 - Disposable pads or bedmats can be used to protect bedding, but also chairs, school bus seats etc for children who are toilet training.
- Washable pads/chair/mattress protectors
 - Washable pads with varying amounts of absorbency can be used to protect bedding, chairs etc during toilet training or for children who continue to have occasional wetting after toilet training

Appendix 8: Abbreviations

- CCG Clinical Commissioning Group
- CE chief executive
- CYP children and young people
- DOH Department of Health
- GP general practitioner
- HCP health care professional
- NHS National Health Service
- NICE National Institute for Health and Care Excellence