

# CYLCHLYTHYR IECHYD CYMRU



Dyddiad Cyhoeddi: 15.09.2017

Llywodraeth Cymru  
Welsh Government

**STATWS: GWEITHREDU**

**CATEGORI: ANSAWDD A DIOGELWCH**

**Teitl:** Canllawiau ar ofalu am blant a phobl ifanc sydd â phroblemau ymataliaeth

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Gadeiryddion BILlau  
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Tîm Cyfathrebu AIGC  
Tîm Digidol AIGC  
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**Dogfen(nau) amgaeedig:** Dim

1. Mae Cylchlythyr hwn yn rhoi canllawiau i fyrddau iechyd ar gyfer darparu cynhyrchion ymataliaeth i helpu plant a phobl ifanc sydd â phroblemau ymataliaeth.
2. Mae'r Canllawiau a Chynllun Gofal Cymru Gyfan ar Ymataliaeth i Blant a Phobl Ifanc yn cael eu diddymu a'u disodli.
3. Bydd Canllawiau newydd ar gyfer darparu cynhyrchion ymataliaeth i helpu'r plant a'r bobl ifanc hyn yn cael eu rhoi ar waith yn lle'r canllawiau blaenorol.
4. Mae helpu plant a phobl ifanc i allu ymatal yn hanfodol bwysig. Dylai pob plentyn a pherson ifanc gael cymorth i gyrraedd ei lefel uchaf o allu i ymatal.
5. Ni ddylid ond darparu Cynhyrchion ymataliaeth i helpu gyda phroblemau ymataliaeth ar ôl cynnal asesiad llawn a phan nad yw'n bosibl i hyfforddiant toiled lwyddo.
6. Mae'n hanfodol bod y gweithwyr iechyd proffesiynol hynny sy'n cynnal asesiad o allu unigolyn i elwa ar hyfforddiant toiled ac o'r angen i ddarparu cynhyrchion ymataliaeth i blant a phobl ifanc na allant elwa ar hyfforddiant toiled, neu sydd â phroblem ymataliaeth ysgarthol neu wrinol, yn weithwyr iechyd sydd â digon o hyfforddiant a phrofiad i fod yn gymwys i gynnal asesiadau o'r fath.
7. Mae Canllawiau a Chynllun Gofal Cymru Gyfan ar Ymataliaeth i Blant a Phobl Ifanc, sydd ar waith ar hyn o bryd, yn cynnwys datganiad sy'n dweud mai pedwar o'r padiau hyn yw uchafswm nifer y cynhyrchion ymataliaeth y ceir eu darparu o fewn 24 awr.
8. Cafodd y datganiad hwn ei herio gan asiantaethau allanol sy'n cynrychioli buddiannau plant. Y teimlad oedd bod y datganiad yn anghyson ag egwyddorion cyfraith gyhoeddus; ei fod yn mynd yn groes i'r angen i gynnal urddas plant; ac nad oedd yn ystyried yr angen i gynnal asesiad llawn.
9. Nid yw'r canllawiau presennol yn bodloni Safon Iechyd a Gofal 4.1 Llywodraeth Cymru sy'n dweud y dylai gofal barchu urddas; y dylai gofal mewn perthynas ag ymataliaeth fod yn ofal priodol sy'n parchu preifatrwydd; ac y dylid darparu cymorth prydlon mewn modd sy'n bodloni anghenion penodol yr unigolyn.
10. Mae'r canllawiau newydd yn rhoi sylw i hyn ac maent yn cynnwys datganiad sy'n dweud mai 4 fyddai nifer mwyaf y mathau hyn o gynnyrch y dylid eu darparu o fewn 24 awr fel arfer, ond yn y pen draw y dylai'r nifer fodloni'r anghenion fel y maent wedi eu hasesu.
11. Mae Fforwm Ymataliaeth Cymru Gyfan wedi mynd ati i adolygu Canllawiau a Chynllun Gofal Cymru Gyfan ar Ymataliaeth i Blant a Phobl Ifanc ac wedi argymhell y dylid disodli'r canllawiau presennol gyda'r *'Guidance for the provision of continence containment products to children and young people'* (2016) er mwyn cael gwared ar yr anghysondeb yn y canllawiau gwreiddiol.
12. Mae'r *'Guidance for the provision of continence containment products to children and young people'* yn ddogfen sydd wedi cael ei datblygu ar y cyd a'i chymeradwyo gan amrywiaeth o sefydliadau o bob rhan o'r DU.

13. Cyhoeddwyd y Canllawiau hyn ar gyfer GIG Lloegr yn 2016, a bellach maent yn cael eu mabwysiadu a'u rhoi ar waith gan GIG Cymru.

# WELSH HEALTH CIRCULAR



Llywodraeth Cymru  
Welsh Government

**Issue Date:** 15.09.2017

**STATUS: ACTION**

**CATEGORY: QUALITY & SAFETY**

**Title:** Guidance for the care of children and young people with continence problems

**Date of Expiry / Review:** 17.10.2018

**For Action by:**

LHB Chairs  
LHB Chief Executives  
LHB Board Secretaries  
LHB Medical Directors  
LHB Directors of Nursing

**For Welsh Government Action (or information):**

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DHSS Comms Team  
DHSS Digital Team  
DHSS Delivery & Finance Team  
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**Action required by:** October 2017

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**Enclosure(s):** None

1. This circular provides guidance for health boards in respect of the provision of continence containment products for children and young people.
2. The current All Wales Children and Young People's Continence Guidance and Care Pathway is being removed and replaced.
3. The new 'Guidance for the provision of continence containment products to children and young people' supersedes the previous guidance.
4. Enabling children and young people to achieve continence is crucially important. All children and young people should receive support to achieve their maximum continence potential.
5. Continence containment products should only be supplied following a full assessment and only when toilet training is not achievable.
6. 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.
7. The current All Wales Children and Young People's Continence Guidance and Care Pathway contains the statement '*The maximum number of products issued will be four pads per 24 hours*'.
8. This statement has been challenged by external agencies representing children's interests. It is felt this statement is inconsistent with public law principles and a breach of children's' dignity and it does not take into account the need for a full assessment.
9. The existing guidance does not meet the Welsh Government's Health and Care Standard 4.1 on dignified care which specifies that 'continence care is appropriate and discrete and prompt assistance is provided as necessary taking into account people's specific needs'
10. The new guidance addresses this and contains the statement '*The number of products issued per 24 hours would normally not exceed four, but provision should meet assessed need.*'
11. The All Wales Continence Forum have undertaken work to review the All Wales Children and Young People's Continence Guidance and Care Pathway and have recommended that the current guidance should be replaced with the newly published 'Guidance for the provision of continence containment products to children and young people' (2016) thereby removing the discrepancy in the original guidance.
12. *The 'Guidance for the provision of continence containment products to children and young people'* is a consensus document developed and supported by a range of organisations from across the UK.
13. The Guidance was released in 2016 to NHS England organisations and is now being adopted for use in NHS Wales.

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

A consensus document

2016



Document Purpose	Guidance
Document name	Guidance for the provision of continence containment products for children and young people:a consensus document
Publication date	<i>August 2016</i>
Target Audience	CCG Clinical Leads, Health Board Clinical Leads, Health and Social Care Board Clinical Leads, Foundation Trust CE's, Directors of Nursing, Local Authority CE's, NHS Trust Boards, Allied Health Professionals, GP's, Paediatricians, Directors of Nursing, Directors of Children's Services, NHS Trust CE's, Continence Service Leads, members of the public including children and young people
Additional Circulation List	Continence Services
Description	Consensus guidance document regarding the provision of continence containment products to children and young people, to ensure all children and young people who have not toilet trained or have urinary or faecal incontinence, undergo a comprehensive assessment and have access to an equitable service
Cross reference	Commissioning Paediatric Continence Services (PCF 2015) Excellence in Continence Care (NHS England 2015) 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 people (2013) NICE QS62 Constipation in children and young people (2014) NICE QS70 Bedwetting in children and young people (2014)
Superseded Docs (if applicable)	N/A
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Review Date	2018

## 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) are currently producing 'Minimum Standards for Paediatric Continence Care in the U.K.', which may be used alongside this document.

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 done 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  
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## 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, 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 clinical expertise.

Assumptions should not be made regarding the ability, or lack of ability of children & 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 & 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 4, but provision should meet assessed need

- The use of two-piece system (pad & 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. These children 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

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August 2016

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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 therefore, providing disposable containment products may delay toilet training (Tarbox et al 2004) and is 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 post code 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 recognised that current bladder and bowel (continence) services for CYP are inequitable with very patchy service provision. In 2004 the Children's National Service Framework found that *...services are currently fragmented and often made up of a collection of professionals providing different levels of intervention in both the community and hospital. This currently results in big gaps in service provision, inappropriate hospital/specialist referrals and a waste of money in providing products instead of expertise.* (NSF pt 6 2004). There has been little, if any improvement. The NHS England document Excellence in Continence Care (2015) refers to an audit by the Healthcare Quality Improvement Partnership (HQIP, 2010) which revealed that *'...the quality of continence care remains variable accross the country...'* In 2014 the Paediatric Continence Forum undertook a Freedom of Information survey of Clinical Commissioning Groups (CCGs). This showed that only 39% of CCGs commissioned fully integrated children's continence services with only 20% being led by a specialist paediatric continence advisor (PCF 2015).

However, the majority of CYP with straight forward 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 (2015) *... 'the provision of continence products to this group of children should be the exception rather than the rule'*.

## 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 (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 also reduce self-esteem at a crucial time for a CYP's emotional development and risk their exclusion from normal social interaction, such as overnight school trips or sleepovers. The absence of pro-active toilet training 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), 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 provision 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 Adult Product Provision document for those over the age of 19 years.

### **1.6 Guideline Development Group**

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## 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, N Ireland and Wales, and parents, and amended a number of times until a consensus was agreed.

## 1.8 External reviewers

Dr. Anne Wright  
Consultant Paediatrician in charge of Children's Bladder Clinic  
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All Wales Continence Forum  
Association of Continence Advice (ACA)  
Community Practitioners and Health Visitors Association (CPHVA)  
British Association Paediatric Urology & Continence Nurses (BAPUCN)  
ERIC Professional 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)  
PromoCon 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 between the ages of 2-3 years. This is in anticipation of a formal structured toilet training programme commencing as soon as full bowel and bladder maturity is reached (see appendix 4). Those who have difficulty in attaining bladder and bowel maturity 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 arbitrarily 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).

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. neuropathic bladder and 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 maintain 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 congenital 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 PromoCon web site [www.promocon.co.uk](http://www.promocon.co.uk)  
<http://www.disabledliving.co.uk/Promocon/Publications/Children/Toilet-Training> and on the ERIC website at: [www.eric.org.uk](http://www.eric.org.uk)  
[http://www.eric.org.uk/PottyTraining/potty\\_training](http://www.eric.org.uk/PottyTraining/potty_training)  
<http://www.eric.org.uk/InformationZone/Leafletsandresources>

## 2.12 Containment product provision

Once 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.

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 DLA)

The following link has lists of where a whole range of products can be found

<http://www.disabledliving.co.uk/Promocon/Products/Product-Information-Sheets>

### 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 their child's needs could change, and that the product order may be suspended until the review has been carried out. 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 any unused products 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 fits 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 choose 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.

It is recognised that different NHS Trusts, CCGs, Health Boards (Scotland and Wales) or Health and Social Care Boards (Northern Ireland) will have contracts with different containment product companies. CYP would normally be assessed for products from an agreed formulary within the range supplied by their contracted company. However, each company has containment products that fit slightly differently from others and no one company will be able to meet the needs of all CYP with incontinence. Therefore, the CYP should be provided with a containment product that meets their need.

Most NHS Trusts, CCGs, Health Boards (Scotland and Wales) or Health and Social Care Boards (Northern Ireland) will have a basic formulary, from which the needs of most CYP can be met. 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.

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. This includes a variety of styles of washable and disposable containment products, such as washables with popper sides, for wheelchair users and belted disposable containment products, as well as sheaths for boys. 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 (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 would be given by the level two service i.e. the Children's 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 CYP's 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.

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 to be 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 ('LAC' children) 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) outlines the characteristics of good transition service, 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

### 3.1 References

- Bakker NJ and Wyndaele JJ (2000) Changes in the toilet training of children during the last 60 years: the cause of an increase in lower urinary dysfunction? *BJU International* 86 (3) 248-52
- Barone J, Jasutkar N and Schneider D (2009) Later toilet training is associated with urge incontinence in children *Journal of Paediatric Urology* 5 (6) 458-61
- Bonner L and Wells M (2008) Effective Management of Bladder and Bowel Problems in Children London, Class Publishing
- Brown, F and Peace, N (2011) Teaching a child with challenging behaviour to use the toilet: a clinical case study *British Journal of Learning Disabilities* 39 321-326
- Butler R.J. and Swithinbank L. (2007) Nocturnal Enuresis and Daytime Wetting: a Handbook for professionals Bristol, ERIC
- Dept for Work and Pensions (2013) Family Resources Survey: United Kingdom 2011/12 p61
- DOH (2008) Transition: moving on well: A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability.
- Duel BP et al (2003) A survey of voiding dysfunction in children with attention hyperactivity disorder. *Journal of Urology* 170 (4 pt2), 1521-3
- Ersoz M et al (2009) Non invasive evaluation of lower urinary tract function in children with cerebral palsy *American Journal of Physical Medicine and Rehabilitation* 88(9) 735-741
- Hyams G et al (1992) Behavioural continence training in mental handicap: a ten year follow up study *Journal of Intellectual Disabilities Research* 36 (6) 551-558
- Ill Child: National Service Framework for Children and Young People part 6 (2004)  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/199954/National Service Framework for Children Young People and Maternity Services - Children and Young People who are Ill.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/199954/National_Service_Framework_for_Children_Young_People_and_Maternity_Services_-_Children_and_Young_People_who_are_Ill.pdf)
- Jansson et al (2005) Voiding pattern and acquisition of bladder control from birth to age 6 years-a longitudinal study *Journal of Urology* 174 (1) 289-93
- Kaerts N et al (2012) Readiness signs used to define the proper moment to start toilet training: a review of the literature. *Neurourology and Urodynamics* 31 4 437-440
- Kroeger K, Sorensen R (2010) A parent training model for toilet training children with autism. *Journal of Intellectual Disability Research* 54,6, 556-567
- NHS England (2015) Excellence in continence care: Practical guidance for commissioners, providers, health and social care staff and information for the public  
<https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/11/EICC-guidance-final-document.pdf>

RCN (Nov 2006) Paediatric Assessment of Toilet Training and readiness and the issuing of products

Richardson D (2016) Toilet training for children with autism *Nursing Children and Young People* 28 2 16-22

Rogers J (2013) Daytime wetting in children and acquisition of bladder control. *Nursing Children and Young People*. Jul;25(6):26-33.

Rogers, J and Patricolo, M (2014) Addressing continence in children with disabilities *Nursing Times* 110 43 22-24

Roijen LE et al (2001) Development of bladder control in children with cerebral palsy *Developmental Medicine and Child Neurology* 43 (2) 103-7

Schum T, Kolb T, McAuliffe T, Simms M, Underhill R and Lewis M (2002) Sequential acquisition of toilet training skills: a descriptive study of gender and age differences in normal children *Paediatrics* 109 (3) 1-7

Simon J and Thompson R (2006) The effects of undergarment type on the urinary continence of toddlers *Journal of Applied Behavior Analysis* 39 (3) 363-8

Stenson, A and Danaher, (2005) Continence issues for people with learning disabilities *Learning Disability Practice* 8, 9 10 - 14

Tarbox et al (2004) Extended diaper wearing: effects on continence in and out of the diaper *Journal of Applied Behavior Analysis* 37 97-100

Taubman B, Blum NJ and Nemeth N (2003) Children who hide while defecating before they have completed toilet training *Archives of Paediatrics and Adolescent Medicine* 157 (12) 1190-92

Van Laecke E et al (2001) Voiding disorders in severely mentally and motor disabled children *Journal of Urology* 166 (6), 2404-6

Von Gontard, A et al (2011) Psychological and psychiatric issues in urinary and fecal incontinence *Journal of Urology* 185 1432-1437

White H (2001) Continence products in the community: towards a more client centred service *Professional Care of Mother and Child* 11(5) 120-3

### 3.2 Suggested further reading

Assessment for toilet training readiness and issuing of products. RCN (2006)  
[www.rcn.org.uk/ data/assets/pdf file/0005/78728/003103.pdf](http://www.rcn.org.uk/data/assets/pdf_file/0005/78728/003103.pdf)

*National Service framework for Children and Young People – Part 6 / page 30 / continence (2004)*  
[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4104032.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4104032.pdf)

*Good Practice in Paediatric Continence Services: Benchmarking in Action (2003)*

[http://collections.europarchive.org/tna/2008112112652/www.cgssupport.nhs.uk/PDFs/articles/good\\_practice\\_paediatric\\_continence\\_services.pdf](http://collections.europarchive.org/tna/2008112112652/www.cgssupport.nhs.uk/PDFs/articles/good_practice_paediatric_continence_services.pdf)

Excellence in Continence Care. Practical guidance for commissioners, providers, health and social care staff and information for the public. (2015) <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/11/EICC-guidance-final-document.pdf>

Understanding bladder & bowel comorbidities in children and young people with additional needs – the importance of assessment  
<http://www.disabledliving.co.uk/DISLIV/media/publicationpdf/The%20Platinum%20Trust%20Resources/17549-bladder---bowel.pdf>

Paediatric Continence Commissioning Guide. A handbook for commissioning and running of paediatric continence services (2015) <http://www.paediatriccontinenceforum.org/wp-content/uploads/2015/09/Paediatric-Contiennce-Commissioning-Guide-2014-PCF.pdf>

Supporting pupils at school with medical conditions. Statutory guidance for governing bodies of maintained schools and proprietors of academies in England (Dec 2015)  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/484418/supporting-pupils-at-school-with-medical-conditions.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/484418/supporting-pupils-at-school-with-medical-conditions.pdf)

### 3.3 Further information

[www.promocon.co.uk](http://www.promocon.co.uk) – PromoCon can provide impartial information and advice regarding all aspects of bladder & bowel care including products, equipment and services.

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 will be available from October 2016 at [www.eric.org.uk](http://www.eric.org.uk). Contact [info@eric.org.uk](mailto:info@eric.org.uk) for further information.

### 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 PromoCon

## 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 pad 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.

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

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

CHILD'S NAME: \_\_\_\_\_

DOB: \_\_\_\_\_

DATE BEGUN: \_\_\_\_\_

	DAY 1		DAY 2		DAY 3		DAY 4		DAY 5	
DATE										
TIME	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
7.00										
8.00										
9.00										
10.00										
11.00										
12.00										
1.00										
2.00										
3.00										
4.00										
5.00										
6.00										
7.00										
8.00										

## 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/unstable 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, for the CYP who 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 therefore 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 bladder assessment is to identify a mature bladder that is able to complete a normal micturition cycle. In order for this to be identified the frequency of voids needs to be recorded. With modern disposable nappies this is difficult for the family to do unless the nappy is left off completely for a number of days which is not practical. The family should therefore be advised on the following strategy:

They are to pick a number of days, preferably at least three, when they will be at home and either put cotton pants on the CYP with the nappy on top, or place a folded kitchen towel inside the nappy (one that does not disintegrate when wet). The parent or carer then checks the CYP's nappy at least every hour and records whether the CYP is wet or dry. A sample toileting chart to facilitate recording is available at appendix 1b. An infant's bladder holds approx 30 mls of urine and this increases by 30mls per year, so by the time the child is around 3 years of age we would expect a bladder capacity of about 120mls with a voiding frequency of about 6-8 per day. So a 3 year old with a maturing bladder should be able to stay dry for at least 2 hours. A frequency of more than 8 voids per day may indicate an unstable bladder and may warrant further investigation, if still occurring at the age of 4-5 years. Any other issues, such as urinary tract infections or continuous dribbling of urine, would warrant earlier investigations.

Many CYP with special needs are prone to developing constipation for a variety of reasons. The bowel assessment should help to identify underlying bowel problems 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.

The family should also record the CYPs fluid intake for the duration of the monitoring period (at least three days) and record this. It will then be apparent whether the CYP is having an appropriate amount to drink each day and if not, 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.

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 around 1½ - 2 hours
- A bowel that is not constipated
- An ability to sit on toilet/potty for sufficient time (with or without support or toilet adaptations)

It must be remembered that 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 / unstable 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<sup>st</sup> assessment: .....

Date of 2<sup>nd</sup> assessment: .....

Date of 3<sup>rd</sup> assessment: .....

		Assess 1	Assess 2	Assess 3
<b>(a) Bladder function –bladder emptied</b>		√	√	√
1 More than once per hour	↓			
2 Between 1-2 hourly				
3 More than 2 hourly				

<b>(b) Bowel function</b>				
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				
3 Has regular normally formed bowel movements				

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

<b>(d) Night-time bowel movements</b>				
1 Occur frequently ie every night	↓			
2 Occur occasionally ie has some clean nights				
3 Never occurs				

<b>INDEPENDENCE</b>				
<b>(e) Sitting on the toilet</b>				
1 Afraid or refuses to sit	↓			
2 Sits with distraction or encouragement				
3 Sits briefly with or without toilet adaptation				
4 Sits long enough to complete voiding or bowel action				

<b>(f) Going to the toilet</b>				
1 Gives no indication of need to go to the toilet	↓			
2 Gives some indication of need to go to the toilet				
3 Sometimes goes to or indicates need for toilet of own accord				

		Date	Date	Date
<b>(g) Handling clothes at toilet</b>		√	√	√
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				

<b>Other components</b>				
<b>(h) Bladder control</b>				
1 Never or rarely passes urine on toilet/potty	↓			
2 Passes urine on toilet sometimes				
3 Passes urine on toilet every time				
4 Can initiate a void on request				

<b>(i) Bowel control</b>				
1 Never or rarely opens bowels on toilet/potty	↓			
2 Opens bowels on toilet sometimes				
3 Opens bowels on toilet every time				

<b>(j) Behaviour problem, that interferes with toileting process eg screams when toileted, faecal smears</b>				
1 Occurs frequently	↓			
2 Occurs occasionally, ie less than once a day				
3 Never occurs				

<b>(k) Wears nappies, disposable pants or similar</b>				
1 Yes	↓			
2 No				

<b>(l) Toilet</b>				
1 Requires toileting aids or adaptations	↓			
2 Uses normal toilet/potty				

<b>(m) Response to basic commands, eg "come here"</b>				
1 Never responds to commands	↓			
2 Occasionally responds				
3 Always responds				

<b>(n) Diet</b>				
1 Refuses/unable to eat any fruit/veg	↓			
2 Will occasionally eat fruit/veg each day				
3 Eats adequate amount (age+5 = grams fibre)				

<b>(o) Fluid intake</b>				
1 Drinks little (sips, small drinks or less than 3 good drinks)	↓			
2 Drinks moderate amount (4-5 small to medium drinks)				
3 Drinks good amount (6+ good size) drinks				

## 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.**

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, with the associated benefits of the CYP achieving their potential, improving independence, self-esteem, self-confidence and in reducing stress to them and their family.

### 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 long term 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. The CYP may need a short term supply of disposable containment products, until they have acquired the appropriate skills for formal toilet training. However they may also be appropriate for the provision of 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.

### 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 congenital 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 have total lack of 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.**

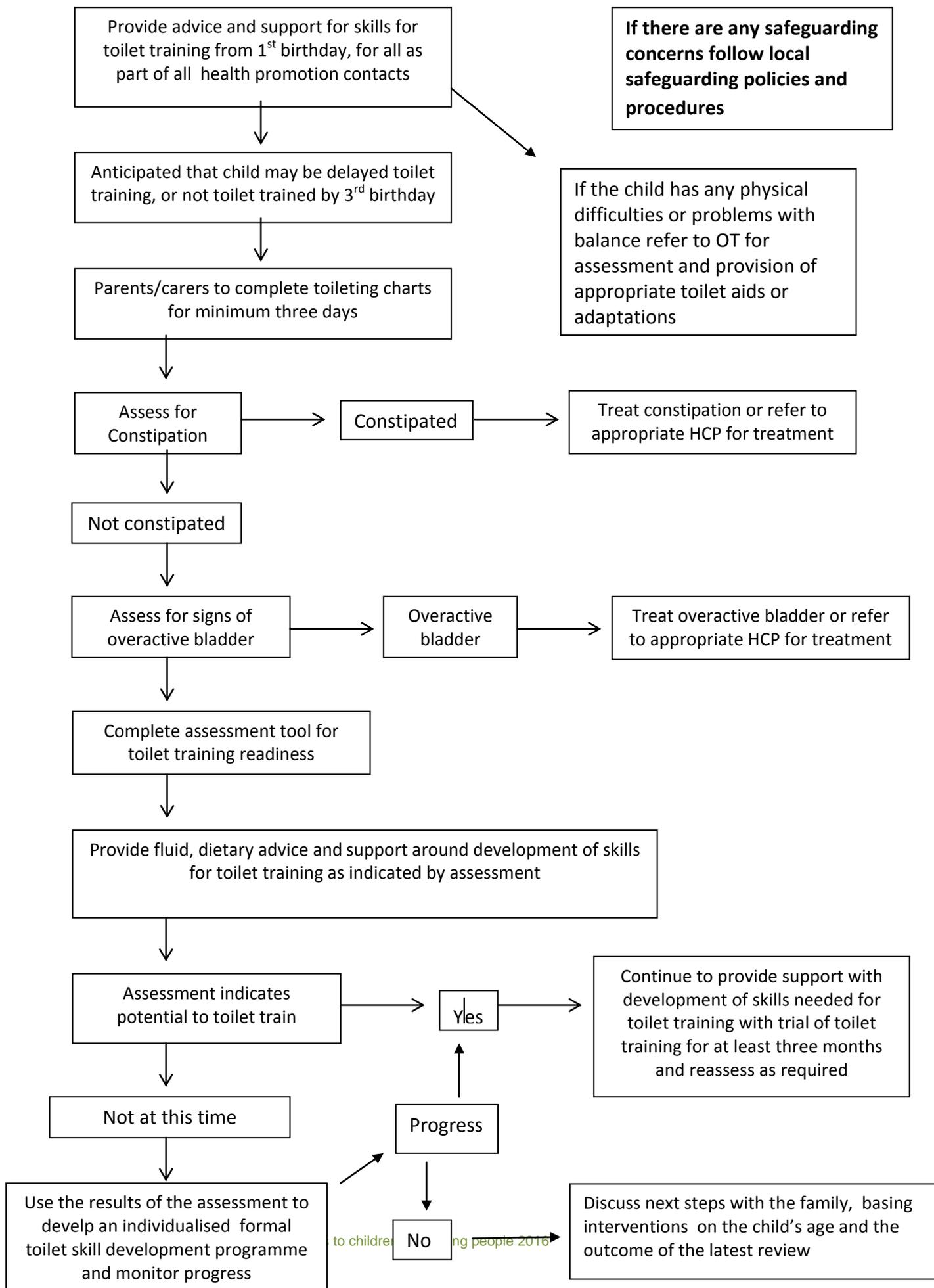
Appendix 3b

**PAEDIATRIC ASSESSMENT TOOL FOR ISSUING OF CONTAINMENT PRODUCTS**

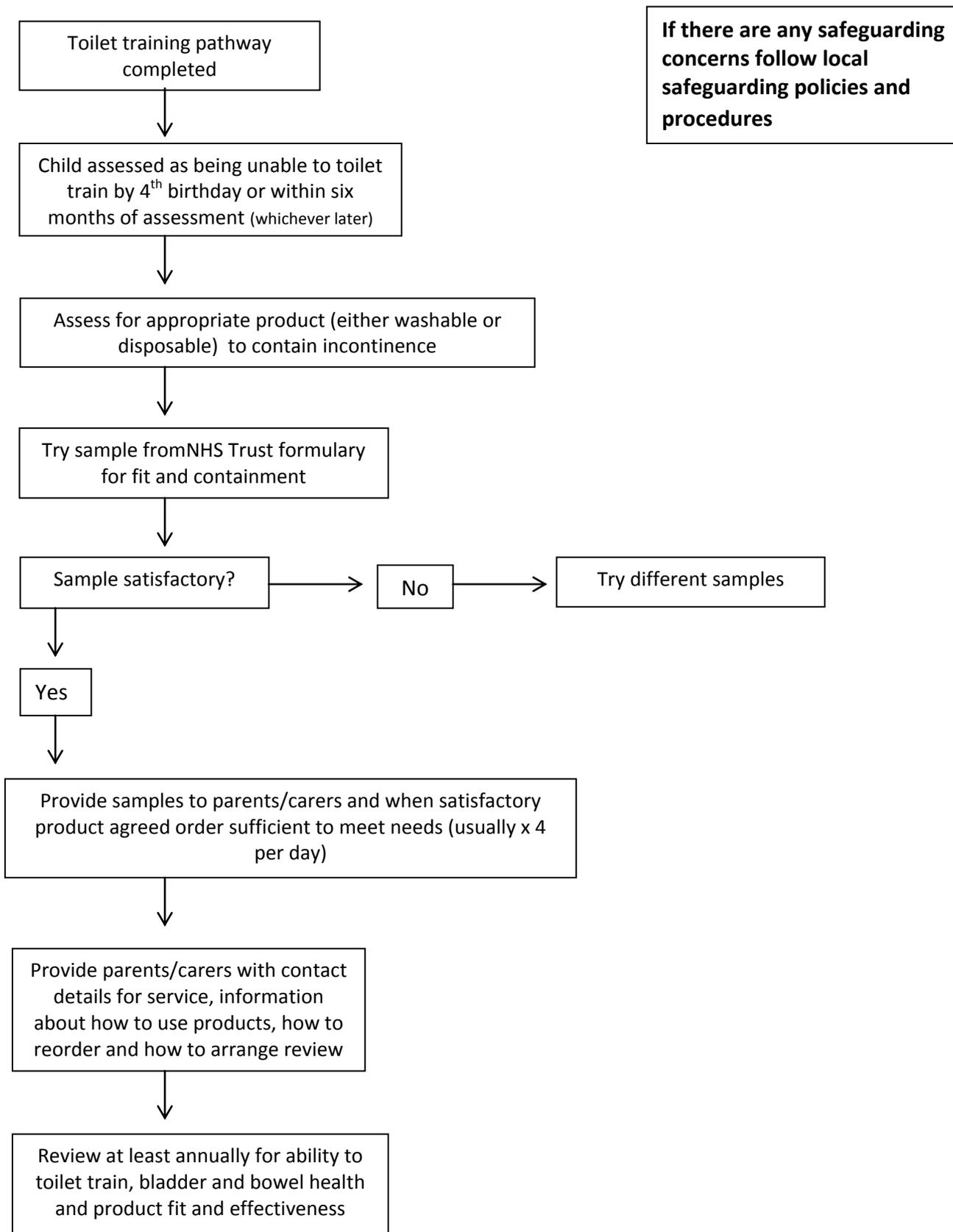
<b>Child's Name:</b> .....	<b>Date of Birth:</b> .....	<b>SCORE</b>	
<b>Assessment completed by:</b> .....	<b>Date of assessment:</b> .....	> 30	<b>HIGH</b> – consider a disposable product (according to local policy)
		17 – 29	<b>MEDIUM</b> – may be able to be toilet trained but may need to consider 2 piece disposable or washable product short term (according to local policy)
		< 16	<b>LOW</b> - consider toilet training programme and try removal of disposable product (if worn)
			Score
<b>BLADDER /BOWEL MATURITY</b>			
<b>(a) Bladder function – bladder emptied</b>			
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>(b) Bowel function</b>			
1 Opens bowels more than three times a day	3	Exclude underlying constipation	
2 Does not always have normally formed bowel movements i.e. is subjected to constipation or diarrhoea	2	Address underlying bowel problem before commencing toilet training (check Bristol Stool Form score)	
3 Has regular normally formed bowel movements	0	Mature bowel – consider toilet training readiness	
<b>(c) Night-time wetting</b>			
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	
<b>(d) Night-time bowel movements</b>			
1 Occur more than once per week	3	Assess for underlying constipation – treat as appropriate	
2 Never occurs	0	Mature bowel	

<b>INDEPENDENCE / AWARENESS</b>			SCORE
<b>(e) Sitting on the toilet</b>			
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	
<b>(f) Going to the toilet</b>			
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	
<b>(g) Handling clothes at toilet</b>			
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	
<b>BEHAVIOUR</b>			
<b>(h) Bladder control</b>			
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 programme	
<b>(i) Bowel control</b>			
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	
<b>(j) Behaviour problems, that interfere with toileting process e.g. screams when toileted</b>			
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	
<b>(k) Response to basic commands, e.g. "come here",</b>			
1 Never/ Occasionally responds to commands	4	Consider introducing 'routine/social stories' to gain co-operation	
2 Usually responds	0	Consider toilet training readiness	

## 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.

Suggested intake of water-based drinks per 24 hours according to age and sex (N.B. Dieticians or medical advice about fluid intake, where provided for individual CYP should be followed) (NICE 2010)

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

CYP need more water when they are very active, or if the weather or environment is hot. Overweight CYP may also need more water.

## Appendix 7: 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