



**Lancashire and  
South Cumbria**  
Integrated Care Board

# **Healthier Lancashire and South Cumbria Integrated Care System (ICS)**

## **Children and Young People's Continence Commissioning Framework**

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## 1. INTRODUCTION

Normal continence function is an important part of a child's/young person's development and their path to adult and independent living.

It is estimated that 6.4% of children/young people nationally have a continence problem<sup>1</sup> though this is expected to be significantly underestimated due to a lack of reporting because of stigma, embarrassment, or a belief that the problem will automatically resolve itself whilst the child grows and develops.

Continence difficulties include constipation, soiling (faecal incontinence), daytime wetting, bedwetting (enuresis) and problems or delay with toilet training. The majority of these are functional, that is they cannot be explained by anatomical, physiological, radiological, or histological abnormalities. Instead, it is believed they are caused by a complex inter-relationship of biological, developmental, genetic, and environmental factors. Structural (anatomical) or neuropathic causes are rare but need to be recognised early.

The negative impact for the child/young person of any continence difficulty should not be underestimated. Children/young people of all ages can be affected by continence difficulties. Children/young people with additional needs and those with neurodevelopmental disorders, such as attention deficit hyperactivity disorder and autism are particularly affected, but often neglected in the mistaken assumption that incontinence is part of their wider condition.

Continence problems occur at a formative time for children/young people and influence their health, wellbeing and emotional development. They are associated with reduced quality of life, affecting peer relationships and cause social isolation and feelings of difference. They are also a cause of reduced self-esteem, a sense of social stigma, distress, and behavioural disorders<sup>2</sup>. It is also noted that bullying, either as victim or perpetrator, is associated with increased lower urinary tract symptoms.<sup>3</sup>

Having an evidence based, person centred continence framework for the child/young person/parent/carer can lead to:

- Increased identification and prevention
- Improved patient experience and patient reported outcome measures
- Commissioning for value i.e., reduced prescription costs
- Reduced urgent and emergency care costs
- Ensuring a baseline paediatric continence assessment for all who need it
- Consistent offer for the child/young person/parent/carer across the Lancashire and South Cumbria system

The development of this Lancashire and South Cumbria Framework aims to:

- Improve the experience and outcomes for the child/young person/parent/carer when accessing continence services
- Improve access to specialist services
- Reduce variation that exists across the Healthier Lancashire and South Cumbria Integrated Care System

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<sup>1</sup> The Paediatric Continence Forum's Children's Continence Commissioning Guide 2019

<sup>2</sup> The Paediatric Continence Forum's Children's Continence Commissioning Guide 2019

<sup>3</sup> Ching C et al (2015) Bullying and lower urinary tract symptoms: Why the paediatric urologist should care about school bullying. *Journal of Urology* 193, 2: 650-654.

The Continence Framework describes ‘what good looks like’ putting the child/young person at the centre of their own care and to take a collaborative, integrated approach in care planning. It is intended to be used to ensure all areas across the HLSC ICS have the relevant services in place to provide the services needed by the child/young person/parent/carer.

The Continence Framework has been developed in partnership with range of stakeholders and networks and has had an extensive engagement and consultation process (details of these groups are listed within Appendix 1)

This Continence Framework will be the basis for all service and pathway provision for continence services for the child/young person/parent/carer across the ICS.

The Continence Framework outlines the three levels of care to ensure a robust pathway is in place to address the needs of those accessing services, based on the national continence framework guide.<sup>4</sup>

A flow chart of the framework can be seen within Appendix 2.

Throughout the review and the development of the Framework, access to products was a significant area of feedback. The key outcome of this Framework (based upon evidence) is that there should be no arbitrary cap in the number of products provided where needed. Rather a clinically assessed need is to be undertaken, with products provided as indicated

There are some indicative numbers (based upon guidance from the paediatric continence forum) within this document, however these are to be used as a guide only and not intended to be utilised as an absolute figure for providing products.

It is also acknowledged that there may be a difference between the clinically assessed need and what the child/young person/parent/carer sees as the need. Here a collaborative approach is anticipated from the outset, so families are part of the journey with the clinical teams, so to maintain a holistic and person-centred approach to the care provided.

## **2. OVERVIEW OF THE FRAMEWORK**

The purpose of this Continence Framework is to determine the assessment process, the care levels, and the criteria for provision of continence products to the child/young person with intractable urinary and faecal incontinence for children and young people aged 5 years and over. The services should however be flexible to respond to needs in the under 5 cohort where clinically necessary and appropriate.

The Framework promotes assessment and treatment of continence problems and where possible ensure that provision of continence products is based on individual clinical need in accordance with government guidance (*Department of Health (DoH) Good Practice in Continence Services, 2000 and Paediatric Continence Forum: Guidance for the provision of continence containment products to children and young people 2016*).

Effective treatment and resolution of urinary and faecal incontinence and promotion and achievement of continence for the individual is the primary aim. When this is not achievable the individual should have access to a high standard of health care and management methods to assist in the maintenance of quality of life, independence, and personal dignity.

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<sup>4</sup> The Paediatric Continence Forum’s Children’s Continence Commissioning Guide 2019

In accordance with the above mentioned guidance, thorough assessment, diagnosis, and treatment will be undertaken for every individual across the ICS with continence needs prior to provision of continence products.

Conservative management interventions such as pelvic floor exercises, bladder retraining, medication (bladder/bowel) should always be considered as a first line of treatment.

Training in continence assessment and initial treatment will be available to all assessing health care professionals via commissioned continence services. This will include annual updates to ensure the latest evidence-based practice is shared with assessors.

Products for the containment of incontinence can only be supplied following comprehensive assessment and/or review using an appropriate Continence Care Pathway

Provision of incontinence products is not means tested, provision is based on proven individual clinical need evidenced using the Paediatric assessment tool for issuing of continence products (Continence UK, 2021) (Appendix 3).

In assessing continence needs, the assessing health care professionals must ensure child/young person/parent/carer understand that product supply is based upon assessed clinical need and will be reviewed/monitored on an annual basis or if needs change.

### **3. CONTINENCE PATHWAY**

All children/young people aged 5 years and over registered with a General Practitioner in Lancashire & South Cumbria (including those in transit and temporarily registered) are eligible to access assessment of continence needs.

It would be an expectation that specialist provision (levels 2 and 3) is provided by the commissioned specialist services where the child/young person resides.

Children/young people will be assessed using the relevant paediatric assessment forms for urinary/bowel incontinence. (Appendix 4)

Children/young people over the age of 5 years (or under 5 in exceptional circumstances i.e., chronic constipation) who have a diagnosed medical condition, which is the cause of their incontinence, may be eligible to receive continence support if indicated if indicated, after a comprehensive assessment and care plan is undertaken by a relevant health care professional.

The setting for assessment may be in a community clinic, at home, or in an education setting depending on which is most appropriate. The child/young person/parent/carer will be involved in the assessment process along with other relevant health professionals.

All continence assessments and treatment plans for children/young people are reviewed by a nurse i.e., with the required competencies e.g., continence nurse, special school nurse, learning disability nurse prior to continence products being issued.

Who should assess children/young people?

Assessments for the child/young person must only be undertaken by a healthcare professional employed in a paediatric post, for example, health visitor, school nurse, continence nurse or community paediatric nurse with appropriate clearance to work with the child/young person, who can also demonstrate their competency and has undertaken additional training in initial

continence assessment and first line treatments. The healthcare professional must be formally employed by a recognised health care sector provider.

General practitioners (GP's) can be included within the overall support in assessing basic need for children or young people with continence needs.

### 3.1 Structure of Continence Care Services

Continence assessment and treatment is structured at three levels:

#### 3.1.1 Level 1 – First Line Support

- For the child/young person/parent/carer who need general continence advice, guidance or signposting, health care professionals will have access to resources to support at level 1
- Use of continence enquiry questions as part of the holistic assessment of children/young people both at core and needs led contacts
- Identify children/young people with incontinence, through an initial clinical assessment process and by using trigger questions opportunistically in all services for children/young people. 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 an initial paediatric continence assessment, if CYP are not toilet trained (appendix 3), or there are continence problems and an assessment has not already been done, or it is more than twelve months since the last assessment
- Help children/young people (where appropriate to age and understanding)/parents and/or carers to understand incontinence and the treatment options that are available.
- Offer individualised treatment in relation to the outcome of the assessment, in keeping with treatment care pathways and best practice guidance
- This level of assessment should be offered as part of a routine holistic health care review and can be carried out by any competent healthcare professional during their normal duties. Any concern following a response to a "trigger question" should always lead to an initial assessment. This applies to all children/ young people regardless of need
- Initial assessment will determine which treatment pathway the patient will follow or if referral [to Level 3] is indicated

#### 3.1.2 Level 2: - Paediatric Continence Services

- Undertakes comprehensive continence assessments and treats children/young people from 5 – 19 years (or in exceptional circumstances i.e., chronic constipation) with bladder and/or bowel problems and/or delayed toilet training, where universal Level 1 interventions have not resolved the issues
- Consists of an experienced and competent multidisciplinary team led by a paediatric continence nurse specialist to determine who is best placed to meet the child/young persons needs this includes special school nursing and learning disability services. Shared care arrangements may be in the best interests of the child/young person e.g., shared care between learning disability services and continence services for a child/young person with a learning disability experiencing continence problems
- Has clear and effective referral and care pathways from Level 1 services to Level 3 (secondary and tertiary care), as well as to other professionals and services e.g., paediatricians, education, allied health professionals, child and adolescent mental

health services (CAMHS), social care and local voluntary services, as the child's/young person's health, social or psychological situation warrants

- Provides specialist training, education and support to primary and community care staff delivering services at Level 1. This is to ensure that all staff are able to identify continence problems early and offer timely intervention. The Children's Community Continence Service also provide training and support to education staff to raise awareness of continence difficulties that may impact at nursery, school or college and ensure children/young people are supported appropriately
- Provides specialist training and education to parent/carers and education staff (trainee) to ensure the clinical needs of child/young person when in their care can be effectively and safely met, such as, but not limited to; clean intermittent catheterisation/mitrofanoff/specialist bowel treatments. Such treatments must have been initially assessed for and recommended by an appropriately trained Doctor, for example Consultant Paediatric Urologist. Training for Education staff will be complimented by an individualised health care plan that has been co-written by the Head teacher or a nominated member of school staff, such as SENCO and the Paediatric Continence Specialist. Any practical elements of training must include competency-based assessment of the trainee and the training requirements should be reviewed/refreshed annually or as clinical needs change. Where appropriate, the child/young person will aim to achieve self management or some level of involvement in their own care, with the appropriate support, training and guidance from the Specialist Continence service or tertiary centre. It is acknowledged that some children/young people will not achieve self-management and will require the support of appropriately trained adults life-long/or as long as the treatment is required.
- Issuing of containment product, only after the child/young person has undergone a comprehensive continence assessment (in collaboration with the Specialist Paediatric Continence service) and has undergone a 6 month toilet training programme<sup>5</sup> unless there are clear underlying medical or neurological reasons for lack of bladder/bowel control

### 3.1.3 Level 3: - Specialist Continence Provision

There are some situations where children/young people may require referral for a medical assessment to a paediatrician, or to specialist secondary or tertiary care, as per the local pathway. These include children/young people with 'red flag' symptoms indicating a serious underlying disorder, children/young people with recurrent febrile urinary tract infections and children suspected of maltreatment, as well as those children/young people who have not responded to optimal interventions and support at Level 2

## 3.2 RED FLAGS

The accessing practitioner would use appropriate knowledge and skills to highlight children/young people with red flag symptoms that will need onward/specialist referral and input.

The list below are examples (but not limited to) of what these may be.

### Wetting

- History of repeated UTIs

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<sup>5</sup> Bladder and Bowel UK 2021

- Child/young person (particularly girls) reported to always be wet during the day (continuous incontinence)
- Any reported straining to void or weak stream

#### Constipation/soiling

- Delay in passage of meconium >48 hours after birth.
- Symptoms in first few weeks of life
- Ribbon stools from birth
- Abdominal distension with vomiting
- Recent leg weakness

Should a practitioner suspect or identify a safeguarding concern during the assessment process, this should be actioned urgently using existing safeguarding protocols and procedures.

### 3.3 Assessment

The primary aim of all continence assessments is to effectively treat the individual's continence problem as per national and local policies and care pathways. Containment of incontinence using washable or disposable products is indicated only where demonstrable improvements in continence cannot be achieved through alternative means.

Assessments will be undertaken using the relevant urinary or faecal incontinence assessment documentation and will include urine testing and a frequency of voiding /incontinence /soiling/bowel habits (as relevant to their condition) and fluid intake chart over a 3 day period this for urinary and 7 day for faecal, as mandatory elements of the assessment (see appendix 7), can be used in collaboration with the toilet skills assessment chart (appendix 6) and the paediatric assessment tool for issuing products (appendix 4).

If staff are unsure or encounter very special circumstances (such as end of life care with a life expectancy of < 6 months / "Amber" or "Red" phases on End of Life Care) then that individual case must be discussed with clinical staff in the continence service.

Referral time to initial assessment will be dependent upon which service is involved (for example school nursing, hospital ward, community learning disability nursing) and the urgency of individual clinical need.

The expectation of timescales are:

- Level 1 – 2 weeks maximum wait
- Level 2 – 18 weeks maximum wait
- Level 3 – 18 weeks maximum wait
- Red Flag – same day emergency access

Wait times will be dependent on clinical need following triage by the right professional, the above is the maximum amount of time the system would be expecting children/young people to wait.

Joint assessment between community and continence specialists is encouraged in complex cases.

The healthcare professional or team who undertook the original initial assessment retain the case holding responsibility for that child/young person unless the service user is formally referred and accepted for care by another service.



### 3.4 Reassessment

Reassessment for those with long term continence needs including product provision should be carried out annually as a minimum, however, in line with good practice guidance children/young people aged 5 to 16 years should be re-assessed by the continence service 6 monthly to ensure care plan remains valid for the child/young person/parent/carer.

Further reassessment may be needed where the individual requests alternative style/more/fewer products indicating a change in need or as determined by the assessing healthcare professional/continence service according to clinical need.

Reassessment will be undertaken in the same settings as outlined in the assessment information above.

Failure to reorder products in a 6 month period, followed by a request for products, automatically triggers re-assessment of need.

If, following reasonable requests a parent/carer is unwilling to make themselves available for periodic reassessment of products then the supply of products will cease until reassessment takes place.

## 4. TRAINING

In accordance with national guidance<sup>6</sup> any health care professional undertaking an initial continence assessment and first line treatment, should have attended appropriate training and be competent to carry out these duties.

Level 2 Continence Services for Lancashire and South Cumbria will be responsible for training of Practitioners involved in supporting the child/young person continence needs and will provide a rolling training programme across the system to develop and retain knowledge and skills.

Employing organisations hold responsibility for appropriate levels of training for staff providing assessments, advice, guidance, or treatments within services providing continence support.

There are no national guidelines regarding continence update training, and it is for the individual practitioner and their line manager to consider whether the health care professional is competent to perform initial continence assessment and first line treatment.

Training for continence should be included within the Knowledge and Skills Framework and Personal Development Plan<sup>7</sup> and the individual service line competency Framework for Practitioners and considered as part of the annual Training Needs Analysis for the team or establishment.

Continence Services should ensure staff meet the minimum expected knowledge base as set out within the minimum standards for paediatric continence care<sup>8</sup>

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<sup>6</sup> Paediatric Continence Forum: Guidance for the provision of continence containment products for children and young people: a consensus document, 2021

<sup>7</sup> Royal College of Nursing 2006

<sup>8</sup> Paediatric Continence Forum, 2016

Level 1 knowledge base standards include:

- To demonstrate an appropriate level of knowledge of anatomy, pathophysiology, and continence status, including the impact of the child/young person's development, environment, or comorbidities on their continence.
- To understand the impact of lower urinary tract and bowel symptoms on children/young people and their parents or carers
- To be aware of NICE guidance
- To be aware of "red flags" and other causes for concern.
- To be aware of the need to discuss "red flags" and concerns with senior staff for referral, or to directly refer onwards, in a timely manner for these and other conditions e.g., recurrent urinary tract infection.
- To demonstrate an understanding of the conservative management of lower urinary tract and bowel conditions, including dietary and fluid intake and lifestyle modifications.
- To be able to communicate sensitively and effectively with child/young person/parent/carer.
- The ability to understand the roles of and work with the wider multidisciplinary team, for example, CAMHS, education settings and social care as appropriate.
- To be able to identify the limits of their competence and provide or request appropriate and timely onward referral.
- To be able to use available technology appropriately.
- To meet NHS and regulatory body professional standards with respect to record keeping
- To understand safeguarding issues and concerns and how to respond according to local policies and procedures.

Level 2 knowledge base standards includes:

- To demonstrate an appropriate knowledge of anatomy, physiology and pathology relating to continence control.
- To demonstrate a knowledge of developmental milestones, both in general development and relating to continence
- The skill set to differentiate where developmental milestones may be delayed in children/young people who have additional needs. i.e., Neurodiversity and/or SEND and offer reasonable adjustments to approaches in continence support, as needed
- To understand the impact of lower urinary tract and bowel symptoms on the child/young person/parent/carer
- To be able to identify "red flags" and be aware of the need for onward referral for these and other conditions or concerns.
- To demonstrate an understanding of the management options for delayed toilet training, urinary and faecal incontinence, and chronic constipation
- To demonstrate understanding of the role of the multidisciplinary team, including administrative, educational, social care staff and the voluntary sectors
- To understand the impact of continence problems on quality of life and integration in the community (e.g., at school and in extracurricular activities)
- To understand safeguarding concerns and how to respond to these in accordance with local policies and procedures.
- To work with the child/young person/parent/carer to set relevant goals and expectations of treatment and arrange review as appropriate.
- Attendance at product training would be advised where available
- To be skilled and competent to provide training to level 1 practitioners and other stakeholders such as education staff supporting a child/young person with continence needs e.g., intermittent catheterisation

- To be skilled and competent in training others in clinical skills such as, but not limited to, clean intermittent catheterisation/mitrofanoff/specialist bowel treatments
- Additional training from specialist teams can be facilitated where specific gaps in knowledge are identified.

## **5. CONTINENCE PRODUCTS**

Where the provision of continence products is indicated, the children and young person's board, on behalf of the ICB expect supply to be strictly based on assessed clinical need (see appendix 3 for initial assessment guidance document and appendix 5 for full assessment guide).

Assessments are to be carried out by suitably trained healthcare professionals and a daily allocation of products will be supplied to meet the assessed clinical need.

There are indicative numbers (based upon guidance from the paediatric continence forum) within this document for continence products, however these are to be used as a guide only and not intended to be utilised as an absolute figure for providing products. It is also acknowledged that there may be a difference between the clinically assessed need and what the family see as the need. Here a collaborative approach is anticipated from the outset, so families are part of the journey with the clinical teams

This framework is expected to apply to cover all areas requiring continence support from mainstream schools and all specialist schools.

Continence products are prescribed and provided on a named individual basis only and must not be shared with or used for other people who are awaiting an assessment or have exhausted their own supply.

Continence containment products are supplied via a contracted manufacturer/distributor following a regulated NHS tender and procurement process. The range of products supplied is strictly limited to those within the contractual arrangements.

Services should engage with child/young person/parent/carer about the products provided and consider feedback on the quality of items provided by the service/NHS supply chain. This is important to maintain good relations with all involved and to support quality care for the individual needing the product. Any feedback indicating poor quality products should be relayed to the supplier, the organisation should request to receive advice around the quality assurance process for their specific product.

Product provision is usually for washable or disposable products. Where a combination is required please ensure clinical need is clearly evidenced.

### **5.1 Washable Padded Underwear**

Washable products include female and male specific briefs and boys and girl's specific underwear as procured via the continence product supply contract.

Children's washable underwear – generally a maximum of six pairs per year will be supplied to children who require products to aid toilet training in children aged 4 years old and over.

An initial trial through provision of one pair, dispatched directly from the continence service, should be considered where the efficacy of this type of containment product is not certain.

To activate a trial the assessing nurse must indicate this on the product ordering form when submitting their assessment to the continence service. The assessing healthcare professional, must follow-up the trial outcomes and report their findings to the continence service to facilitate ongoing care/product provision.

## 5.2 Washable Bed Pads

Three washable bed pads may be supplied every 48 weeks, delivered to service users by the contracted product provider.

Two types of washable bed pads are available:

‘Quick Dry’ bed pads are designed for single beds and have fabric tuck-in flaps to secure them to the bed, a separate waterproof sheet, and are designed to air dry after laundering in 24 hours.

‘Community bed pads’ comprise of a single pad with integral waterproof backing and are suitable for use with double beds and where less frequent laundering is required.

Bed pads are promoted as an alternative to disposable continence products for service users who have urinary incontinence only. Washable bed pads are NOT suitable for faecal incontinence.

Provision is in consideration of one or more of the following criteria:

- The bed pad is the only product used at night.
- The individual is a child/young person undergoing treatment for nocturnal enuresis via an enuresis clinic.
- The individual is highly mobile overnight and body worn products become dislodged on a frequent basis (more than 3 nights in 7)
- The individual is incontinent more than 3 nights per week, but this may not occur every night.
- There is a specific clinical need

## 5.3 Disposable continence products

Absorbent disposable products are supplied for faecal and urinary incontinence.

Disposable padded briefs commonly referred to as “Pull up” products, are not a standard formulary item due to their relatively low absorbency level and high cost. A two-piece system would be preferable.

Criteria under which “Pull Ups” are provided are as follows:

- Pull-Ups are only supplied on a short term basis (3 - 6 months) where there is a toileting programme, supervised by a Healthcare Professional and the treatment programme is designed to promote independent / lone toileting.
- Pull-Ups are not supplied for use at night.
- Continued provision of Pull Ups must be reviewed by the assessing healthcare professional at least 6 monthly – where a 6 monthly reassessment has not been carried out, product provision will be suspended pending reassessment.

## 5.4 Product Selection

Product selection will be based upon clinical assessed need.

Training in product selection is available via the continence service or product suppliers.

When selecting a disposable product, the assessor must consider the degree of incontinence vs. the absorbency of the product selected to ensure an appropriate product is chosen.

It is the responsibility of the assessing healthcare professional who prescribes the continence product for the service user, to inform the service user and/or carer regarding the correct fitting, use and safe disposal (or laundering if a washable product) of the product concerned, in accordance with the manufacturer's instructions and local waste disposal and infection control policies.

Where possible service users should be provided with a two-piece system – a disposable pad and stretch pants (to ensure secure fit) are advocated.

Accurate hip and waist measurements must be supplied to ensure correct fit and function of all-in-one products for children over 5, in cases where children under 5 are being supplied weight would be utilised.

Children's/young people's nappies are supplied via NHS Supply chain. The assessing healthcare professional must accurately provide the child's weight to ensure correct product selection.

Children/young people over 30kgs must be measured around their hips and waist and an appropriately sized product from the adult all-in-one range selected.

Disposable continence products will be supplied considering individual requirements following clinical assessment including accurate assessment of volumes voided, and careful selection of an appropriately absorbent product. This will allow for effective management of most incontinence problems where other measures have not been successful'

Provision of a combination of washable and disposable products will only occur where one disposable item is required for night-time use and washable products are used during the day.

Disposable bed pads are not within the Product Guide and may only be issued exceptionally as an alternative. Where patients are unsuitable for a body worn product and a disposable bed pad is being requested, a separate risk assessment must be provided along with the continence assessment documentation. For further guidance or advice contact a continence nurse specialist.

Furniture protection products do not fall within the remit of this framework.

## 5.5 Delivery Service

- child/young person/parent/carer will receive delivery of their continence products via a contracted supply company as per the continence product provision contract (held by the Continence service)
- A confidential and secure electronic data base containing service user's personal and continence product delivery related information is co-ordinated by the contracted provider and accessed by the continence service, product provider and the home delivery company

It is the responsibility of the assessing healthcare professional to inform the service user that their details will be shared with the three parties detailed above.

#### 5.6 Termination of product provision

Parents/carers who have not reordered disposable products in a continuous 6 month period will be contacted to understand current need prior to being removed from the service (18 months for washable products). If a child/young person is removed from the service and should they require a restart of product provision, they will be re-assessed to establish any changes in need.

#### 5.7 Exceptions

Non-contract products are occasionally provided where children and young people's needs cannot be met with standard products. Use of the home delivery service may not be possible where non-standard products must be sourced from outside the contractual arrangements.

### **6. SERVICE USER SATISFACTION**

A survey of patient satisfaction with the provision of continence service and products should be undertaken at a minimum of annually and findings incorporated in future policy and procurement processes. At all times children/young person/parent/carer compliments, comments, concerns and complaints will inform future reviews of this policy.

Children/young person/parent/carer are encouraged to forward any compliments, comments, concerns and complaints in accordance with provider policy and procedure.

### **7. CHILDREN/YOUNG PEOPLE AND FAMILY/CARER EMPOWERMENT IN CARE**

The impact of incontinence on children/young people/parent/carer should not be underestimated. Clear communication and involvement in decisions and care planning is vital to creating a supportive and holistic continence service.

Discussions should be undertaken with family/carers to ensure support is clear with all parties involved, particularly where the status quo is being changed.

It is important for families/carers to be fully informed of who to contact in terms of reassessments or changes in needs outside of the planned 6 monthly reassessments. Families should be fully supported in understanding the best fitting of products (where they have been provided) to minimise leaks or other fit issues/ this will enable families/carers and child/young person to become experts in their own care, enabling them to educate other professionals they may encounter to support them in the best individualised way.

### **8. SAFEGUARDING**

All healthcare professionals have a duty to safeguard the wellbeing of children and young people. If they become aware of any concerns, they should seek advice and take appropriate action according to their local safeguarding policies and procedures.

Children in Care under Section 20 or 31 of the Children Act 1989 should not be discriminated against if they move from one area to another. The health authority, ICB, 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 plan 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 health care professional (HCP), school, or family support workers, to ensure their child/young person gets the same assessment as any other child/young person. It is not in the child's/young persons 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 child/young person/parent/carer. Services should consider the Accessible Information Standards (AIS) when supplying written information or requests parents/carers and children/young people. If there are concerns, the HCP should request guidance from their safeguarding supervisor(s).

Children/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/young person 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.

## **9. DISCHARGE AND TRANSITION PLANNING**

Children will be discharged after appropriate assessment/re assessment when no ongoing medical interventions are required with information on how to re access the service if needed. The provider should inform the child/young person/parent/carer of the clinical progress/discharge management and any further treatment plans to be sent to their GP within 5 working days.

The transition into adult services should be made in advance and coordinated by the service in a planned and seamless process recognising the need for flexibility based on the individual young person's needs and be developmentally appropriate with the involvement of the young person and parents/carers if required.

## **10. APPENDIX**

### **Appendix 1**

This document has been developed collaboratively by engaging the following groups:

- Universal services 0-19
- Blackpool Teaching Hospital Trust
- East Lancashire Hospital Trust
- Lancashire Teaching Hospital Trust
- Morecambe Bay Hospitals Trust
- Blackpool Clinical Commissioning Group (CCG)
- Fylde and Wyre CCG

- Chorley and South Ribble CCG
- Greater Preston CCG
- East Lancashire CCG
- Blackburn with Darwen CCG
- Morecambe Bay CCG
- West Lancashire CCG
- Local Area Partnerships – East Lancs, South Area, Lancaster, Fylde and Wyre
- Lancashire County Council,
- Blackburn with Darwen Council,
- Cumbria County Council
- Blackpool Council
- Lancashire and South Cumbria Parent/Carer Forum

## Appendix 2



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## Appendix 3



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## Appendix 4



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## Appendix 5



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## Appendix 6



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## Appendix 7



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