Bath and North East Somerset,
Swindon and Wiltshire
Clinical Commissioning Group

Children's Continuing Care: NHS Bath and North East Somerset, Swindon and Wiltshire CCG Policy and Process

Final v 1.0

NHS Bath and North East Somerset, Swindon and Wiltshire (BSW) Clinical Commissioning Group (CCG)

July 2020

NHS BSW CCG

Policy:	Children's Continuing Care Policy
Policy Reference:	
Policy Statement:	This policy describes the way in which the CCG will provide health care for children and young people who may have needs that are eligible for funding under Children's Continuing Care. The policy describes the way in which the CCG will commission care in a manner which reflects the choice and preferences of individuals but balances the need for the CCG to commission care that is safe and effective and makes the best use of available resources.
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Document Control

Reviewers & Approvals

This document requires the following reviews and approvals.

Name	Position		Version Approved	Date Approved

Revision History

Version	Revision Date	Details of Changes	Author
0.1	13/05/2020	Joining of Swindon, BANES and Wilts existing policies	Fiona Corless
0.2	23/07/2020	Formatting and Content	Fiona Corless Sally Beckley
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0.4	30/11/2020	Addition of Appendices and update of overlapping policies	Fiona Corless
1.0	14/01/2021	Final Version signed off by QPAC	Fiona Corless Sally Beckley

Acknowledgement of External Sources:
List any policies or from external institutions that have been used to inform the writing of this policy.

Title/Author	Institution	Comment / Link

Links or overlaps with other key documents & policies:

Document Title	Version and Issue Date	Link/Document
Continuing Healthcare Operational Policy – BANES, Swindon and Wiltshire	05/05/2020	https://intranet.bswccg.nhs.uk/tools-and-resources/resource-library/policies-and-guidance/patient-policies
Continuing Health Care: Choice & Equity Policy – Wiltshire CHC Disputes Policy – Wiltshire CHC Local Resolution Policy – Wiltshire CHC Options for Care Policy - Wiltshire	05/05/2020 05/05/2020 05/05/2020 05/05/2020	https://intranet.bswccg.nhs.uk/tools-and-resources/resource-library/policies-and-guidance/patient-policies
Personal Health Budget Policy	V0.10 November 2020	
Compliments Concerns and Complaints Policy – September 2020	05.05.2020	https://intranet.bswccg.nhs.uk/tools-and-resources/resource-library/policies-and-guidance/patient-policies
Exceptional Funding Requests Prior Approval Policy	23.07.2020	https://intranet.bswccg.nhs.uk/tools-and-resources/resource-library/policies-and-guidance/patient-policies
Safeguarding Adults Children and Looked After Children Policy	02.04.2020	https://intranet.bswccg.nhs.uk/tools-and-resources/resource-library/policies-and-guidance/patient-policies

Distribution and Consultation:
This document has been distributed to the following people for consultation

Name	Date of Issue	Version
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Head of Service and Care Outcomes (BANES Council)	24/07/2020	0.2
Integrated Service Manager (Swindon Borough Council)	24/07/2020	0.2
Disabled Children's Team Service Manager (Wiltshire Council)	24/07/2020	0.2
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Document versions numbered "0.1, 0.2, 2.4", are draft status and therefore can be changed without formal change control. Once a document has been formally approved and issued it is version numbered "Issue 1.0" and subsequent releases will be consecutively numbered 2.0, 3.0, etc., following formal change control.

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Accessibility

This document is available in other styles, formats, sizes, languages and media in order to enable anyone who is interested in its content to have the opportunity to read and understand it.

These alternatives include but are not limited to:

- Alternative languages and dialects
- Larger and smaller print options (font 8 to 18)
- Simplified versions including summaries and translation into symbols
- Audio or read versions
- Web based versions that can be zoomed into or shrunk on screen
- Braille

Table of Contents

1 Foreword

1.1 Clinical Commissioning Groups (CCGs) have a legal statutory responsibility for securing and funding to a reasonable extent the health care which an individual needs. This guidance describes the local process which should be followed for the equitable discharge of that responsibility for children and young people with complex needs in Bath, North East Somerset, Swindon and Wiltshire (BSW).

1.2 The National Framework for Children and Young Peoples Continuing Care (called the Children's Framework from here on in) was published in March 2010, and the 2016 revision takes account of the new structures of NHS commissioning created by the Health and Social Care Act 2012 and the new integrated approach to the commissioning of services for children and young people with SEND which the Children and Families Act 2014 introduced. In particular, where a child or young person has a special educational need or disability (SEND), which will often be the case, then CCGs, local authorities and providers will endeavour to coordinate the assessment and agreement of the package of continuing care, as part of the process to develop the child's Education, Health and Care plan.

2 Introduction

2.1 This policy details BSW approach to children and young people's continuing care using the principles established in the Children Framework. It supports partnership working between the CCG, the three Local Authorities, BaNES Council, Swindon Borough Council and Wiltshire Council and providers of children and young people's continuing care.

2.2 The Children's Framework states:

2.2.1 A children's continuing care package will be required when a child or young person has needs arising from disability, accident, challenging behaviour or illness that cannot be met by existing universal or specialist services alone [and may or may not include health needs]

2.2.2 Some children and young people (up to their 18th birthday), may have very complex health needs. These may be the result of congenital conditions, long-term or life-limiting or life-threatening conditions, disability, or the after-effects of serious illness or injury

2.2.3 These needs may be so complex, that they cannot be met by the services which are routinely available from GP practices, hospitals or in the community commissioned by clinical commissioning groups (CCGs) or NHS England. A package of additional health support may be needed. This additional package of care has come to be known as children's continuing care (CCC)

2.2.4 Children's continuing care is not needed by children or young people whose needs can be met appropriately through existing universal or specialist services through a case management approach.

2.3 The Children's Framework does not give guidance on the content or funding of the actual package of continuing care, if a child or young person is deemed eligible. Local continuing care decision-making should be based on the assessed needs of the individual child or young person and specialist and universal services available in the area.

2.4 BSW CCG acknowledges that not all children and young people will be eligible for continuing care as needs can be met via ordinarily commissioned services. In exceptional circumstances identified by the assessor it may be appropriate for BSW CCG to fund additional health support through other processes. Information about these processes can be found through the locality children's commissioners.

3 Purpose and Scope

3.1 The purpose of this policy is to establish BSW CCGs responsibilities to meet the continuing care needs of children and young people. In addition this policy seeks to clarify the CCG's processes for assessment and eligibility of children and young people who may have continuing care needs.

3.2 This policy, in line with the Children's Framework, covers young people from birth up to their 18th birthday. Thereafter, the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (revised 2018) and the supporting guidance and tools applies.

4 Roles and Responsibilities

4.1 BSW CCG remains responsible for establishing and managing appropriate governance arrangements for the process across all three areas, including where this responsibility has been delegated to providers.

4.2 The Director of Nursing and Quality in BSW CCG has executive responsibility for children and young peoples' continuing care and will ensure there is effective liaison with the Local Authority and other partners. They will also ensure the effective management of the continuing care process. The Director of Nursing and Quality also has oversight of the CCGs' participation in local arrangements for Special Educational Needs and Disability (SEND).

4.3 BSW CCG Quality and Performance Assurance Committee will provide the organisational governance through quarterly reports of the children and young people's continuing care process and outcomes for children and young people.

4.4 Parents and carers with parental responsibility have the primary responsibility for the care of their child or young person with statutory agencies supporting them to meet the child or young person's identified needs.

5 The Process

5.1 **Referral**

5.1.1 Children and young people needing a continuing care assessment will, in most cases, already be known to local services.

5.1.2 A referral should be made when a health need is identified that cannot be met through universal, targeted or specialist services. Consent from the young person and/or parents/carers must be obtained to refer to BSW CCG including consent to share information

5.1.3 The additional needs must have been identified through a robust holistic assessment, this may be through early help assessment or social work and/or child in need review or Education, Health and Care Plan Annual Review.

5.1.4 A referral using BSW CCG referral form (Appendix 1) should be made electronically to BSW CCG for the assessment process to be initiated. It should clearly identify the unmet health need. Only professionals who have received training should complete the referral; training can be arranged via the Designated Clinical Officer in the CCG.

5.1.5 End of life referrals will be fast tracked and a decision about a package of support will be made as quickly as possible; see section 7

5.2 **Assessment**

5.2.1 The assessment undertaken with consent is led by a children and young people's health assessor nominated by the CCG, (called the

Assessor from here on in) who will draw on the advice of other professionals.

5.2.2 This phase may include a pre-assessment/triage using information supplied in the referral form to determine whether a full assessment is necessary. A clinical decision will be determined by the Assessor in collaboration with Designated Clinical Officers (where required) as to whether a full assessment should be completed. If the information suggests the child or young person may meet the Continuing Care threshold, the assessor will arrange for a full assessment to take place in order to provide the information required to support decision making.

5.2.3 Where it is determined that a full assessment will not take place the assessor will inform the referrer in a written response including the rationale for that decision.

5.2.4 The Assessor will liaise with the family/carer and arrange an appropriate time to undertake the assessment. Where possible, assessments will take place jointly with the referrer, and/or with keyworkers already involved with the young person, e.g. social worker. If the referrer is not available to attend the assessment, they will be asked to provide relevant information.

5.2.5 The Assessor is responsible for collating the evidence and assessing the risks to support the assessment recommendation and all aligned processes within the agreed system.

5.2.6 There are key four areas of evidence that should be considered in the assessment:

5.2.6.1 The preferences of the child or young person and their family;

5.2.6.2 A holistic assessment of the needs of the child or young person and their family;

5.2.6.3 Reports and risk assessments from a multidisciplinary team or evidence collated during the Education, Health and Care plan assessment

5.2.6.4 The documented use of the Decision Support Tool for children and young people

5.2.7 The Decision Support Tool assesses needs across 10 domains;

5.2.7.1 Breathing

5.2.7.2 Eating and Drinking

5.2.7.3 Mobility

5.2.7.4 Continence and Elimination

5.2.7.5 Skin and Tissue Viability

5.2.7.6 Communication

5.2.7.7 Drug Therapies and Medicines

5.2.7.8 Psychological and Emotional Needs

5.2.7.9 Seizures

5.2.7.10 Challenging behaviour (This domain is only in relation to individuals with a diagnosis of learning disability or autistic spectrum disorder. Challenging behaviour is defined by NICE as: “when it affects the person's or other people's quality of life and or jeopardises their safety.)

5.2.8 On completion of the assessment the assessor will make a recommendation regarding eligibility and suggestions of what is required to meet identified needs. This will be submitted to panel in a report that includes the Decision Support Tool and required supporting information.

5.2.9 A child is likely to have continuing care needs if assessed as having a severe or priority level of need in at least one domain of care, or a high level of need in at least three domains of care and has identified unmet needs in relation to these domains.

5.2.9.1 Note. The level of need in a single domain may not on its own indicate that a child or young person has a continuing care need. Diagnosis of a particular disease or condition is not in itself a determinant of a need for continuing care. A child or young person may have a rare condition which is difficult to diagnose, but will still have support needs. There should be no differentiation based on whether the health need is physical, neurological or psychological. The continuing care process should be (and be seen to be) fair, consistent, transparent, culturally sensitive, and non-discriminatory. All needs are considered as part of a picture of overall care needs across all domains.

5.2.10 The national framework states that two or more professionals must be involved when using the DST and when making recommendations as to whether a child or young person is eligible for Continuing Care before presentation at the Continuing Care panel.

5.2.11 The outcome of the assessment and accompanying report is taken to a multi-agency panel who will make the decision.

5.3 **Decision Making**

5.3.1 The Continuing Care Panel is a multi-agency panel that sits monthly consisting of education, health and social care.

5.3.2 The panel considers the evidence and the assessor's recommendations to reach a decision as to whether or not the child or young person is eligible for continuing care. The establishment of a continuing care need should not be determined by the existing package of care a child or young person receives.

5.3.3 When a child or young person is eligible for continuing care, the assessor will work closely with the family and other professionals involved to identify the most appropriate package of care. Resources will be allocated using a graduated approach based on individual circumstances and indicated clinical needs.

5.3.4 Once CCC funding has been agreed, the package of care will be set up as a Personal Health Budget. This can either be a direct payment, via a third party or as a notional budget.

5.3.5 When a child or young person is not eligible for CCC and has needs that can be met by universal provision the child or young person and their family will be informed and directed to services described in the Local offer including; community nursing service, GP, paediatrician.

5.3.6 When a child or young person is not eligible for CCC but has needs over and above universal or targeted services provision consideration should be given at panel as to whether alternative CCG or joint funding would be appropriate; this could include commissioning on an individual basis or agreement to purchase one off specialist medical equipment such as cough assist machines where clinically indicated.

5.3.7 Once a decision has been made and a suitable provision has been identified it will be signed off by the panel members and confirmed in writing to the child and their family, along with relevant stakeholders and will include details of how to appeal.

5.3.8 Any disputes about who has commissioning responsibility will be resolved through escalation to relevant executives within BSW CCG and relevant local authority.

5.3.9 BSW CCG is responsible for overseeing delivery of the community support package and will provide ongoing monitoring from a commissioning and quality assurance perspective.

5.4 **Review**

5.4.1 As a minimum the child or young person's continuing care needs will be reviewed by the assessor three months after the package of care has commenced or changed. Thereafter, they will reviewed annually by the assessor or when the needs are known to have changed. All reviews will be transparent, involving the child/young person and their family.

5.4.2 Reviews should consider the effectiveness of the package and if it is achieving the desired outcomes for the child/young person and family.

5.4.3 If there is a significant change in a child's/young person's needs consideration should be given to whether a full reassessment is necessary.

5.4.4 Reviews should take place with the referrer or another professional who knows the child well where possible, such as social workers or community nurses. Wherever possible reviews should be aligned with existing multi-agency processes such as EHCP reviews, Child Looked After Reviews or Child in Need Reviews.

5.4.5 Review reports should be developed with the child/young person and family clearly show their contributions.

5.4.6 All reviews should be presented and agreed at panel.

6 Personal Health Budgets (PHB)

6.1 The families of a child or young person eligible for continuing care have a 'right to have' a personal health budget, covering the part of their care package which would be provided by the NHS.

6.2 Where possible Personal Health Budgets should be reviewed at the same time as the continuing care package.

6.3 For more guidance on PHBs, see: BSW CCG Personal Health Budgets Policy and Guidance on the "right to have" a Personal Health Budget in Adult NHS Continuing Healthcare and Children and Young People's Continuing Care (September 2014) www.england.nhs.uk/personal-health-budgets/personal-health-budgets-in-nhs-continuing-healthcare-and-continuing-care-for-children/

7 Fast Track for Exceptional Circumstances

7.1 It is recognised that some children and young people will as a result of their condition rapidly decline; and require end of life bespoke support. End of life care refers to a child or young person whose condition is deteriorating rapidly characterised by an increasing level of dependency and where a lifespan is thought to be days or weeks rather than months or years.

7.2 To facilitate quick decision making full assessment is not necessary, referrals can be made using the fast track referral form (Appendix 2). All cases will be reviewed by an assessor prior to decision-making being confirmed through consultation with panel members, outside of panel if necessary. In some cases retrospective approval can be sought.

8 Transition

8.1 There are significant differences between children and young people's continuing care and NHS Continuing Healthcare for adults. Although a child or young person may be in receipt of a package of children's continuing care, they may not be eligible for NHS Continuing Healthcare or NHS funded Nursing Care once they turn 18.

8.2 The CCG will ensure that we are actively involved, with our partners, in the strategic development and oversight of local transition planning processes.

8.3 The CCG will ensure that adult NHS continuing healthcare is appropriately represented at all transition planning meetings to do with individual young people whose needs suggest that they may be eligible for NHS Continuing Healthcare.

8.4 Future entitlement to adult NHS Continuing Healthcare will be clarified as early as possible in the transition planning process, especially if the young person's needs are likely to remain at a similar level until adulthood, and this will be accomplished by undertaking an initial screening for NHS Continuing Healthcare at a suitable point when aged 16-17. If young people are currently in receipt of CCC funding the CCG will trigger an adult CHC assessment.

8.5 The transition summary from the framework states:

- At **14** years of age, the young person should be brought to the attention of the CCG as likely to need an assessment for NHS Continuing Healthcare.
- At **16 -17** years of age, screening for NHS Continuing Healthcare should be undertaken using the adult screening tool, and an agreement in principle that the young person has a primary health need, and is therefore likely to need NHS Continuing Healthcare .
- At **18** years of age, full transition to adult NHS Continuing Healthcare or to universal and specialist health services should have been made, except in instances where this is not appropriate.

8.6 For more guidance on adult NHS Continuing Healthcare, see: BSW NHS Continuing Healthcare Policy and national guidance for NHS Continuing Healthcare: https://www.gov.uk/government/publications/national-framework-for-nhs-continuinghealthcare-and-nhs-funded-nursing-care

9 Complaints, Appeals and Dispute Resolution

9.1 BSW CCG recognises that there may be times when parents/carers or a child or young person may wish to raise concerns about the care provided or the decision the multi-agency panel made around eligibility. BSW CCG are keen to ensure that these disputes are managed locally and resolved at the earliest opportunity. As such the CCG has developed a clear process for either making a complaint or appealing against a multi-agency panel decision.

9.2 All letters sent out from the CCG post decision making will have the appeals process and the CCG complaints process clearly documented.

10 Safeguarding

10.1 BSW CCG has a statutory responsibility to ensure safeguarding is embedded across the work of the CCG and that safeguarding is integral to Children's Continuing Care. When commissioning Children's Continuing Care, BSW CCG will take all possible measures to ensure that the safeguarding of children is evidenced within contracts and that any arrangements minimise the risks of harm and promote the wellbeing of individuals.

10.2 BSW CCG is accountable for delivering the statutory functions for safeguarding children under section 11 of the Children Act 2004. In addition to fulfilling their responsibilities under the Children Act 20014, BSW CCG must comply with the statutory guidance contained within Working Together to Safeguard Children (2015) . For more guidance on children's safeguarding policies, see: Safeguarding Adults Children and Looked After Children Policy

10.3 BSW CCG is required to deliver the statutory functions for safeguarding adults under the Care Act 2014. Although this policy relates to children, it is recognised that a situation may arise during the commissioning or delivery of a children's package which places an adult at risk of harm. The Safeguarding Adults Multi-Agency Policy, agreed by the BSW Safeguarding Adults Boards must be followed if there are concerns.

11 Data Protection

11.1 Data held by the CCG is governed by the General Data Protection Regulation (GDPR) and the Data Protection Act 2018 (DPA).

12 Appendix 1: Referral Form

Children and Young People's Continuing Care
Consent for referral and assessment

Name	NHS No	DOB

Statement	Yes	No
I agree to an assessment of my/my child's care needs being undertaken in accordance with the National Framework for Children and Young People's Continuing Care. I understand this is led by BSW CCG in conjunction with Social Services and Education staff. I consent to contact and access to records held by other organisations to gather information to support this assessment as required, including access to records held by my GP practice.		
Information gained in this assessment may be shared with providers who may deliver Health and/or Social Care services to my child. I understand that this eligibility for Children's Continuing Care is subject to review. However, I do not want the following information shared with (please specify the details below):		
I agree that information gained as part of this assessment will be stored securely by the CCG in line with General Data Protection Regulations.		

Signature of child/young person named above	
Date	

OR

Signature on behalf of the child/young person named above	
Date	
Relationship to the child/young person	

NB. In line with the Mental Capacity Act 2012 if the young person is 16 years or older they must sign the consent themselves unless a Best Interest Decision Form is completed and signed on the young person's behalf.

Children and Young People's Continuing Care

Referral / checklist form

Part 1: To be completed by Referrer				
Child, Young Person and Family Details				
Name		DOB	Gender	NHS No
Home Address		Place of Current Residence		
Others living in the home (and relationship to child)		GP Name and Address		
Parent/Carer(s)		First Language		
		Other communication needs (including preferred method of communication		
NB. details of one parent only are acceptable, but it must be the parent with responsibility.				
Parental responsibility held by		Contact Number:		
Basis of parental responsibility	(e.g. legal guardian, LA section 20)	Email		
Local Authority				

Referral Details	
Date of Referral	
Name and Designation of Person Completing Referral	
Telephone and Email	

Please return this form to:	BSW Clinical Commissioning Group E-MAIL: bswccg.childrensclinicalteam@nhs.net

Professionals Involved

Lead Professionals

	Name and title	Contact Details
Lead Education Case Officer		
Lead Social Worker		
Lead Health Professional(s)		

Other Professionals

Team			
Name		Professional	
Address			
Email Address		Contact Number	

Team			
Name		Professional	
Address			
Email Address		Contact Number	

Team			
Name		Professional	
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Email Address		Contact Number	

Team			
Name		Professional	
Address			
Email Address		Contact Number	

Team			
Name		Professional	
Address			
Email Address		Contact Number	

Reason for Referral Please summarise below details of any relevant assessments (and their outcomes) made in the last 2 years to support this referral. Please indicate what the unmet needs are and what additional support might be needed to meet these needs.

Health Needs
What are the child's presenting health difficulties/needs? **What is the impact of these on the child's daily functioning?** **What provision is currently in place?** **What UNMET health needs are there?** **Please list any relevant diagnoses**
Please consider the following areas and include rationale for checklist scoring: • *Breathing* • *Eating and drinking* • *Mobility* • *Continence or elimination* • *Skin and tissue viability* • *Communication* • *Drug therapies and medication* • *Psychological and emotional needs* • *Seizure* • *Challenging behaviour*

Education	
Name of nursery, school or college attending	
Year group	
Contact details	
What additional support or reasonable adjustments are required in that setting?	
Does the child or young person have special educational needs	
Does the child or young person have an EHCP? (if so this should be attached)	

Social Care Needs
What are the child's social care needs? **What is the child's family/living situation and background?** **What provision/support is in place to meet needs?** **What UNMET social care needs are there?**
Please provide a brief history and current overview of the child's social care needs

Please List Supporting Documents and other key evidence that was taken into account in completing this referral *Please provide copies of current care plans and risk management plans from placements/health services, specialist reports, EHC plans, Social Care reports; hospital discharge letters; clinical letters etc.*			
Supporting Document Title	**Report From** (inc. name and contact details)	**Date of Document**	**Date Received**

Pre-Assessment Checklist Summary

Using Appendix A for reference please identify what you feel the level of need is for each domain in the summary table below. For anything scoring high or above evidence needs to be provided in supporting information and health needs sections above.

Pre-Assessment Checklist Summary	
Domain	**Level of Need**
	From Checklist
Breathing	Choose an item.
Eating and Drinking	Choose an item.
Mobility	Choose an item.
Continence and Elimination	Choose an item.
Skin and Tissue Viability	Choose an item.
Communication	Choose an item.
Drug Therapies and Medication	Choose an item.
Psychological and emotional needs	Choose an item.
Seizures	Choose an item.
Challenging Behaviour	Choose an item.

NB. A child is likely to be eligible for Children and Young People's Continuing Care if they meet the criteria for one severe, one priority or three highs in the below domains. For more information place contact BSW CCG or go to: http://www.nhs.uk/CarersDirect/guide/practicalsupport/Documents/National-framework-for-continuing-care-england.pdf

Part Two: To be completed by CCG

Pre-Assessment Checklist Score Summary		
Domain	**Level of Need**	
	From Checklist	**From Clinical Reviewer**
Breathing	Choose an item.	Choose an item.
Eating and Drinking	Choose an item.	Choose an item.
Mobility	Choose an item.	Choose an item.
Continence and Elimination	Choose an item.	Choose an item.
Skin and Tissue Viability	Choose an item.	Choose an item.
Communication	Choose an item.	Choose an item.
Drug Therapies and Medication	Choose an item.	Choose an item.
Psychological and emotional needs	Choose an item.	Choose an item.
Seizures	Choose an item.	Choose an item.
Challenging Behaviour	Choose an item.	Choose an item.

Clinical Recommendation	
Decision	
Date of Review	
Reviewed by	

Appendix A
Preassessment Checklist

BREATHING	
Description	**Level of need**
• Breathing typical for age and development.	No additional needs
• Routine use of inhalers, nebulisers, etc.; **OR** • care plan or management plan in place to reduce the risk of aspiration.	Low
• Episodes of acute breathlessness, which do not respond to self-management and need specialist-recommended input; **OR** • intermittent or continuous low-level oxygen therapy is needed to prevent secondary health issues; **OR** • supportive but not dependent non-invasive ventilation which may include oxygen therapy which does not cause life-threatening difficulties if disconnected; **OR** • child or young person has profoundly reduced mobility or other conditions which lead to increased susceptibility to chest infection (Gastroesophageal Reflux Disease and Dysphagia); **OR** • requires daily physiotherapy to maintain optimal respiratory function; **OR** • requires oral suction (at least weekly) due to the risk of aspiration and breathing difficulties; **OR** • has a history within the last three to six months of recurring aspiration/chest infections.	Moderate
• Requires high flow air / oxygen to maintain respiratory function overnight or for the majority of the day and night; **OR** • is able to breath unaided during the day but needs to go onto a ventilator for supportive ventilation. The ventilation can be discontinued for up to 24 hours without clinical harm; **OR** • requires continuous high level oxygen dependency, determined by clinical need; **OR** • has a need for daily oral pharyngeal and/or nasopharyngeal suction with a management plan undertaken by a specialist practitioner; **OR** • stable tracheostomy that can be managed by the child or young person or only requires minimal and predictable suction / care from a carer.	High
• Has frequent, hard-to-predict apnoea (not related to seizures); **OR** • severe, life-threatening breathing difficulties, which require essential oral pharyngeal and/or nasopharyngeal suction, day or night; **OR** • a tracheostomy tube that requires frequent essential interventions (additional to routine care) by a fully trained carer, to maintain an airway; **OR** • requires ventilation at night for very poor respiratory function; has respiratory drive and would survive accidental disconnection, but would be unwell and may require hospital support.	Severe
• Unable to breath independently and requires permanent mechanical ventilation; **OR** has no respiratory drive when asleep or unconscious and requires ventilation, disconnection of which could be fatal; **OR** • a highly unstable tracheostomy, frequent occlusions and difficult to change tubes.	Priority

EATING AND DRINKING	
Description	**Level of need**

Able to take adequate food and drink by mouth, to meet all nutritional requirements, typical of age.	No additional needs
Some assistance required above what is typical for their age; **or** needs supervision, prompting and encouragement with food and drinks above the typical requirement for their age; **or** needs support and advice about diet because the underlying condition gives greater chance of non-compliance, including limited understanding of the consequences of food or drink intake; **or** needs feeding when this is not typical for age, but is not time consuming or not unsafe if general guidance is adhered to.	Low
Needs feeding to ensure safe and adequate intake of food; feeding (including liquidised feed) is lengthy; specialised feeding plan developed by speech and language therapist; **or** unable to take sufficient food and drink by mouth, with most nutritional requirements taken by artificial means, for example, via a non-problematic tube feeding device, including nasogastric tubes.	Moderate
Faltering growth, despite following specialised feeding plan by a speech and language therapist and/or dietician to manage nutritional status,. **or** dysphagia, requiring a specialised management plan developed by the speech and language therapist and multi-disciplinary team, with additional skilled intervention to ensure adequate nutrition or hydration and to minimise the risk of choking, aspiration and to maintain a clear airway (for example through suction); **or** problems with intake of food and drink (which could include vomiting), requiring skilled intervention to manage nutritional status; weaning from tube feeding dependency and / recognised eating disorder, with self-imposed dietary regime or self-neglect, for example, anxiety and/or depression leading to intake problems placing the child/young person at risk and needing skilled intervention; **or** problems relating to a feeding device (e.g. nasogastric tube) which require a risk-assessment and management plan undertaken by a speech and language therapist and multidisciplinary team and requiring regular review and reassessment. Despite the plan, there remains a risk of choking and/or aspiration.	High
The majority of fluids and nutritional requirements are routinely taken by intravenous means.	Severe

MOBILITY	
Description	**Level of need**
Mobility typical for age and development.	No additional needs
Able to stand, bear their weight and move with some assistance, and mobility aids. **or** moves with difficulty (e.g. unsteady, ataxic); irregular gait.	Low
Difficulties in standing or moving even with aids, although some mobility with assistance. **or** sleep deprivation (as opposed to wakefulness) due to underlying medical related need (such as muscle spasms, dystonia), occurring three times a night, several nights per week; **or** unable to move in a way typical for age; cared for in single position, or a limited number of positions (e.g. bed, supportive chair) due to the risk of physical harm, loss of muscle tone, tissue viability, or pain on movement, but is able to assist.	Moderate
Unable to move in a way typical for age; cared for in single position, or a limited number of positions (e.g. bed, supportive chair) due to the risk of physical harm, loss of muscle tone, tissue viability, or pain on movement; needs careful positioning and is unable to assist or needs more than one carer to reposition or transfer; **or** at a high risk of fracture due to poor bone density, requiring a structured management plan to minimise risk, appropriate to stage of development; **or** involuntary spasms placing themselves and carers at risk; **or** extensive sleep deprivation due to underlying medical/mobility related needs, occurring every one to two hours (and at least four nights a week).	High
Completely immobile and with an unstable clinical condition such that on movement or transfer there is a high risk of serious physical harm; **or** positioning is critical to physiological functioning or life.	Severe

CONTINENCE OR ELIMINATION	
Interpretation Note: Take into account any aspect of continence care associated with behaviour in the Behaviour Domain	
Description	**Level of need**
Continence care is routine and typical of age.	No additional needs
Incontinent of urine but managed by other means, for example, medication, regular toileting, pads, use of penile sheaths; **or** is usually able to maintain control over bowel movements but may have occasional faecal incontinence.	Low
Has a stoma requiring routine attention, **or** doubly incontinent but care is routine; **or** self-catheterisation; **or** difficulties in toileting due to constipation, or irritable bowel syndrome; requires encouragement and support.	Moderate
Continence care is problematic and requires timely intervention by a skilled practitioner or trained carer; **or** intermittent catheterisation by a trained carer or care worker; **or** has a stoma that needs extensive attention every day. **or** requires haemodialysis in hospital to sustain life.	High
Requires dialysis in the home to sustain life.	Severe

SKIN AND TISSUE VIABILITY

Interpretation Note:

Evidence of wounds should derive from a wound assessment chart or tissue viability assessment completed by an appropriate professional. Here, a skin condition is taken to mean any condition which affects or has the potential to affect the integrity of the skin.

Where a child or young person has a stoma, only the management of the stoma itself as an opening in the tissue should be considered here (i.e. a tracheostomy should only be considered here where there are issues relating to the opening; the use of the tracheostomy to aid breathing, and its management should be considered under **Breathing**.)

Description	**Level of need**
No evidence of pressure damage or a condition affecting the skin.	No additional needs
Evidence of pressure damage or a minor wound requiring treatment; **or** skin condition that requires clinical reassessment less than weekly; **or** well established stoma which requires routine care; **or** has a tissue viability plan which requires regular review.	Low
Open wound(s), which is (are) responding to treatment; **or** active skin condition requiring a minimum of weekly reassessment and which is responding to treatment; **or** high risk of skin breakdown that requires preventative intervention from a skilled carer several times a day, without which skin integrity would break down; **or** high risk of tissue breakdown because of a stoma (e.g. gastrostomy, tracheostomy, or colostomy stomas) which require skilled care to maintain skin integrity.	Moderate
Open wound(s), which is (are) not responding to treatment and require a minimum of daily monitoring/reassessment; **or** active long-term skin condition, which requires a minimum of daily monitoring or reassessment; **or** specialist dressing regime, several times weekly, which is responding to treatment and requires regular supervision.	High
Life-threatening skin conditions or burns requiring complex, painful dressing routines over a prolonged period.	Severe

COMMUNICATION	
Interpretation Note: If child or young persons have communication needs, these should be reflected in the MDT assessment. This section relates to difficulties with expression and understanding, not with the interpretation of language	
Description	**Level of need**
Able to understand or communicate clearly, verbally or non-verbally, within their primary language, appropriate to their developmental level. The child/young person's ability to understand or communicate is appropriate for their age and developmental level within their first language.	No additional needs
Needs prompting or assistance to communicate their needs. Special effort may be needed to ensure accurate interpretation of needs, or may need additional support visually – either through touch or with hearing. Family/carers may be able to anticipate needs through non-verbal signs due to familiarity with the individual.	Low
Communication of emotions and fundamental needs is difficult to understand or interpret, even when prompted, unless with familiar people, and requires regular support. Family/carers may be able to anticipate and interpret the child/ young person's needs due to familiarity. **or** support is **always** required to facilitate communication, for example, the use of choice boards, signing and communication aids. **or** ability to communicate basic needs is variable depending on fluctuating mood; the child/young person demonstrates severe frustration about their communication, for example, through withdrawal.	Moderate
Even with frequent or significant support from family/carers and professionals, the child or young person is rarely able to communicate basic needs, requirements or ideas.	High

DRUG THERAPIES AND MEDICATION

Interpretation Note:
The child or young person's experience of how their symptoms are managed and the intensity of those symptoms is an important factor in determining the level of need in this area. Where this affects other aspects of the life, please refer to the other domains, especially the psychological and emotional domain. The location of care will influence who gives the medication. References below to medication being required to be administered by a Registered Nurse do not include where such administration is purely a registration or practice requirement of the care setting (such as a care centre requiring all medication to be administered by a Registered Nurse).

Description	Level of need
Medicine administered by parent, carer, or self, as appropriate for age.	No additional needs
Requires a suitably trained family member, formal carer, teaching assistant, nurse or appropriately trained other to administer medicine due to: age; non-compliance; type of medicine; route of medicine; and/or site of medication administration	Low
Requires administration of medicine regime by a registered nurse, formal employed carer, teaching assistant or family member specifically trained for this task, or appropriately trained others; **or** monitoring because of potential fluctuation of the medical condition that can be non-problematic to manage; **or** sleep deprivation due to essential medication management – occurring more than once a night (and at least twice a week).	Moderate
Drug regime requires management by a registered nurse at least weekly, due to a fluctuating and/or unstable condition; **or** sleep deprivation caused by severe distress due to pain requiring medication management – occurring four times a night (and four times a week). **or** requires monitoring and intervention for autonomic storming episodes.	High
Has a medicine regime that requires daily management by a registered nurse and reference to a medical practitioner to ensure effective symptom management associated with a rapidly changing/deteriorating condition; **or** extensive sleep deprivation caused by severe intractable pain requiring essential pain medication management – occurring every one to two hours **or** requires continuous intravenous medication, which if stopped would be life threatening (e.g. epoprostenol infusion).	Severe
Has a medicine regime that requires at least daily management by a registered nurse and reference to a medical practitioner to ensure effective symptom and pain management associated with a rapidly changing/deteriorating condition, where one-to-one monitoring of symptoms and their management is essential.	Priority

PSYCHOLOGICAL AND EMOTIONAL NEEDS	
Interpretation Note: This considers psychological and emotional needs beyond what is expected from a child or young person of there age. A separate domain considers **Challenging Behaviour** for children and young people with autism or learning disabilities and assessors should avoid double counting the same need.	
Description	**Level of need**
Psychological or emotional needs are apparent but typical of age and similar to those of peer group.	No additional needs
Periods of emotional distress (anxiety, mildly lowered mood) not dissimilar to those typical of age and peer group, which subside and are self-regulated by the child/young person, with prompts/ reassurance from peers, family members, carers and/or staff within the workforce.	Low
Requires prompts or significant support to remain within existing infrastructure; periods of variable attendance in school/college; noticeably fluctuating levels of concentration. Self-care is notably lacking (and falls outside of cultural/peer group norms and trends), which may demand prolonged intervention from additional key staff; self-harm, but not generally high risk; **or** evidence of low moods, depression, anxiety or periods of distress; reduced social functioning and increasingly solitary, with a marked withdrawal from social situations; limited response to prompts to remain within existing infrastructure (marked deterioration in attendance/attainment / deterioration in self-care outside of cultural/peer group norms and trends).	Moderate
Rapidly fluctuating moods of depression, necessitating specialist support and intervention, which have a severe impact on the child/young person's health and well-being to such an extent that the individual cannot engage with daily activities such as eating, drinking, sleeping or which place the individual or others at risk; **or** acute and/or prolonged presentation of emotional/psychological deregulation, poor impulse control placing the young person or others at serious risk, and/or symptoms of serious mental illness that places the individual or others at risk; this will include high-risk, self-harm.	High

SEIZURES	
Description	**Level of need**
No evidence of seizures.	No additional needs
History of seizures but none in the last three months; medication (if any) is stable; **or** occasional absent seizures and there is a low risk of harm.	Low
Occasional seizures including absences that have occurred with the last three months which require the supervision of a carer to minimise the risk of harm; **or** up to three tonic-clonic seizures every night requiring regular supervision.	Moderate
Tonic-clonic seizures requiring rescue medication on a weekly basis; **or** 4 or more tonic-clonic seizures at night.	High
Severe uncontrolled seizures, occurring at least daily. Seizures often do not respond to rescue medication and the child or young person needs hospital treatment on a regular basis. This results in a high probability of risk to his/her self.	Severe

CHALLENGING BEHAVIOUR	
Interpretation Note: This domain refers to culturally abnormal behaviour in those diagnosed with LD or ASD (as defined by NICE) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in jeopardy, or behaviour which is likely to seriously limit use of or result in the person being denied access to ordinary community facilities as a result of a diagnosis of autism or learning disability. Behaviours linked to mental health conditions should be measured in the psychological and emotional domain.	
Description	**Level of need**
No incidents of behaviour which challenge parents/carers/staff.	No additional needs
Some incidents of behaviour which challenge parents/carers/staff but which do not exceed expected behaviours for age or stage of development and which can be managed within mainstream services (e.g. early years support, health visiting, school).	Low
Occasional challenging behaviours which are more frequent, more intense or more unusual than those expected for age or stage of development, which are having a negative impact on the child and their family / everyday life.	Moderate
Regular challenging behaviours such as aggression (e.g. hitting, kicking, biting, hair-pulling), destruction (e.g. ripping clothes, breaking windows, throwing objects), self-injury (e.g. head banging, self-biting, skin picking), or other behaviours (e.g. running away, eating inedible objects), despite specialist health intervention and which have a negative impact on the child and their family / everyday life.	High
Frequent, intense behaviours such as aggression, destruction, self-injury, despite intense multi-agency support, which have a profoundly negative impact on quality of life for the child and their family, and risk exclusion from the home or school.	Severe
Challenging behaviours of high frequency and intensity, despite intense multi-agency support, which threaten the immediate safety of the child or those around them and restrict every day activities (e.g. exclusion from school or home environment).	Priority

13 Appendix 2: Fast Track Referral Form

Children and Young People's Continuing Care

Fast Track Referral Form

Part 1: To be completed by Referrer				
Child, Young Person and Family Details				
Name		DOB	Gender	NHS No
Home Address		Place of Current Residence		
Others living in the home (and relationship to child)		GP Name and Address		
Parent/Carer(s)		First Language		
		Other communication needs (including preferred method of communication		
NB. details of one parent only are acceptable, but it must be the parent with responsibility.				
Parental responsibility held by		Contact Number:		
Basis of parental responsibility	(e.g. legal guardian, LA section 20)	Email		
Local Authority				

Referral Details	
Date of Referral	
Name and Designation of Person Completing Referral	
Telephone and Email	

Please return this form to:	BSW Clinical Commissioning Group E-MAIL: bswccg.childrensclinicalteam@nhs.net

Fast Track will be considered if the child / young person meets the following criteria:

- A deteriorating condition where the child/young person is referred for end of life care.
- End of life care is deemed appropriate where a child/young person has a short life expectancy (within 12 weeks of the referral date).

Description of nature of illness/condition and how this fits above criteria

Please include:
Written supportive evidence outlining the presenting needs and short life expectancy of the child/young person from a named Consultant.

Description of what support is required, including proposal on how this might be delivered

Key professionals involved	Contact details

Supporting Information Please summarise below details of any relevant assessments made in the last 6 months to support this referral.

Consent ✓ as appropriate	**Yes**	**No**
I have gained the consent of the child/young person/family to provide the above information to be used in a fast track referral.		
Recommendation ✓ as appropriate	**Yes**	**No**
I confirm this information and supporting evidence is accurate and up to date to the best of my knowledge.		

Signature:		Print Name:	
Date:		Relationship/Designation:	
E-mail:		Contact Number:	

Part Two: To be completed by CCG	
Fast Track Decision (including rationale)	Eligible / Not Eligible
Details of Package Agreed	
Date	
Review date Must be within 3 months	
Reviewed by	