NHS
Bath and North East Somerset,
Swindon and Wiltshire
Integrated Care Board

Children's Continuing Care: NHS Bath and North East Somerset, Swindon and Wiltshire Integrated Care Board (ICB) Policy and Process

NHS Bath and North East Somerset, Swindon and Wiltshire (BSW) Integrated Care Board (ICB)

February 2022

NHS BSW continuing care

Policy:	Children's Continuing Care Policy
Policy Reference:	
Policy Statement:	This policy describes the way in which the ICB 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 ICB will commission care in a manner which reflects the choice and preferences of individuals but balances the need for the ICB to commission care that is safe and effective and makes the best use of available resources.
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Author:	Sally Beckley; Designated Clinical Officer
Responsible Owner:	Sharren Pells; Deputy Director of Nursing and Quality
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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
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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://www.bswicb.nhs.uk/your-health/continuing-healthcare (Adults)
Personal Health Budget Policy	V0.10 November 2020	https://www.bswicb.nhs.uk/your-health/continuing-healthcare (Adults)
Compliments Concerns and Complaints Policy – September 2020	05.05.2020	https://www.bswicb.nhs.uk/docs-reports/policies-and-governance
Exceptional Funding Requests Prior Approval Policy	23.07.2020	https://www.bswicb.nhs.uk/docs-reports/exceptional-funding-requests
Safeguarding Adults Children and Looked After Children Policy	07/08/2020	https://www.bswicb.nhs.uk/docs-reports/policies-and-governance/1119-safeguarding-adults-children-and-looked-after-children-policy-2020

Distribution and Consultation

This document has been distributed to the following people for consultation

Name	Date of Issue	Version
Designated Medical Officer	24/07/2020	0.1
Professional Lead for Community Children's Nursing (BANES, Swindon and Wiltshire Local authorities)	24/07/2020	0.2
Parent Carer Forums (BSW Wide)	24/07/2020	0.1
Head of Education and Inclusion Service (BANES, Swindon and Wiltshire Local authorities)	26/06/2022	0.2
Disabled Children's Team Service Manager (BANES, Swindon and Wiltshire Local authorities)	26/07/2022	0.2
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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

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1 FOREWORD

Integrated Care Boards (ICBs) 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 this responsibility for children and young people who may have continuing care needs in Bath, Northeast Somerset, Swindon and Wiltshire (BSW).

The National Framework for Children and Young Peoples Continuing Care 2016 (called the Children's Framework from here on in) covers young people up to their 18th birthday. Thereafter, the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care and the supporting guidance and tools should be used. The National Framework sets out guidance for the process of assessment and agreement of eligibility for child or young person's continuing care and should be read in conjunction with this policy.

2 INTRODUCTION

A continuing care package will be required when a child or young person has needs arising from disability, accident, or illness that cannot be met by existing universal or specialist services alone. Any package of care must be sustainable and integrated with other relevant commissioned services.

This document is designed to provide a recognised policy for children and young people's continuing care. It describes the BSW policy by which a child or young person's is assessed using the principles established in the Department of Health's National
Framework for Children and Young People's Continuing Care, 2016 (Appendix 1 - National Framework). www.gov.uk/government/publications/children-and-young-peoples-continuing-care-national-framework

The Children and Young people's Framework, incorporates the new structure of NHS commissioning created by the Health and Social Care Act 2012. This is also reflected the Children and Families Act 2014, which outlines a new integrated commissioning approach for services for children with special educational needs and disability (SEND) and the changes to adult social care included in the Care Act 2014.

Local authorities and ICBs must collaborate to ensure education health care plans (EHCP) reflect all areas of the child/young person's current needs and how joint arrangements should include an agreement as to how continuing care fits with the EHCP process.

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. 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.

BSW ICB 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 ICB 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

The purpose of this policy is to establish the ICBs' responsibilities to meet the continuing care needs of the child or young person, also to clarify the ICBs' process for assessment and eligibility following the National Framework guidance.

The ICB aim is to work with providers to ensure that robust risk assessment management systems are in place and that they are transparent and open.

4 ROLES AND RESPONSIBILITIES

The **ICB** is accountable and responsible for establishing and managing appropriate governance arrangements for the process and effective management of packages of continuing care. In some instances, the responsibility to deliver packages has been delegated to providers.

Parents and Carers with parental responsibility have the primary responsibility for the care of their children and young people with statutory agencies supporting them to meet the child or young person's identified outcomes.

A team of clinicians listed below who triage, assess and deliver Children's Continuing Care packages for those CYP eligible for NHS funded packages of support.

The Chief Nurse in BSW ICB has executive responsibility for children and young peoples' continuing care and will ensure there is effective liaison with the Local Authority and other partners to ensure the effective management of the continuing care process. The Chief Nurse also has responsibility for quality assurance in relation to Continuing Care and provides assurance is to the Quality and Performance Assurance Committee

The **Children's Continuing Care Panel** works to its Term of Reference in relation to quality, and it feeds back any concerns about continuing care to the appropriate Governance Group.

The **ICB Chief Finance officer** with responsibility for continuing care must ensure that procedures for receiving financial assurance in relation to Continuing Care is in place and is a regular Agenda item at the Finance and Planning Meeting.

The **Children Clinical Assessor's** role is to act as the single point of contact with whom professionals can liaise with if they wish to discuss a child or young person with possible continuing care needs work closely with the local authority (who are responsible for assessing social care and education requirements). They will act as the lead for the assessment phase of the continuing care process and liaise with family and carers to undertake an assessment. The assessor will make recommendations regarding eligibility to panel members. Where eligibility is confirmed, they will work with the family to develop a support plan that identifies the provision required to meet identified health needs. They will ensure the delivery of this plan either via a personal health budget or via a notional budget from the ICBs community services provider.

The arrangements for children with special educational needs or disability (SEND) provide a framework for outcomes-focused joint assessments (Education, Health and Care Plan, (EHCP) involving different partners across Education, Health and Social Care, and many children and young people who need continuing care will have SEND. There may be common elements to both the continuing care assessment and the EHCP, and where appropriate there should be joint working to bring together a single set of outcomes.

5. DEFINITIONS

Child or Young Person (child or young person)

A child or young person referred to within this policy will be aged from 0 up to the date of their 18th birthday. Thereafter, the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care and the supporting guidance and tools should be used. There are significant differences between a child or young person's continuing care and NHS Continuing Healthcare for adults. Although a child or young person's may be in receipt of a package of continuing care, they may not be eligible for NHS Continuing Healthcare or NHS-funded Nursing Care once they turn 18. Further information on how to support transition is given below.

Children and Young People's Continuing Care

A continuing care package will be required when a child or young person's has on-going health needs arising from disability, accident, or illness that cannot be met by existing universal or specialist services alone.

A child or young person may have very complex health needs. These needs 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. These needs may be so complex that they cannot be met by the universal services which are routinely available from GP practices, hospitals or in the community commissioned by ICBs or NHS England. A package of additional health support may be needed. This additional package of care has come to be known as continuing care.

Continuing care is not needed by a child or young person whose needs can be met appropriately through existing universal or specialist services.

The Children's Framework supports ICBs in determining if a child or young person's needs are such that they require a package of continuing care. It provides advice based on existing practice across the country on undertaking a holistic assessment of the child or young person's needs. ICBs have autonomy as to how they fulfil this function and what process they adopt.

Package of Care

A package of care from a care provider, personal health budget or residential service to support the family in meeting the child or young person's health needs. This is arranged and funded by the ICB to meet needs which have arisen from disability, accident, or illness.

6. BSW CHILDREN and YOUNG PEOPLE'S CONTINUING CARE PROCESS

Timescales

A decision on whether a child or young person has a continuing care need is made in a timely way. The clock starts at the point of recognition that a child or young person should have a full Continuing Care Assessment i.e., following any pre-assessment.

The ICBs aim for a decision to be given to the child or young person's and their family within six weeks. However, given the complexity and variety of needs which the ICBs may be assessing, there should be scope for flexibility – where it is not contrary to the best interests of the child or young person. For example, if an assessment is being made pending a child's discharge from hospital which is not planned for several months, other assessments may be reasonably given priority. In cases of very complex needs, there may be several professionals involved. There may also be a need for a simultaneous social care assessment. If the child or young person has a sudden change in health, then the process may be halted to reflect a timely reflection in the assessment.

Stage 1: Identification

The continuing care process begins when there is a recognition that a child or young persons **may** have needs that require additional health services. A child or young person's may be referred for assessment through several different routes, settings and care pathways.

The child or young person's pre-assessment checklist should be completed (with parents' or person with parental responsibility's signed consent) and returned to: Bswicb.childrensclinicalteam@nhs.net

The consent of:
The child or young person (where a child is Gillick competent, or a young person has capacity)
or

A person with parental responsibility for the child or young person (**parental responsibility** means the legal rights, duties, powers, responsibilities, and authority a parent has for a child and the child's property).

Consent must be obtained before the assessment begins. The child or young person's or their parent(s) / carer(s) must be informed what this consent covers, including the sharing of personal information between different professionals and organisations involved in their care.

If a child or young person's or their parent(s) do not give consent to an assessment, the ICBs should discuss the implications with the local authority, as in any other case where consent to treatment is withheld. If the young person is 16 or over, the Mental Capacity Act 2005 may apply if they lack the capacity to consent and a continuing care A is deemed to be in their best interests.

The ICBs consider the referral based on the information in the completed checklist and determines what action is required. It may be appropriate to obtain professional advice to inform a pre-assessment decision. Where possible, this pre- assessment should take no longer than 2-3 days. This is likely that a relatively quick paper-based assessment will give a suitable indication if a child or young person should proceed to a full assessment.

Stage 2: Assessment

The nominated child or young person's health assessor should lead the assessment phase of the continuing care process on behalf of the ICBs. The health assessor should, as a minimum, have the appropriate expertise as set out at paragraph 73 of the Children's Framework.

There are four broad areas of assessment, and each is important for determining the need for continuing care, these are listed below.

- The preferences of the child or young person's and their family
- Holistic assessment of the child or young person's
- Reports and risk assessments from the professionals in the child or young persons' multidisciplinary team
- The DST is not a stand-alone tool and is designed to ensure that relevant needs are assessed, captured, and described in a consistent way.

The nominated child or young person's clinical assessor should demonstrate evidence based professional judgment in each of the four areas to support their recommendation. The assessment of the level of need must recognise that where a child or young person requires constant supervision or care which is largely provided by family members or primary caregivers. There may be a need for support to allow the family time off from their caring responsibilities. This may require a social care assessment.

The results of the assessment should be shared with the child or young person's and their family and care givers and the wider multi-agency team as appropriate.

On review of a care package and where a potential change in provision is considered a full Health Needs Assessment must be completed. If it is determined that a continuing care package is no longer required, a presentation at Panel may be necessary to consider whether to reconfigure the package or to decommission the entire package. In the event of a care package being discontinued there should be a planned withdrawal of care, with the withdrawal period being no earlier than 28 days

At any assessment/ review/ transition assessment if it is identified that the child/young person does not meet the criteria then the following actions will be taken:

- The family are informed of the outcome in writing and are advised of their right to appeal against this decision.
- The family are advised that the ineligibility for continuing care does not affect eligibility for assessment for universal, targeted specialist services. The respective Panel/commissioner will direct the child, young person, family, or key worker to appropriate service provision as required

Exceptionally, information may be withheld from a child or young person's or someone with parental responsibility for them if the ICBs consider that it would be likely to cause significant harm to the physical or mental health or condition of the child or young person's or would otherwise not be in their best interests.

Stage 3: Recommendation
Following the completion of the four areas of assessment, the nominated health assessor should produce recommendations for presentation to the continuing care panel. The evidence should be documented and available for the child or young person's continuing care panel to consider.

Stage 4: Decision
The child or young person's continuing care panel has responsibility for the decision on whether a child or young person has continuing care needs. It is expected that the child or young person's continuing care panel will be able to resolve any disputes regarding the scoring of the domains in the DST.

A decision should ideally be made within six weeks of the commencement of the assessment.

Stage 5: Inform
Following the continuing care panel's decision, the child or young person and their family should be notified within five working days. Decisions should be given verbally to the child or young person and their family or their representative, to be followed by a clear written explanation for the decision.

Key professionals and organisations should also be informed. Methods for information-sharing should fully comply with the ICBs' Information Governance and Data Protection policies. Advice, recommendations, and decisions should be recorded and stored in accordance with the ICBs Information Governance policy.

Resolving disputes: The child or young person's and their family should be informed of their rights and of the local resolution process in the case of a decision which does not meet their preferences and / or expectations.

Stage 6: Arrangement of Provision

The process of assessment will provide an evidence base to inform the development of options for a care package. It is essential that the child or young person's continuing care panel reaches a decision first on whether a child has a continuing care need, before potential packages of care are considered, to avoid a provision-led decision. Where a package has been requested through the ICB, the ICB will liaise with providers.

A package of continuing care should be put in place as soon as possible once the decision has been made, and the child or young person's and their family has been informed. The package of care must be shaped by the child or young person's support needs, rather than by what is offered by providers, offering a "bespoke" package whenever possible.

Involvement of the family / carers / care givers is essential. However, the care package should not be driven by the family / carers / care givers' preference where this conflicts with the needs of the child or young person's or the ICBs' commissioning strategy.

The domains of the DST for child or young person's allows consideration of actual needs, how these are being met, what is working and what interventions or referrals must be made to facilitate unmet needs.

A child or young person's needs are best addressed holistically by all the agencies that are involved in providing them with public services. It is likely that a continuing care package will include a range of services commissioned by the ICB, local authority and sometimes others. The National Framework sets out clear expectations for collaborative working:

> *"Unless there is a good reason for this not to happen, continuing care should be part of a wider package of care, agreed and delivered by collaboration between Health, Education and Social Care."*

Regard should be given to other packages of care already in place and work with other teams to ensure that the continuing care provided fits seamlessly with other care being received. Care planning should begin early, consider hospital discharge needs where appropriate, and be simplified to enable community-based services to provide home-based care wherever possible.

Decisions about residential care and other social care support must be made by the local authority with health working alongside to identify how the child or young person's health needs can be met. Residential care should be used only when other interventions have failed and / or where there are safeguarding issues and it is judged in the best interests of the child or young persons.

Continuing care is intended as provision of essential health support needed by a child or young person's complex needs. It is not intended to be social care provision or any other form of non-clinical support. Where an NHS commissioned carer is providing support in the home as part of a package of continuing care, they should not be providing social care support, or acting as a childminder, unless such a role is explicitly part of a joint package agreed with the local authority, or alternatively, the support constitutes health-funded respite.

It is essential that families / carers / care givers do not rely on continuing care support to fulfil their primary caring responsibilities for a child or young person's (e.g. to allow them to go out or to go to work). Equally, social care support should not be providing what is primarily health care. There will be an acknowledgement of the holistic needs of the family and signposting to alternative services such as social care will be provided as required. A continuing care package is only intended to provide support for an individual child or young person with complex needs and should not support siblings.

BSW ICB and Wiltshire local authority will continue to work together to ensure short breaks services are commissioned to provide further choice of provision and will accommodate the increasing complexity of children with complex and life limiting and life limiting conditions. Packages of continuing care are often, by their nature, providing support – for example, when overnight care is provided to allow parents to sleep, as well as preventing family breakdown, improve the health of the child and the health of their parents/carers.

Throughout the arrangement of provision stage, the child or young person and their family / carers should be kept informed of progress and involved in implementation. Where the proposed package of care varies from the preferred option of the child or young person's or their family / carers, a clear written explanation of the rationale for the decision should be provided.

Stage 7: Review

All children and young people receiving continuing care packages must have a specified review date which the child/young person their parents/carers are informed of. For all new packages of care a review must take place 3 months following initial agreement. This review is undertaken by the Children and Young People's Continuing Care Health Needs assessor and can be a 'light touch' review not to establish appropriateness of the care package. This review does not require formal presentation at a multiagency panel.   Following initial review at 3 months review dates are set at an appropriate interval no greater than 12 months.

Parents/carers must be made aware that they can request a review of the package at any time, and that this request will be considered and progressed accordingly by the Children and Young People's continuing care Health Needs Assessor and/or Commissioner.

A review should also take place when a child or young person's health or function is known to have changed. The purpose of a review is to assess the child or young person's needs and how they are being addressed by the package of care.

On review of a care package and where a potential change in provision is considered a full Health Needs Assessment must be completed. If it is determined that a continuing care package is no longer required, a presentation at Panel may be necessary to consider whether to reconfigure the package or to decommission the entire package. In the event of a care package being discontinued there should be a planned withdrawal of care, with the withdrawal period being no earlier than 28 days.

The child or young person and their family/carers should be informed that:
The reviews are designed to ensure that the child or young person's continuing care needs are being met on an ongoing basis and that they are not financially motivated However, the responsibility to commission continuing care is not indefinite as needs may change.

The Clinical Assessor will arrange a suitable time and venue to carry out the review in partnership with the child or young person's, their family/carers, and a representative from the local authority, if appropriate.

If there is only a minor change in a child or young person's health or function, a full re-assessment is not necessary. If the child or young person's continuing care needs have significantly changed or the means in which needs are being met change then a full reassessment will be required (this may include key transition points such as starting or moving school settings to ensure provision is appropriate to the change in circumstance)

The health assessor undertaking the review should produce recommendations for presentation to the child or young person's continuing care panel. The evidence should be documented and available for the panel to consider.

In instances where transition back into universal or specialist services is appropriate, the child or young person's and their family / carers should be supported throughout this transition.

7. PERSONAL HEALTH BUDGETS (PHB)

Under the National Health Service Commissioning Board and Integrated Care Board (Responsibilities and Standing Rules) (Amendment) Regulations 2013, the families / carers of a child or young person's eligible for continuing care have a “right to have” a PHB, covering the part of their care package which would be provided by the NHS.

Where a child or young person (or their family / carers) eligible for continuing care requests a PHB, the ICB must arrange for the provision of the care by means of a PHB.

This can be achieved in one of several ways

- a direct payment made to the young person or their family / carer
- the agreement of a notional budget to be spent by the ICB following discussions with the child or young person, and their family / carers (or other representative) as to how best to secure the provision they need

- the transfer of a real budget agreed as above, to a person or organisation which applies the money in a way agreed between the ICB and the child or young person, and their family / carers (or another representative).

For more guidance on PHBs, see: 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/**

8. FAST TRACK FOR EXCEPTIONAL CIRCUMSTANCES

End of Life Care (EOL) services are required for a child or young person with a rapidly deteriorating condition and expected short-term life expectancy where a lifespan is thought to be days or weeks rather than months or years. A child or young person who requires fast-track assessment because of the nature of their needs should be identified early and their needs met as quickly as possible. The child or young person's continuing care team will receive a Fast Track referral from professionals working with the child or young person's and appropriate provision will be sourced. The ICBs will work in partnership with local services.

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. A child or young persons who requires fast-track assessment because of the nature of their needs should be identified early and their needs met as quickly as possible.

The child or young person's continuing care team will ensure that such a child or young person's is known to the specialist palliative care services for assessment (hospices are considered the specialist palliative care services, these are charitable organisations). If there is an existing EOL pathway in progress, this should be followed in the first instance. A child or young person who meets the criteria for children's palliative care nursing services, and whose needs can be met, should receive that service, and does not need to go through the continuing care process; they should be able to receive continuing care immediately. If the health needs can no longer be met by the children's palliative care nursing service, then a fast-track referral should be submitted for consideration for a package of continuing care funded by the ICBs.

9. TRANSISTION FROM CHILD TO ADULT SERVICES.

Principles and Process

Transition from children's services to adult services begins at the age of 14 (Year 9). For all young people aged 14 or above, interventions which work towards fostering independence within the family unit will be promoted. This will involve the child/ young person assuming responsibility for decision making wherever this is feasible.

Adult continuing healthcare commissioners will be notified of all young people in receipt of continuing care packages when they become 14 years of age and be provided with a completed and current Health Needs Assessment. This will be undertaken by the children and young people's continuing care health needs assessor.

In line with the recommendations within the National Framework, Adult continuing care services must screen Young People who are receiving continuing care at age 16. Therefore, the children's continuing care lead will formally refer the young person to the adult NHS continuing healthcare team to the relevant NHS commissioner. 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. 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 continuing care funding the ICB will trigger an adult CHC assessment.

If a young person who receives children's continuing care has been determined by the relevant NHS Commissioner not to be eligible for a package of adult NHS continuing healthcare in respect of when they reach the age of 18, they should be advised of their non-eligibility and of their right to request an independent review, on the same basis as NHS continuing healthcare eligibility decisions regarding adults. The Children's Continuing Care service should continue to 21 participate in the transition process, in order to ensure an appropriate transfer of responsibilities, including consideration of whether they should be commissioning, funding or providing services towards a joint package of care.

A key aim is to ensure that a consistent package of support is provided during the years before and after the transition to adulthood. The nature of the package may change because the young person's needs or circumstances change. However, it should not change simply because of the move from children to adult services or because of a change in the organisation with commissioning or funding responsibilities. Where change is necessary, it should be carried out in a planned manner, in full consultation with the young person. No services or funding should be unilaterally withdrawn unless a full joint health and social care assessment has been carried out and alternative funding arrangements have been put in place.

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

10. MONITORING AND EVALUATION.

This policy has been approved in accordance with ICB guidance and will be reviewed every two years. Where review is necessary due to legislative change, the review will occur immediately.

11. SAFEGUARDING.

All organisations providing services for children are required to work together effectively to safeguard children and promote their welfare (Working Together, 2018). Concerns should be raised using local processes as described in the ICBs' Adult and Child Safeguarding policy.

12. DATA PROTECTION / INFORMATION GOVERNANCE

Data held by the ICB is governed by the General Data Protection Regulation (GDPR) and the Data Protection Act 2018 (DPA). Please refer to the ICB's Individual Rights Policy, available on the intranet.

13. EQUALITY STATEMENT

In applying this policy, the ICBs will have due regard to the aims of the general equality duty when making decisions and setting policies for the need to eliminate unlawful discrimination, promote equality of opportunity and provide for good relations between people of diverse groups, in particular on the grounds of the following characteristics protected by the Equality Act (2010); age, disability, sex, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, and sexual orientation, in addition to offending background, trade union membership, or any other personal characteristic.

14. COMPLAINTS, APPEALS AND DISPUTE RESOLUTION

BSW ICB 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 ICB are keen to ensure that these disputes are managed locally and resolved at the earliest opportunity. As such the ICB has developed a clear process for either making a complaint or appealing against a multi-agency panel decision.

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

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 continuing care G in conjunction with Social Services and Education staff. It may also be necessary to contact other organisations to gather information to support this assessment.		
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 continuing care G 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 Integrated Care Board E-MAIL: bswicb.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**	
Address			
Email Address		**Contact Number**	

Team			
Name		**Professional**	
Address			
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 continuing care G or go to: http://www.nhs.uk/CarersDirect/guide/practicalsupport/Documents/National-framework-for-continuing-care-england.pdf

Part Two: To be completed by continuing care G

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	
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 • can breathe 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

<u>Interpretation Note:</u> 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 their 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/herself.	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 everyday activities (e.g. exclusion from school or home environment).	Priority

Children and Young People's Continuing Care Decision Support Tool

Part 1: Child, Young Person, Family and Professional Details

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	
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			
Current education setting			

Assessment Details			
Date of Assessment			
Name and Designation of Person Completing Assessment			
Telephone and Email			
Over 14 years, offer care act assessment	Yes	No	n/a
Has transitions been discussed	Yes	No	n/a

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	
Address			
Email Address		Contact Number	

Team			
Name		Professional	
Address			
Email Address		Contact Number	

Team			
Name		Professional	
Address			
Email Address		Contact Number	

Team			
Name		Professional	
Address			
Email Address		Contact Number	

Please List Supporting Documents and other key evidence that was taken into account in completing the DST
e.g. Hospital discharge letter; Clinic Letters; EHCP; Care Plans; Social Care Assessment

NB. some forms are Essential * any domain scored high or above should have evidence to support needs identified.

Supporting Document Title	**Report From** (inc. name and contact details)	**Date of Document**	**Date Received**

Part 2: Child, Young Person and Family Views

Involvement	
Was the child or young person involved in the completion of the DST?	
Was the child or young person offered the opportunity to have a representative such as a parent, carer, family member or other advocate contribute to the DST?	
Please state who was present during assessment meeting	
How the child or young person (or their representative) contributed to the assessment of their needs.	

Summary of child/young person and family views

Include:

- Pen portrait of the child/young person, their strengths, current situation and needs, include one page profile where available.
- Child/Young Person and Family's view of most significant needs and support that would help them.
- Whether they are in agreement with the proposed levels of needs for any of the domains (and if not the reasons for the disagreement).

Part 3: Professional Summary

Holistic summary of child/young person’s needs
Please describe what support is currently being accessed and any potential support options that are not currently being accessed

Part 4: Care Domains

For each domain Provide the referenced supporting evidence that informs on which domain level is proposed/appropriate, including the frequency and intensity of needs, unpredictability, deterioration and any instability.

Breathing

Describe the child or young person's specific needs relevant to this domain, reference supporting evidence and clinical rational for assessor score	
Evidence:	
Level of need identified by assessor	Parent/carer comments regarding level of need

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; • 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

Describe the child or young person's specific needs relevant to this domain, reference supporting evidence and clinical rational for assessor score	
Level of need identified by assessor	Parent/carer comments regarding level of need

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	High Dysphagia management plan ordinarily applies when tube feeding is not possible. *Please note this section is related to eating disorders not other vomiting issues which could be linked to paragraph above about faltering growth.

reassessment. Despite the plan, there remains a risk of choking and/or aspiration.	
The majority of fluids and nutritional requirements are routinely taken by intravenous means.	Severe

Mobility

Describe the child or young person’s specific needs relevant to this domain, reference supporting evidence and clinical rational for assessor score	
Level of need identified by assessor	Parent/carer comments regarding level of need

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.

Describe the child or young person's specific needs relevant to this domain, reference supporting evidence and clinical rational for assessor score	
Level of need identified by assessor	Parent/carer comments regarding level of need

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**.)

Describe the child or young person's specific needs relevant to this domain, reference supporting evidence and clinical rational for assessor score	
Level of need identified by assessor	Parent/carer comments regarding level of need

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.

Describe the child or young person's specific needs relevant to this domain, reference supporting evidence and clinical rational for assessor score	
Level of need identified by assessor	Parent/carer comments regarding level of need

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).

Describe the child or young person's specific needs relevant to this domain, reference supporting evidence and clinical rational for assessor score	
Level of need identified by assessor	Parent/carer comments regarding level of need

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**	Severe

requires continuous intravenous medication, which if stopped would be life threatening (e.g. epoprostenol infusion).	
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

(beyond what would typically be expected from a child or young person of their age)
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.

Describe the child or young person's specific needs relevant to this domain, reference supporting evidence and clinical rational for assessor score	
Level of need identified by assessor	Parent/carer comments regarding level of need

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

Describe the child or young person’s specific needs relevant to this domain, reference supporting evidence and clinical rational for assessor score	
Level of need identified by assessor	Parent/carer comments regarding level of need

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.

Describe the child or young person's specific needs relevant to this domain, reference supporting evidence and clinical rational for assessor score	
Describe the actual needs of the child or young person, including any episodic needs. Provide the evidence that informs the decision overleaf on which level is appropriate, such as the times and situation when the behaviour is likely to be performed across a range of typical daily routines and the frequency, duration and impact of the behaviour.	
Level of need identified by assessor	Parent/carer comments regarding level of need

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

Part 5: Assessor Recommendations

Summary of assessors scores from DST

Care Domain	**Priority**	**Severe**	**High**	**Moderate**	**Low**	**No Additional Needs**
Breathing						
Eating and drinking						
Mobility						
Continence and elimination						
Skin and tissue viability						
Communication						
Drug therapies and medicines						
Psychological and emotional						
Seizures						
Challenging Behaviour						
Totals						

Clinical Recommendation

Please give a recommendation as to whether or not the child or young person has complex needs that exceeds those provided for by Universal, targeted and Specialist Services.

This should take into account the range and levels of need recorded in the Decision Support Tool; key characteristics in the table above and from the Children's Framework (see appendix A). Any disagreement on levels used or areas where needs have been counted against more than one domain should be highlighted here.

Date of Review	
Reviewed by	

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 Integrated Care Board E-MAIL: bswicb.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.

Brief Description of nature of illness/condition:

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 continuing care G	
Fast Track Decision (including rationale)	Eligible / Not Eligible
Details of Package Agreed	
Date	
Review date Must be within 3 months	
Reviewed by	

APPENDIX 3 - CHILDREN AND YOUNG PEOPLE'S CONTINUING CARE (CYPCC) FRAMEWORK

www.gov.uk/government/publications/children-and-young-peoples-continuing-carenational-framework

Process for assessing, deciding and agreeing continuing care for children with complex health needs.

Published 22 January 2016
Department of Health and Social Care

This guidance is for Integrated Care Boards when assessing the needs of children and young people (0 to 17 years) whose complex needs cannot be met by universal or specialist health services.

The 'Decision support tool', which should be used with the framework, provides a structure to help in reaching a decision

The guide for young people and parents is for use by local health organisations who can add their own contact details.

The updated framework follows a public consultation. Comments and suggestions received in the consultation are reflected in the new framework

APPENDIX 4 - CYPCC DECISION SUPPORT TOOL (DST)

www.gov.uk/government/publications/children-and-young-peoples-continuing-carenational-framework

National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (CHC and FNC)
www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcareand-nhs-funded-nursing-care

This guidance sets out the principles and processes of the national framework for NHS continuing healthcare and NHS-funded nursing care

APPENDIX 5 - CHC CHECKLIST

www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcareand-nhs-funded-nursing-care

GLOSSARY

CHC	Continuing Healthcare
CYP	Children and Young People
CYP CC	Child or Young Person Continuing Care
DH	Department of Health
DPA	Data Protection Act
DST	Decision Support Tool
EHCP	Education Health and Care Plan
EOL	End of Life
GP	General Practitioner
PD	Personal Data
PHB	Personal Health Budget
SEND	Special Education Needs and Disability
TOR	Terms of Reference