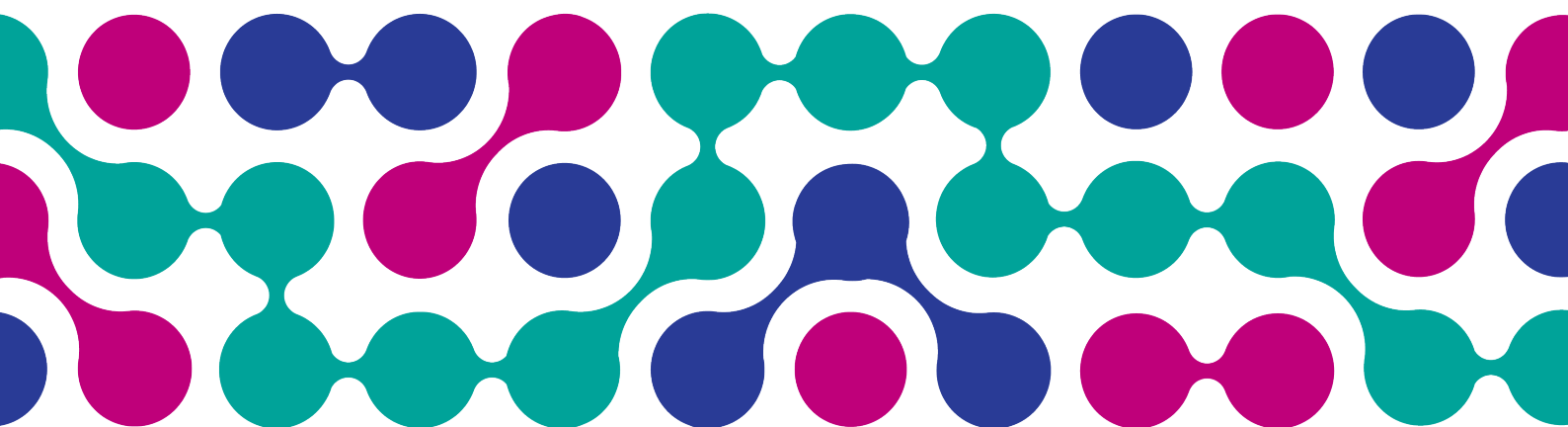


Children's and Young People's Continuing Care Policy

BSW ICB policies can only be considered to be valid and up-to-date if viewed on the intranet. Please visit the intranet for the latest version.



BSW ICB Children's Continuing Care Policy

Purpose	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.
Document type	Policy
Reference Number	PA04
Version	2.1
Name of Approving Committees/Groups	Executive Management
Operational Date	20 December 2023
Document Review Date	December 2026
Document Sponsor (Job Title)	Chief Nurse
Document Manager (Job Title)	Designated Clinical Officer
Document developed in consultation with	Children Complex Needs Assessors
Intranet Location	Continuing Healthcare (CHC) policies (icb.nhs.uk)
Website Location	https://bsw.icb.nhs.uk/documents-and-reports/
Keywords (for website/intranet uploading)	BSW ICB Children and Young People's Continuing Care Policy

BSW ICB Children’s Continuing Care Policy

Review Log

Version Number	Review Date	Name of reviewer	Approval Process	Reason for amendments
1.0	14/01/2021		Original version	
2.0	18/12/2023	Sharren Pells – Deputy Director of Nursing and Quality	BSW ICB Quality and Outcomes Committee	Implementation of the national framework for Children and Young People’s Continuing Care and BSW pathway.
2.1	17/02/2023	Sharren Pells - Deputy Chief Nurse	Executive Management	Routine review and update of appeals section reviewed by Policy Steering Group 11 November 2023. Amendments completed; Policy Steering Group recommended policy for Executive Approval 11 December 2023. Executive Management Approval completed 20 December 2023.

BSW ICB Children's Continuing Care Policy

Summary of Policy

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.

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.

BSW ICB Children’s Continuing Care Policy

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INTRODUCTION & PURPOSE

1. 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.
2. This Operational Policy is the overarching statement of approach for the delivery of a Children and Young People's Continuing Care for the population (0-18yrs) for whom NHS Bath and North East Somerset, Swindon and Wiltshire Clinical Commissioning Group (NHS BSW CCG) is the responsible commissioner.
3. The National Framework for Children and Young People's Continuing Care (2016) describes the principles and the process for establishing eligibility.
www.gov.uk/government/publications/children-and-young-peoples-continuing-care-national-framework
4. The framework also describes how Local authorities and ICBs must collaborate to ensure Education Health and 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.
5. The National Framework for Children and Young People's Continuing Care 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.

SCOPE

6. This Policy covers children and young people aged 0-18yrs, for those older than this please refer to the Adult Continuing Healthcare Policy.
7. 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 including the appeals process, following the National Framework for Children and Young People's Continuing Care.
8. This policy is related only to Children and Young Peoples Continuing Care (as per the National Framework 2016) and is not intended to describe the ICBs position on any other complex needs or joint funding agreements.
9. NHS principles set out within the Who Pays? Guidance (2022) will apply in all instances.

This policy describes the processes that will be followed by NHS BSW ICB and should be read in conjunction with the following documents:

- The National Framework for Children and Young People's Continuing Care (2016). www.gov.uk/government/publications/children-and-young-peoples-continuing-care-national-framework
- Who Pays? Determining responsibility for payments to providers (NHS England 2022) <https://www.england.nhs.uk/who-pays/>
- National Framework for NHS Continuing Healthcare and NHS funded Nursing Care (2023) [National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care - July 2022 \(Revised\) - corrected May 2023 \(publishing.service.gov.uk\)](https://www.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/114444/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care-july-2022-revised-corrected-may-2023.pdf)

PROCESS

Timescales

10. 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.
11. 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

12. 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 may be referred for assessment through several different routes, settings, and care pathways.
13. 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
14. If a child who is under 16 does not have the capacity to give consent, someone with parental responsibility can consent for them, but that person must have the capacity to give consent.
15. Consent must be obtained before the assessment begins. The child or young person 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.
16. If a child or young person or their parent(s) do not give consent to an assessment, the

ICB 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 assessment is deemed to be in their best interests.

17. The ICB will consider the referrals based on the information provided by the referrer. It may be appropriate to obtain additional professional advice to inform a pre-assessment decision. Where possible, this pre- assessment should take no longer than 2-3 days to determine if a full assessment is warranted.
18. The Pre-Assessment Checklist indicates whether the child/young person may meet the continuing care criteria and will therefore move to a full assessment. If the Pre-Assessment Checklist indicates that the child/young person is highly unlikely to meet the eligibility for continuing care funding, they will not move to a full assessment. A case manager will meet with the referrer to explain the rationale for this decision, the family will then be notified by the referrer of the decision. There is no right of appeal for a checklist. If a parent/carer wish to make a complaint the ICB complaints team can be contacted: scwcsu.palscomplaints@nhs.net or by phone 0300 561 0250.

Stage 2: Assessment

19. The nominated child or young person's Case Coordinator should lead the assessment phase of the continuing care process on behalf of the ICB.
20. 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 and their family
 - Holistic assessment of the child or young person
 - 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.
21. The nominated child or young person's Case Coordinator 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.
22. The results of the assessment should be shared with the child or young person and their

family and care givers and the wider multi-agency team as appropriate.

23. 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.
24. 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

25. Following the completion of the four areas of assessment, the nominated Case Coordinator should produce recommendations for presentation to the Children and Young People's Continuing Care Panel. The evidence should be documented and available for the panel members to consider.

Stage 4: Decision

26. The panel has responsibility for deciding eligibility and on the suitability of recommended provision to meet identified needs. Panel members will resolve any uncertainty regarding the scoring of the domains in the DST.
27. A decision should ideally be made within six weeks of the commencement of the assessment. However, it is recognised that in some circumstances this timeline may not be possible.

Stage 5: Inform

28. Following the continuing care panel's decision, the child or young person and their family should be notified within seven 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.
29. 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.

30. **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

31. The process of assessment will provide an evidence base to inform the development of options for a care package. It is essential that the Children and Young People'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 the Children, young person and their families / carers to review options and gain preferences on how this will be delivered.
32. 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 and their families / carers views have been captured. 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.
33. 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 or the ICBs' commissioning strategy.
34. The domains of the Decision Support Tool for child or young person allows consideration of needs, how these are being met, what is working and what interventions or referrals must be made to facilitate unmet needs.
35. 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."

Individual discussions will take place with Social Care and Education partners to ensure each agency is financially accountable for the provision their service has statutory responsibility for, e.g., ICB will fund health provision, whilst social care and education will fund their services contribution to the overall package. Panel administrator will confirm with ICB finance teams decisions made in respect of NHS funding agreements.

36. 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.

37. 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 person.
38. 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.
39. It is essential that families / carers do not rely on continuing care support to fulfil their primary caring responsibilities for a child or young person (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.
40. BSW ICB and its coterminous local authorities 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 conditions. Packages of continuing care are often, by their nature, providing support /short breaks – 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.
41. 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

42. 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 Case Coordinator and can be a 'light touch' review to establish appropriateness of the care package to ensure it is meeting expected outcomes. Following this initial review, eligibility and care packages including Personal Health Budgets will be reviewed annually. The Case Coordinator will arrange a suitable

time and venue to carry out the review in partnership with the child or young person, their family/carers, and a representative from the local authority, if appropriate.

43. Parents/carers can request a review of the package if there are any significant changes in the needs of the child, and that this request will be considered and progressed accordingly by the Case Coordinator and/or Commissioner.
44. 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.
45. On review of a care package and where a potential change in provision is considered, a full Health Needs Assessment should also be completed. If it is determined that a continuing care package is no longer required, a presentation at the Children and Young People's Continuing Care Panel may be necessary to consider decommissioning the 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.
46. 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.
47. If there is only a minor change in a child or young person's health or circumstances, a full re-assessment is not always 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)
48. The Case Coordinator undertaking the review should produce recommendations for presentation to the Children and Young People's Continuing Care Panel. The evidence should be documented and available for the panel to consider.
49. 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.

Personal Health Budgets

50. 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 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.
51. 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.

52. 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).

53. 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/

Fast Track for Exceptional Circumstances

54. 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 Case Coordinator 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 palliative care services.
55. 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 and by a children’s continuing care assessor and a senior clinical or operational manager of all age continuing care team in order to agree eligibility for a support package that meets the needs of the child or young person as quickly as possible.
56. The Case Coordinator will ensure that the 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; 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.

Transition from Child to Adult Services

Principles and Process

57. 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.
58. 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.
59. In line with the recommendations within the National Framework the formal referral for adult screening for adult CHC should take place at 16. As soon as practicable after the 17th birthday eligibility should be determined in principle by the relevant ICB. Entitlement to adult NHS Continuing Healthcare should be initially established using the process set out in the adult framework, including the checklist and Decision Support tool.
60. At 18 years of age, full transition to adult NHS Continuing Healthcare or to universal and specialist health services should have been made, except in instances where this is not appropriate.
61. The Case Coordinator will formally refer the young person to the adult NHS Continuing Healthcare Team to the relevant NHS commissioner.
62. There are significant differences between Child and young Person'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.
63. 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.
64. If a young person who receives Child and young Person'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.
65. 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.

66. 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>

Appeals of Eligibility and Complaints

67. BSW ICB recognise 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 concerns are managed locally and resolved at the earliest opportunity (please refer to appeals section below).
68. All emails/letters sent out from the ICB following decision making will have information of how to appeal a decision or to make a formal complaint through the NHS complaints process.

Complaints:

69. If a parent/carer have a complaint regarding a package of care or service already being provided, they should contact the complaints team of that service or can contact the Case Coordinator for advice. The team can be contacted via the central email inbox: bswicb.childrensclinicalteam.nhs.net or the ICB complaints team can be contacted: scwcsu.palscomplaints@nhs.net or by phone 0300 561 0250

Grounds for Appealing of Eligibility Decision

70. There are considered to be only two occasions which would arise and provide grounds for appeal:
- The parent/carer or the young person or believes inaccurate or out of date information was used in the assessment process.
 - The parent/carer or the young person believes that there has been a failure to follow the National Child and young Person's Continuing Care Framework (2016) which has impacted on the panel's decision.

Appealing a Panel Decision Regarding Eligibility

71. If a parent/carer or the young person wish to appeal a decision made by the Child and

young Person's Continuing Care Panel they should follow the process below, clearly stating the reason for the appeal.

72. Appeals should be made in writing with any additional clinical information or evidence within 28 days of the notification of the decision to: - Bswicb.childrensclinicateam.nhs.net

Or tracked delivery to: -
Children's Continuing Care Team
Bath Swindon & Wiltshire Integrated Care Board
Jenner House
Unit3 Langley Park
Avon Way
Chippenham
SN15 1GG

73. If the parent/carer and/or the young person is unable to submit an appeal in writing, they should phone the Case Coordinator for further assistance.
74. Appeals may only be made by the parent/carer or the young person with their written consent provided.
75. The grounds for appealing eligibility decision (see reasons permitted above) must be clearly stated in the letter of appeal and must include details of the perceived error or updated clinical reports that would have been available at the time the assessment was completed.

Stage 1

76. A Case Coordinator will meet with the family for an informal discussion regarding the process and levels of the Child or Young Persons health needs.
77. The Case Coordinator will meet with an ICB Senior Manager to review the appeal along with any new information and make a decision on the relevance of any additional information and consider if the correct procedure was followed. If this process concludes that there have been no procedural errors or there is no additional information of relevance, then the appeal will not be accepted. This decision is final.
78. The decision will be communicated in writing to the parent/carer and/or the young person. If a parent/carer wish to make a complaint the ICB complaints team can be contacted: scwcsu.palscomplaints@nhs.net or by phone 0300 561 0250.

Stage 2 – Appeal to Panel

79. If stage 1 identifies that there has been an error in process or there is relevant additional clinical information that should have been considered, then the Case Coordinator will

update the assessment and re-present this to an independent panel for review of the decision.

80. If the parent/carer and/or the young person remain dissatisfied, they may raise a formal complaint via the NHS complaints process via the ICB complaints Team: scwcsu.palscomplaints@nhs.net or by phone 0300 561 0250.

Organisational Disputes

81. Continuing care arrangements have the potential to generate disputes regarding responsibilities for health, social care, and education funding.
82. The National Framework for Children and Young People's Continuing Care (2016) states that disputes about who should have commissioning responsibility should be resolved through escalation to relevant executives, or through the involvement of impartial peers.

ROLES & RESPONSIBILITIES

83. 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.
84. **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.
85. 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.
86. **The Chief Nurse in BSW ICB** has executive responsibility for children and young people's 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.
87. 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.
88. The **Case Coordinator'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.

89. The arrangements for children with special educational needs and 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, some children and young people who are found eligible for continuing care may also have SEND, where appropriate there should be joint working to bring together a single set of outcomes.

TRAINING

90. The Case Coordinator deliver training to partners to ensure they are aware of the Child and Young Person's Continuing Care Framework and Local BSW polices and processes.

EQUALITY IMPACT ASSESSMENT

91. 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.

MONITORING EFFECTIVENESS

92. The ICB is committed to monitoring any incidents, the Chief Nurse will provide oversight to ensure the Policy is implemented correctly and the effectiveness of this policy will be reviewed the Nursing and Quality Team.

REVIEW

93. This document is reviewed every three years unless organisational changes, legislation or guidance prompt an earlier review. Recurrent instances of non-compliance will be investigated to ascertain the source of non-compliance. If it is found that the policy itself is a source of non-compliance, e.g., is not sufficiently clear, this will trigger a review also.

REFERENCES AND LINKS TO OTHER DOCUMENTS

References

Title/Author	Institution	Comment / Link
Department of Health and Social Care		https://www.gov.uk/government/publications/children-and-young-peoples-continuing-care-national-framework

Other documents

BSW ICB Continuing Healthcare Operational Policy <https://www.bswicb.nhs.uk/your-health/continuing-healthcare> (Adults)

Personal Health Budget Policy <https://www.bswicb.nhs.uk/your-health/continuing-healthcare> (Adults)

Compliments Concerns and Complaints Policy – September 2020
<https://www.bswicb.nhs.uk/docs-reports/policies-and-governance>

Exceptional Funding Requests Prior Approval Policy <https://www.bswicb.nhs.uk/docs-reports/exceptional-funding-requests>

Safeguarding Adults Children and Looked After Children Policy
<https://www.bswicb.nhs.uk/docs-reports/policies-and-governance/1119-safeguarding-adults-children-and-looked-after-children-policy-2020>

The National Framework for Children and Young People's Continuing Care (2016).
www.gov.uk/government/publications/children-and-young-peoples-continuing-care-national-framework

Who Pays? Determining responsibility for payments to providers (NHS England 2022) <https://www.england.nhs.uk/who-pays/>

National Framework for NHS Continuing Healthcare and NHS funded Nursing Care (2023)
[National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care - July 2022 \(Revised\) - corrected May 2023 \(publishing.service.gov.uk\)](https://www.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/111111/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care-july-2022-revised-corrected-may-2023.pdf)

APPENDICES

A – Continuing Care Panel Terms of Reference

The Terms of Reference are appended for information and reference. They do not form part of the policy.

1. Introduction

- 1.1 Integrated Care Boards (ICBs) have a legal statutory responsibility for securing and funding to a reasonable extent the health care which an individual needs.
- 1.2 The terms of reference for the BSW Children's Continuing Care (CYPCCC) describe the local process to ensure equitable discharge of that responsibility for children and young people with complex needs in Bath, North East Somerset, Swindon and Wiltshire (BSW).

2. Purpose and Scope

- 2.1 To provide a forum for partnership working with the Local Authorities and to comply with the National Children and Young People's Continuing Care Framework (2016) to consider the eligibility and funding for children and young people's continuing care (0-18yrs) across BaNES, Swindon, and Wiltshire.
- 2.2 To share expertise, Decision Support Tools (DST) and information on individual cases and provide a joint decision forum across BaNES, Swindon, and Wiltshire.
- 2.3 Work collectively across BaNES, Swindon and Wiltshire to ensure consistency and equality of decision making.
- 2.4 The panel is responsible for the review and quality assurance of children's continuing care packages for BSW (and associated Personal Health Budgets).

The three Local Authority areas have their own arrangements and forums in place consider and agree as appropriate the management of children with complex needs who do not meet CCC criteria but who require additional support or out of area provision.

3. Objectives

For the cases considered within the purpose and scope outlined above:

- 3.1 To provide a consistent approach to providers and local authorities and provide consistent communication to parents across the area.
- 3.2 To provide a clear multi agency decision making process which is robust, transparent, and equitable.

3.3 To review appeals: NB this will require different decision makers to the original panel members.

4. Membership

Panel Chair	Deputy Chief of Nursing
Deputy Chair	Children's Commissioner (from relevant locality)
Lead Clinicians	Designated Clinical Officer Designated Looked After Children's Nurse
SEND representative	As delegated by each local authority
Social Care Representative	As delegated by each local authority
Presenting Clinician/Practitioner	Case Co-ordinators
Panel Administrator	Commissioning Support Officer
Specialist advisors	e.g., maybe CAMHS or LD specialist, or representative from children's continuing care teams if case requires specialist advice.
Adult/Transitions Representative (for children 14+)	As delegated by each local authority
Adult/Transitions Representative (for children 14+)	ICB
External SW Children's Continuing Care Representative	From SW Children's Continuing Care Network for Peer Review and Quality Assurance as required

5. Quorum

5.1 The quorum necessary for the panel to convene should be agreed prior to the panel taking place. This should be at least one representative from ICB, education and social care. The panel administrator should advise The Chair, or in their absence, the Deputy as soon as practically possible of any changes to the panel membership. The Chair/Deputy will make the decision as to whether the membership is sufficient for the panel to proceed. It is the responsibility of panel members to feedback to their own organisations regarding the decisions made in panel.

6. Meeting Frequency

6.1 The Panel will meet monthly.

6.2 Meetings will be held virtually via MS Teams to maximise representation from each locality. Local authority Colleagues will only attend the session of the panel which relates to cases from their own Locality.

6.3 Where there are no identified cases for panel, the panel administrator will advise The Chair, or the Deputy, as soon as possible, the Chair/Deputy, will make the decision to cancel the panel if necessary.

7. Process

- 7.1 All referrals to the Panel will be made via e-mail bswicb.childrensclinicalteam@nhs.net to the Panel Administrator as soon as possible, but no later than 7 working days ahead of the panel date.
- 7.2 Referrals should include the name of the referrer; the name and date of birth of the child or young person; supporting evidence outlining the child's needs and any costing for proposed packages of care.
- 7.3 The Panel Administrator will ensure that a list of cases to be presented and supporting documents is made available to panel members no less than 5 days prior to panel. The case list should stipulate what category the case falls into and the name of the presenting clinician/practitioner.
- 7.4 The Local Authority Social Care representative will provide information and guidance on the social care provision and relevant issues relating to their own locality.
- 7.5 The ICB Children's Commissioners or Lead Clinicians will provide information and guidance on health provision and relevant issues relating to individual cases. They will agree health components of the package or advise the relevant panels for the case to be taken for sign off.
- 7.6 The SEND Local Authority representative will provide information and guidance on SEND/education provision and relevant issues relating to individual cases. They will agree any changes to social care provision as part of a holistic review of care needs or advise the relevant social care panels for the case to be taken for sign off.
- 7.7 For CCC cases the case manager will present the case to panel once the decision support tool has been completed (with involvement from multi-agency professionals and the child and family). The presentation should include the DST along with additional supporting information and the assessor's recommendations for required package of care.
- 7.8 Where the Panel do not agree with the clinical assessor's domain scores or recommended package this will be documented, and the rationale clearly explained.
- 7.9 A suitable period of review for each case will be discussed and recorded as part of the discussion. As a minimum each case should be reviewed annually or where there is a change in a child or young person's needs.
- 7.10 The eligibility decision of the panel will be final. The chair of the panel will have the final say if panel members cannot agree a majority decision. All panel decisions will be clearly documented and shared with the referrer and members of the panel in writing.
- 7.11 All decisions relating to CCC eligibility will be followed up with a letter to the parent/carer sharing the outcome of the decision and details of the appeals and complaints process (see section 9).
- 7.12 Panel notes will be checked and signed by the Panel Chair/Deputy to ensure accuracy. Once checked they will **only** be circulated to panel members as they will contain

information about a number of children. Wherever possible professionals known to the child (i.e., social worker or SEND lead worker) will be invited to attend discussion related to that individual.

8. Decision Making

8.1 Panel members will:

- 8.1.1 Use a solution focussed approach to decision making.
- 8.1.2 Ensure agreed recommendations/decisions which require actions are completed within agreed timescales.
- 8.1.3 Provide expertise on the proposed service to be offered [current or planned] identifying how these will meet the needs of the child or young person in relation to achieving successful outcomes.

8.2 Panel decisions will be based on:

- 8.2.1 The identified, health and social care needs of child or young person based on the 10 domains described in the National Children and Young People's Continuing Care Framework (2016).
- 8.2.2 The quality and suitability of the proposed provision for the child or young person and the extent to which it meets their needs.
- 8.2.3 The child or young person's views on the proposed provision
- 8.2.4 The parent/carers views on the proposed provision.
- 8.2.5 The costs of any proposed packages.

8.3 All packages agreed through panel should:

- 8.3.1 Be sufficient to meet the identified needs of the child or young person.
- 8.3.2 Offer value for money for the ICB/LA
- 8.3.3 Have a clear outcome focused plan that is achievable for the young person and will deliver a quality service.
- 8.3.4 Have clear timescales for review.
- 8.3.5 Should be reviewed to consider if a Personal Health Budget would be suitable to meet the needs of the child or young person.

9. Accountability

9.1 The BSW Children's Continuing Care Panel is accountable to BSW Quality and Outcomes committee and seeks to fulfil responsibilities for the ICB and local authorities under:

9.1.1 The Children and Families Act 2014

"Local authorities must do so with a view to making sure that services work together where this promotes children and young people's wellbeing or improves the quality of

special educational provision (Section 25). Local Authorities must work with one another to assess local needs. Local authorities and health bodies must have arrangements in place to plan and commission education, health and social care services jointly for children and young people with SEN or disabilities (Section 26)."

9.1.2 The National Framework for Children and Young People's Continuing Care 2016

"The second phase, decision-making involves a multi-agency forum or panel considering the evidence and the assessor's recommendation, to reach a decision as to whether or not the child or young person has a continuing care need. (Paragraph 10)"

"The panel should be independent from those involved in assessment, and include key ICB and local authority professionals, and at least one clinician. (Paragraph 84)"

10. Appeals and Complaints

10.1 Parents/carers can appeal against the Children's Continuing Care Assessment eligibility decision in accordance with the Framework, including if they feel the assessment has not been completely accurately (refer to CYP CCC Policy).

10.2 The right to appeal will be communicated to parents/carers in all letters containing panel decisions. Parents/Carers will be given 28 days from the date of the letter in which to submit any appeals to the bswicb.childrenscontinuingcare@nhs.net

10.3 Complaints can be taken forward through the processes outlined in the BSW Compliments, Concerns and Complaints Policy.

11. Safeguarding

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

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

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

12. Data Protection

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

B – Glossary of terms

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

C – Children and Young People’s Continuing Care (CYPCC Framework)

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

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.

D – CYPCC Decision Support Tool (DST)

www.gov.uk/government/publications/children-and-young-peoples-continuing-care-national-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

E – Continuing HealthCare (CHC) Checklist - Adult

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