Bedfordshire, Luton and Milton Keynes
Integrated Care Board

Children and Young People's Continuing Care Operational Policy

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Document Control	
Document Owner:	Chief Nurse Officer
Document Author(s):	AACC Quality & Assurance Manager
Directorate:	Nursing
Approved By:	BLMK ICB Operational Group
Date of Approval:	30-07-2025
Date of Next Review:	30-07-2027
Effective Date:	06-07-2022

Version Control			
Version	**Date**	**Reviewer(s)**	**Revision Description**
Final v1	06-07-2022		
Draft v2.0	02-06-2025	AACC Quality & Assurance Manager	Changes to reflect organisation restructure
Final v2.0	30-07-2025	Operational Group	Biennial review of the policy approved by BLMK ICB Operational Group

Implementation Plan

Development and Consultation:	The following individuals were consulted and involved in the development of this document within BLMK ICB: • Head of Children and Young People's Integrated and Personalised Care • Senior Nurse Assessors for Children's Continuing Care • Designated Nurse Safeguarding Children and Looked After Children • Mental Capacity Act and Deprivation of Liberty Safeguards Facilitator • PHB Commissioning Manager • Head of Information Governance/DPO • Acting Head of Quality • Associate Director Children and Maternity Commissioning Services • Associate Director Quality and Safeguarding • Associate Director All Age Continuing Care • Head of All Age Continuing Care • All Age Continuing Care Quality & Assurance Manager • Children's Continuing Care Operational Lead • All Age Continuing Care Commissioning Manager
Dissemination:	Staff can access this document via the website and will be notified of new / revised versions via the staff briefing. This document will be included in the organisation's Publication Scheme in compliance with the Freedom of Information Act 2000.
Training:	The following training will be provided to make sure compliance with this document is understood: • Dissemination training to Local Authorities Children's Services, Children's Community Services, Children's Tertiary Centres and Acute Hospital Children's staff
Monitoring:	Monitoring and compliance of this document will be carried out via: • Clinical Audit and Peer Review of anonymised cases • Children Young people, Parent/Carer and/or Partner feedback • Local Resolution and Lessons Learned
Review:	The Document Owner will ensure this document is reviewed in accordance with the review date on page 2.
Equality, Diversity and Privacy:	Appendix 1 - Equality Impact Assessment Appendix 2 - Data Protection Impact Assessment

Associated Documents:	The following documents must be read in conjunction with this document: ▪ National Framework for Children and Young People's Continuing Care ▪ SEND Code of Practice 2014 ▪ Children and Families Act 2014 ▪ National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care July 2022 (Revised) ▪ Mental Capacity Act 2005 ▪ Healthy Child Programme (0-5) & (5-19) October 2009 ▪ NHS 'Who Pay's' commissioning guidance
References:	The following articles were accessed and used to inform the development of this document: ▪ http://www.workingtogetheronline.co.uk/index.html ▪ https://www.england.nhs.uk/wp-content/uploads/2020/08/Who-Pays-final-24082020-v2.pdf ▪ In addition, the associated documents above

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1.0 Introduction

1.1 The Department of Health published The National Framework for Children and Young People's Continuing Care in 2016, which provides non-statutory guidance for Clinical Commissioning Groups (prior to the formulation of Integrated Care Boards) on supporting the most complex of children and young people's health needs.

1.2 The framework sets out a clear and timely process for needs assessment, review and decision making in respect of a child or young person whose health needs cannot be met within the currently commissioned universal or specialist health services.

1.3 The purpose of this policy is to detail, for transparency, the approach that is taken by Bedfordshire; Luton and Milton Keynes Integrated Care Board (BLMK ICB) in ensuring their responsibilities within children and young people's continuing care are upheld and to demonstrate how the principles of the framework are embedded to inform best practice.

1.4 Children and young people's needs are multi-faceted and can change rapidly as they progress through the stages of development to reach adulthood. As their physical, emotional, social and educational being maturates they require differing levels of support at varying intensity, thus it is essential that a holistic approach is taken for those with continuing care needs. This policy therefore promotes a partnered approach with the Local Authorities (Milton Keynes City Council, Luton Borough Council, Bedford Borough Council and Central Bedfordshire Council) and the practitioners working within the network around the child or young person.

2.0 Scope

2.1 This policy applies to all ICB staff members, including Ordinary Members of the Board of the ICB, involved in policy-making processes, whether permanent, temporary or contracted-in under a contract for service (either as an individual or through a third-party supplier).

2.2 The responsibilities between the ICB and Local Authorities (LA) described within this policy give clear guidance to practitioners on their duties in supporting appropriate assessments within the defined timeframes.

2.3 BLMK ICB children's continuing care applies to children and young people up to their eighteenth birthday, who may require additional support to meet their health needs that cannot be met by universal, targeted or specialist services that are commissioned by either BLMK ICB, or NHS England.

2.4 The child or young person requiring continuing care must be registered with a General Practice surgery within the Bedfordshire Luton or Milton Keynes footprint. If the child or young person is placed in an 'out of area' placement but originated from the BLMK

area, then BLMK ICB should consult the NHS 'Who Pay's' commissioning guidance in respect of identifying the Responsible Commissioner.

2.5 This policy does not extend to children or young people requiring Section 117 after care arrangements identified within the Mental Health Act, Individual Funding Requests and/or any other commissioning requests for children and young people residing within Bedfordshire Luton and Milton Keynes.

3.0 Definitions

3.1 **Children's Continuing Care (CCC):** A national framework that supports ICBs in determining if a child's needs are such that they require a package of continuing care. 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/targeted services alone. A child or young person may have very complex health needs that they cannot be met by the health 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.

3.2 **Child or Young Person (CYP):** A person aged under eighteen years of age.

3.3 **Decision Support Tool (DST):** a tool providing a framework used by clinicians to collate the multidisciplinary assessment of needs of an individual and apply the evidence in a single practical format to facilitate consistent, evidence-based decision-making regarding NHS CCC eligibility. The DST itself **is not** an assessment.

3.4 **Education, Health and Care Plan (EHCP):** Education, health and care plans describe a child or young person's special educational, health and social care needs. It explains the extra help that will be given to meet those needs and how that help will support the child or young person to achieve what they want to in their life.

3.5 **Multiagency Eligibility and Provision Panel:** Multi-agency panel across BLMK landscape. The panel confirms eligibility for CCC from presented evidence gathered around a child/young person. The panel also agree a collaborative package of care.

3.6 **End of Life:** End of life refers to a child or young person whose condition is deteriorating rapidly characterised by an increasing level of dependency and where a lifespan is thought to be days or weeks rather than months or years.

3.7 **Health Needs:** These are related to the treatment, control, or prevention of a disease, illness, injury or disability and the care or aftercare of a person with these needs.

3.8 **Fast Track:** Referrals for continuing care support requiring a quick decision due to the nature of the child/young person's condition, usually when end of life. In these cases, a continuing care assessment may not be completed, decisions are made on best available evidence and usually outside of eligibility and provision panel.

3.9 **Nurse Assessor:** A qualified experienced Nurse with expertise in assessment of a range of children/young people's health needs.

3.10 **Package of Care:** A suite of services (nursing, therapies, home care etc.) that are designed to match the assessed needs of a child or young person.

3.11 **Universal NHS Services:** Health services outlined within The Healthy Child Programme (HCP) which are available to everyone in England from birth, including primary care provided by GP practices, Health Visiting, School Nursing and Accident and Emergency services. The Healthy Child Programme also supports a targeted approach to other community services such as Child and Adolescent Mental Health Services (CAMHs), as required.

3.12 **Specialist NHS Services:** Specialised services are those less common interventions needed by a relatively small group of patients, which require a clinical team with very specific training and often, equipment, which it would be impractical to commission or provide at a local level. These services are usually located in specialised hospital trusts that can recruit a team of staff with the appropriate expertise and enable them to develop their skills needed.

3.13 **Continuing HealthCare (CHC):** An individual, over the age of 18, is eligible for NHS Continuing Healthcare if they have a 'primary health need'. This is a concept developed by the Secretary of State to assist in determining when the NHS is responsible for providing for all of the individual's assessed health and associated social care needs. In order to determine whether an individual has a primary health need, a detailed assessment and decision-making process must be followed, as set out in National Framework. Where an individual has a primary health need and is therefore eligible for NHS Continuing Healthcare, the NHS is responsible for commissioning a care package that meets the individual's assessed health and associated social care needs.

4.0 Policy Statement

4.1 The purpose of this policy is to safeguard adherence to the Framework, and to assure that the ICB complies with its legal responsibilities in delivering an NHS Children's (& Young person's) Continuing Care (CCC) process that is appropriate, fair and equitable across Bedfordshire Luton and Milton Keynes.

4.2 The ICB will commission and provide care in a manner that reflects the preferences of CYP and their families, whilst balancing the need to commission safe and effective provision and make the best use of available resource. The ICB will work towards value-based commissioning of care to ensure the best possible care at the best possible price in accordance with the Secretary of State for Health & Social Care's direction on the use of public funds.

4.3 The appropriate care of children with profound multiple disabilities or chronic severe illness, generally involves input from all statutory agencies: Health, Social Care and Education. High quality care for this small, but highly complex group of children depends on timely, comprehensive interagency assessment and co-ordination of services.

4.4 Parents have the primary responsibility for the care of their child with statutory agencies supporting them to meet the child's identified outcomes. CCC assesses and supports the delivery of identified health outcomes for the child. It is essential that families do not rely on CCC support to fulfil their primary caring responsibilities for a CYP (e.g. to allow them to go out to work).

4.5 A CCC package only provides support for the individual CYP with complex needs and should not support the siblings.

4.6 BLMK ICB work closely with the Local Authorities in the area (Bedford Borough Council, Central Bedfordshire Council, Luton Council and Milton Keynes City Council) who are responsible for assessing social care and education requirements.

4.7 CCC package of care is not statutory and families by no means should be forced or prescribed to have this type of support. The ethos of CCC within BLMK ICB is to promote family resilience, reduce dependence and enable CYP to be cared for by their families at home.

4.8 A CCC assessment is health needs led and should not be undertaken to shift commissioning responsibility, either within BLMK ICB or between Health and Local Authority.

5.0 Roles and Responsibilities

5.1 The following have specific responsibilities in relation to this policy.

5.2 **Governing Body**

The ICB's Governing Body has a responsibility to scrutinise, review and approve this policy in conjunction with the overall aims of the ICB and its statutory obligations under the NHS Act (2006).

5.3 **Chief Executive**

The ICB has legal responsibilities under the NHS Act and Standing Rules Regulations (2012) to have regard to the Framework and exercise its functions in regard to NHS CCC. The Chief Executive for BLMK ICB has overall responsibility to ensure suitable governance arrangements are in place.

5.4 **Chief Nursing Officer**

The Chief Nursing Officer holds the Executive position for oversight of NHS CCC performance, strategic planning using NHS CCC intelligence for wider commissioning, contracting and procurement and financial authority.

5.5 **Associate Director All Age Continuing Care**
Responsible for the direct oversight of this policy's implementation and operation, including governance. Provides financial scrutiny and authority.

5.6 **Children's Continuing Care Operational Lead**
Responsible for the direct implementation and operation, providing assurance and risk management.

5.7 **Children's Continuing Care Clinical Team Lead**

- Enact this policy and ensure that the processes associated with it are followed.
- Ratify assessments and proposed packages of care, ensuring they are safe, meet the health needs of the CYP in accordance with the Framework and are affordable whilst providing value for money
- Act as the conduit for the CCC process and verification of the recommendations from the Nurse Assessors
- Ensure there is a named Nurse Assessor for each case

5.8 **Nurse Assessors for Children's Continuing Care**

- Co-ordinate DST assessments for children and young people
- To produce evidenced/analysis/proposed costed care packages to be presented at eligibility and provision panels
- Triage cases / equipment requests / individual packages
- Work in partnership with Children, families, local authorities and providers.
- Work as a named Nurse Assessor and link nurse for allocated place
- Respond to patient queries
- To work within the remit of this policy and associated policies and processes

5.9 **Health, Social Care and Education Practitioners**
It is the duty of health, social care, and education practitioners to identify children and young people who may have a health need that cannot be met by currently commissioned universal or specialist health services. It is the responsibility of the practitioners to attend CCC training, to adhere to the Framework and to work in a collaborative manner.

5.10 BLMK ICB will commit to delivering an annual programme of training across practitioners, including providers as necessary.

6.0 Processes and Procedures

6.0.1 BLMK ICB CCC is delivered in line with the National Framework for Children and Young People's Continuing Care (2016) Children and young people's continuing care national framework - GOV.UK through a three phased process: **Assessment,**

Decision-making and **Implementation of provision.** This process is comprised of steps including:

1. Needs identification
2. Assessment of needs (if consented)
3. Recommendations of findings (if threshold for support under the National Framework for Children's Continuing Care is met as well as what potential support is proposed)
4. Decision making
5. Communication/Informing of decision
6. Delivery/Implementation of support (if consented)
7. Review of needs

6.0.2 The BLMK ICB Children and Young People's Continuing Care Pathway can be found in appendices.

6.0.3 The CCC process should be, and be seen to be fair, consistent, transparent, culturally sensitive, and non-discriminatory. All needs are considered as part of a picture of overall care needs.

6.1 Assessment Phase (Step 1: Needs Identification)

6.1.1 The process begins when a CYP is recognised to have needs that may not be being met by already commissioned health services potentially because of a change in need which may or may not be in conjunction with a change on social care need or education need. In most circumstances these CYP will already be known well to local services and may also have an allocated Social Worker with regular multi – agency meetings.

6.1.2 The referral process should be led by the lead practitioner within any of the statutory services – Health, Education or Social Care – who work closely with the child/young person and their family. It is important to note that referrals cannot be made by the child/young person or their families.

6.1.3 The referral process must include evidence from practitioners around the CYP needs which will inform the decision to progress to assessment and to the assessment itself. The information may have been submitted as part of other assessment/documents such as the EHCP.

6.1.4 The referrer must seek written consent from the CYP and/or their parents/guardians as appropriate, documenting this on the BLMK ICB Children and Young People's Continuing Care Consent form (see appendices). BLMK ICB works within accordance of the Mental Capacity Act 2005 thus consent must be sought from the young person if they are aged over 16 years (see further section 9). Gaining consent for the assessment to take place must include discussions around information sharing and accessing computerised records (e.g. Systm1). A guide to parental consent can be found in appendices.

6.1.5 The referral must be completed on the BLMK ICB Children and Young People's Continuing Care referral form and pre-assessment checklist and sent electronically, along with supporting documents, to:

blmkicb.childrenscontinuingcare@nhs.net

6.1.6 The referral should clearly identify the unmet health need. Practitioners can request discussions with regards to making a referral with BLMK ICB and can request this in writing to the above email address or view the “How to make a referral” power point presentation (available on request). This will also be included in the CCC training delivered by BLMK ICB.

6.1.7 Referrals are screened by two BLMK ICB CCC Nurse Assessors and the referrer is updated with the outcome within two working days. If the outcome of the screening is not to progress to assessment the Nurse Assessor clearly states, the rationale for the decline and signposts the referrer to services that can support the CYP’s needs. **It is the responsibility of the referrer to communicate this outcome with the CYP and their family, to enable the referrer to have further discussions around how needs can be supported moving forward.**

6.1.8 The outcome of the screening may also be that further information is required. In this circumstance the Nurse Assessor will contact the referrer and discuss what information is required and where to obtain the detail from, if needed. The referrer then has 10 working days to submit the additional evidence, to the above email address. The referral will be presented at panel to be escalated/closed if the additional information is not received.

6.1.9 End of life referrals will be fast tracked and a decision about a package of support will be made as quickly as possible based on best available information and evidence; see section 6.10

6.1.10 If a CYP is in crisis, it is often not appropriate to assess during this period and a multi-agency collaborative meeting should take place to address immediate needs and consider when the best time is to make the referral.

6.2 Assessment Phase (Step 2: Assessment of Needs)

6.2.1 Once the decision has been made to progress to assessment, the allocated BLMK Nurse Assessor will contact the CYP and their family to arrange a date and time for a full assessment.

6.2.2 Where possible, assessments will take place jointly with the referrer, and/or with keyworkers already involved with the CYP, e.g. social worker. If the referrer is not available to attend the assessment, they will be asked to provide relevant information. In exceptional circumstances an assessment will take place solely by the Nurse Assessor whereby, information from Social Care will be requested and required within statutory framework timeframes to avoid a breach and delay in decision making.

6.2.3 The Nurse Assessor is responsible for collating of the evidence and assessing the risks to support the assessment recommendation and all aligned processes within the agreed system. The Nurse Assessor will give practitioners around the CYP deadlines to submit supporting evidence or attend a collaborative meeting. If practitioners miss this, the nurse assessor will escalate to senior management to

reduce the risk of evidence not being included in the final assessment document, potentially impacting the outcome, recommendations and/or delaying care provision.

6.2.4 The assessment will consider four key areas of evidence to identify need:

1) The preferences of the CYP and their family
2) A holistic assessment of the needs of the CYP and their family
3) Reports and risk assessments from a multidisciplinary team or evidence collated during the Education, Health and Care plan assessment
4) The documented use of the DST for CYP

6.2.5 The Decision Support Tool is set out within the National Framework and comprises of 10 domains of health needs, each with criterion, set by the Department of Health, to determine level of need within each domain. The Nurse Assessor will ascertain which criterion is met by using the evidence gathered and is clearly referenced within the DST. The Nurse Assessor may also use clinical judgement when a CYP's needs may not fit exactly with the descriptors, in this case there must be clear rationale and peer review.

6.2.6 A CYP is likely to have continuing care needs if assessed as having, *a severe or priority level of need in at least one domain of care, or a high level of need in three domains of care*. In addition, there must be evidence that there is not an NHS universal or specialist service that can meet these needs.

6.2.7 The level of need in a single domain may not on its own indicate that a CYP has a CCC need but will contribute to a picture of overall care needs across all domains. The Nurse Assessor should not equate a number of incidences of one level with a number of incidences of another level, for example, needs assessed as 'moderate' in two domains are not the equivalent of one 'high' level of need. Nurse Assessors must ensure that evidence of the level of need is documented under the relevant domain and is not assessed twice.

6.2.8 It should be noted from the National Framework that diagnosis of a particular disease or condition is not in itself a determinant of a need for CCC. There should be no differentiation based on whether the health need is physical, neurological or psychological.

6.3 Assessment Phase (Step 3: Recommendation of findings)

6.3.1 Following the assessment, the Nurse Assessor should have collaborative discussions with Social Care and Education, and, of course most importantly, thoughts from the family regarding support, will help inform a proposed joint package of care.

6.3.2 The Nurse Assessor will also make recommendations with regards to eligibility for CCC, around any outstanding actions required to further support the CYP and how the proposed package of support will meet the desired health outcomes the CYP and their family wish to be achieved.

6.3.3 The Nurse Assessor will present the case, jointly with Social Worker where possible, at the monthly Multiagency Eligibility and Provision Panel.

6.4 Decision Making Phase (Step 4: Decision by Eligibility and Provision panel)

6.4.1 The Panel must be Chaired by the Head of Integration and Personalisation for Children and Young People or nominated person with equivalent seniority; understanding of the Continuing Care process and has financial decision-making responsibility Depending on individual local authority TOR, panel will be chaired by an appropriate person from health, local authority or education and to be quorate must include representatives from said agencies who have financial decision-making responsibility.

6.4.2 The panel members must consider the evidence presented, associated recommendations of the presenting practitioners (Nurse Assessors and Social Workers) and decide together if eligibility for CCC is met.

6.4.3 If eligibility is confirmed the panel will consider together the proposed collaborative package. In instances whereby panel members may not be in agreement with each other, and a further complex case discussion may need to be held to allow members opportunity to liaise with senior colleagues within their respective agencies. The complex case discussion should be held as soon as possible after the panel to prevent potential delay to packages of support.

6.4.4 The Nurse Assessor must complete financial documentation of the agreed package to be authorised following internal process and regulatory guidelines.

6.4.5 If the CCC eligibility criteria is not met, then it is expected that the CYP's needs would be primarily met by existing universal, or specialist health services and the Nurse Assessor can help to signpost in this instance.

6.5 Decision Making Phase (Step 5: Communicating/Informing of the Eligibility and Provision panel decision)

6.5.1 Nurse Assessors must document the outcome of the panel and share this with the CYP and their family within 5 working days of the panel. The network of practitioners around the CYP should also be notified of the outcome.

6.5.2 Should there be a delay in decision making the Nurse Assessor must keep the CYP and their family updated at regular intervals.

6.5.3 Should the outcome of the Panel be that the CYP needs do not meet criteria for CCC a clear written rationale should be provided to the family following a verbal discussion.

6.5.4 The family should be advised of what services are available to meet their CYPs health needs and supplied with a copy of the BLMK ICB Children and Young People's Continuing Care Dispute Policy should they wish to dispute decisions made at the panel.

6.6 Delivery Phase (Step 6: Implementation of Care package)

6.6.1 Collaborative packages of support to meet the identified needs can be procured by BLMK ICB or by Local Authority.

6.6.2 BLMK ICB contracts a lead provider who have a number of providers available (in house or through Any Qualified Provider Framework), who are experienced in meeting the complex needs of CYP.

6.6.3 BLMK ICB and the lead provider work closely to ensure there is a robust Quality Assurance and monitoring process in place for these providers.

6.6.4 The provision should be in place as soon as safely possible accounting for potential recruitment and training required as appropriate. Family should be updated by the lead provider regularly through this process.

6.6.5 The lead provider will meet with the CYP and their family to discuss and sign the home care agreement which enables all parties to have a clear understanding of the responsibilities and their expectation of others. The home care agreement can be amended and personalised to reflect each CYP's situation.

6.7 Delivery Phase (Step 7: Review Care Needs and relating Package of Care)

6.7.1 As a minimum the CYP's CCC needs will be reviewed 3 months after commencement of, or amendment to, a package of support and annually thereafter by the allocated Nurse Assessor.

6.7.2 Reviews should be responsive to changes in a CYP's needs, as there will be cases where successful management of a condition has permanently reduced or removed an ongoing need.

6.7.3 The responsibility to commission care is not indefinite as needs may change and this should be made clear to the CYP and their family. Equally, BLMK ICB must guard against making changes to a package of care, where the CYP's underlying needs have not changed, any changes must be evidenced by the review conducted by BLMK ICB Nurse Assessor.

6.7.4 The review must remain transparent, and involvement of the CYP and their family is fundamental to the equity and consistency of the review.

6.7.5 In instances where the review indicates a transition back into universal or specialist health services is appropriate, the child or young person and their family should be supported through the transition.

6.8 Timescales

6.8.1 The process, from the date of assessment to the final decision at Eligibility and provision should take no longer than 6 weeks.

6.8.2 However, given the complexity and variety of needs which BLMK ICB may be assessing, there should be scope for flexibility – where it is not contrary to the best interests of the CYP. For example, if an assessment is being made pending a CYP'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 practitioners involved.

6.9 Residential Care

6.9.1 The National Framework recognises that decisions about residential care and other social care support must of course be made by the local authority, as a lead commissioner in this circumstance, even though the CYP may have CCC needs. BLMK ICB will not fund towards a CYP's home or residence, however, will work alongside the local authority to identify how and ensure that, health needs are met within these circumstances.

6.9.2 If there are concerns about home care on grounds of care, risk or capacity, interventions should be planned which will enable home care to continue whilst addressing the care, risk or capacity issues (e.g. by implementing positive behaviour support for a CYP with severely challenging behaviour). 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 CYP.

6.9.3 If a CYP has CCC needs and is receiving a package of care when the local authority commission a residential placement then funding continues for three months at the same cost as BLMK ICB were contributing prior to the admission and/or prior to any period of crisis. This is to allow the CYP to settle before reassessment. If the CYP no longer meets CCC threshold on reassessment, then funding will cease from the date of reassessment.

6.10 Fast Track

6.10.1 BLMK ICB recognises that some CYP will, as a result of their condition, rapidly decline; and require end of life bespoke support. End of life care refers to a CYP whose condition is deteriorating rapidly characterised by an increasing level of dependency and where a lifespan is thought to be days or weeks rather than months or years.

6.10.2 To facilitate quick decision-making in these circumstances, a full assessment is not necessary. Referrals should be made in the usual way, however **clearly** identifying the need for fast tracking including the relevant rationale. All cases will be reviewed by a Nurse Assessor prior to decision-making being confirmed through consultation with panel members, outside of Multiagency Eligibility and Provision Panel if necessary.

6.11 Personal Health Budgets

6.11.1 CYP eligible for CCC have had a legal right to a personal health budget (PHB) since 1st October 2014, (unless in exceptional circumstances), as announced by the Government in October 2013 and provided for in the National Health Service Commissioning Board and Integrated Care Boards (Responsibilities and Standing Rules) (Amendment) (No. 3) Regulations 2014.

6.11.2 The purpose of PHB's is to give CYP and their families better flexibility, choice and control over their care. A PHB helps people to get the services they need to achieve

their agreed health and wellbeing outcomes (agreed between the CYP, their families and Nurse Assessor). Financially, personal health budgets can be managed in a number of ways including:

- A notional budget held by the delegated Lead Provider
- A budget managed on the individual's behalf by a third party, and

6.11.3 CYP eligible for a CCC package of support will be introduced to the concept of PHBs as part of each assessment, depending on the circumstances and preference of the CYP and their family. If they would like to investigate this option, based on the outcome of the DST, an indicative budget will be produced and shared with the CYP and their family during an introductory meeting to explain the PHB process.

6.11.4 The Nurse Assessor, along with support from BLMK ICB PHB team, will work with the CYP and their family to agree health and wellbeing outcomes and develop a support plan. They will then also work with the individual to think creatively about how they could best make use of their available budget to meet their health and wellbeing outcomes.

6.11.5 Once a care plan has been agreed the Nurse Assessor and PHB team will work to put the care plan in place along with the allocated Social Worker, if appropriate.

6.11.6 Should the CYP be in receipt of direct payments from the local authority when eligibility for CCC is confirmed, their personal health budget can be added, as part of the collaborative package of support, and can continue to be received by this means. BLMK ICB will encourage this approach to avoid any unnecessary changes or added complexities.

6.12 Transition

6.12.1 The National Framework for Children and Young People's Continuing Care (2016) is in effect until the young person's eighteenth birthday. The responsibilities of Health, Education and Social Care differ between children's and adult's services and during the transition period CYP and their families must be supported to understand the differences. There are 4 key stages within the transition period:

Age 14 Years

Young people receiving Continuing Care will automatically be discussed at the quarterly meeting with Continuing Healthcare (CHC) Team

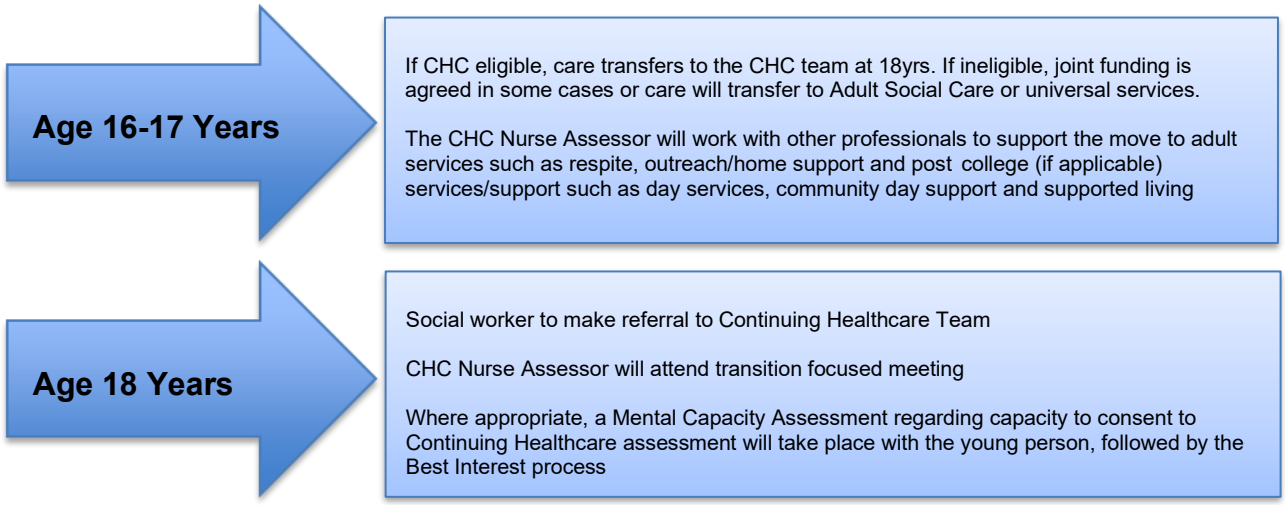
Day to day needs continue to be managed by Social Care, Children's health services and the Children's Continuing Care Team until age 18yrs

These services will begin to talk to the young person and their families about transitioning to adult services.

Age 16 Years

The CHC Nurse Assessor will work alongside Social Workers to gather information for adult health and social care assessments and plan a smooth transition to adult services

Assessment for CHC carried out at Multi disciplinary team meeting; young people, parents/carers, and professionals, including Children's Continuing Care Nurse Assessor, involved in care attend. Outcome given within 28 days



6.13 Mental Capacity Act and Mental Capacity Assessment

6.13.1 BLMK ICB work in line with the Mental Capacity Act 2005, The Deprivation of Liberty Safeguards 2009.

6.13.2 If the CYP is 16 years or older, they must sign to consent for a CCC assessment themselves. If there is concern regarding their mental capacity to make this informed decision, a Mental Capacity Assessment must be carried out by the Nurse Assessor. The Nurse Assessor should provide information in a format that will help the person understand the information and should try everything practicable to try to empower the individual to make their own decision where possible.

6.13.3 It is key to remember that mental capacity is time and decision specific, so if separate decisions need to be made if there are concerns about that person's capacity a separate mental capacity assessment should be completed at the time the decision needs to be made.

6.13.4 The Nurse Assessor shall follow the five principles of the Mental Capacity Act (See Appendices). These principles are of such importance that they are set out at the start, before the legal test to determine if a person lacks mental capacity.

6.13.5 The Nurse Assessor assessment of a CYP's capacity must be made on the balance of probabilities, show in the documentation why and how the conclusion has been reached for that decision at that time.

6.13.6 The Nurse Assessor must involve and consult with family, friends, advocate or other practitioners as appropriate throughout.

6.14 Deprivation of Liberty Safeguards

6.14.1 Article 5 of the Human Rights Act states that *'everyone has the right to liberty and security of person. No one shall be deprived of his or her liberty [unless] in accordance with a procedure prescribed in law'.*

6.14.2 The Deprivation of Liberty Safeguards is the procedure prescribed in law when it is necessary to deprive of their liberty a person who lacks capacity to consent to their care and treatment (that is necessary and proportionate) in order to keep them safe from harm. Nurse Assessors don't have to be experts about what is and is not a deprivation of liberty. They need to know when a person might be deprived of their liberty and take action.

6.14.3 When Nurse Assessors are putting together the care plans of patients who are unable to consent to their care and treatment, they should consider whether any restrictions or restraint being proposed are in the best interests of the person and whether they amount to a deprivation of liberty. See appendices for information on how Deprivation of Liberty Safeguards (DoLS) is authorised.

6.14.4 Deprivation of Liberty that occurs outside of Care Homes and Hospitals, could be anywhere in the community can also be termed “Court of Protection Deprivation of Liberty” (COPDOL), “Community Deprivation of Liberty”, “Re X Streamlined procedure,” so these applications have to be sent to the Court of Protection for authorisation using Court of Protection procedures and forms. These applications could also include those who may be under 18 years of age.

6.14.5 If a person is living in a community setting, such as a residential school or their own home, it is still possible to deprive the person of their liberty in their best interests, via an application to the Court of Protection.

6.14.6 The funding authority is responsible for making lawful any care regime that may amount to a deprivation of liberty. If the person is solely funded by the BLMK ICB it is our responsibility to gain lawful authorisation via the Court of Protection.

6.15 Safeguarding

6.15.1 BLMK ICB has a statutory responsibility to ensure safeguarding is embedded across the work of the ICB and that safeguarding is integral to CCC.

6.15.2 When commissioning CCC, BLMK ICB will take all possible measures to ensure that the safeguarding of CYP is provided for within provider contracts and that care arrangements minimise the risk of harm and promote the wellbeing of individuals.

6.15.3 BLMK ICB is accountable for delivering the statutory functions for safeguarding children under section 11 of the Children Act 2004 and fulfilling their responsibilities under the Children Act 1989. The Children’s Act 1989 and 2004 are the overarching legislation concerning the welfare of children. These Acts support the principle that the welfare of the child is the paramount consideration. They place a duty on all staff / volunteers to consider children in the course of their work, even where their client group may be adult.

6.15.4 BLMK ICB must comply with the statutory guidance contained within Working Together to Safeguard Children (2018). Key principles as outlined in Working Together to Safeguard Children (2018) are:

- Safeguarding is everyone's responsibility: for services to be effective each professional and organisation should play their full part.
- Everyone should work using a child centred approach: for services to be effective they should be based on a clear understanding of the needs and views of children.

6.15.5 The Child Protection Procedures for each Local Authority provide the operational procedures that all BLMK ICB staff must follow if a situation arises during the commissioning or delivery of a CYP's CCC package which places a CYP at risk of harm.

6.16 Disputes

6.16.1 BLMK ICB recognises there may be occasions when CYP and their families may not be completely satisfied with the outcome of referral triage, assessment, panel process or provision. It is also recognised that they may wish to raise a dispute or complaint.

6.16.2 BLMK ICB would initially encourage Local Resolution in an informed and timely manner. BLMK ICB have also developed a Dispute policy and process that is clear for the staff of BLMK ICB and CYP and their families.

NHS
Bedfordshire, Luton and Milton Keynes
Integrated Care Board

Appendix 1 - Equality Impact Assessment Initial Screening

Name of Policy:	Children and Young People's Continuing Care Operational Policy
Date of assessment:	2/6/2025
Screening undertaken by:	AACC Quality & Assurance Manager

Protected characteristic and inclusion health groups. Find out more about the Equality Act 2010, which provides the legal framework to tackle disadvantage and discrimination: https://www.equalityhumanrights.com/en/equality-act/protected-characteristics	Could the policy create a disadvantage for some groups in application or access? (Give brief summary)	If Yes - are there any mechanisms already in place to mitigate the potential adverse impacts identified? If not, please detail additional actions that could help. If this is not possible, please explain why
Age A person belonging to a particular age (for example 32 year olds) or range of ages (for example 18 to 30 year olds).	Policy relates to children and young people from Birth to 18 years as set out in the National Framework for Children and Young people's Continuing Care	BLMK ICB have a similar policy in respect of adults (Continuing Health Care) as set out in the National Framework for Continuing Health Care
Disability A person has a disability if she or he has a physical or mental impairment which has a substantial and long-term adverse effect on that person's ability to carry out normal day-to-day activities.	No	
Gender reassignment The process of transitioning from one gender to another.	No	
Marriage and civil partnership Marriage is a union between a man and a woman or between a same-sex couple. Same-sex couples can also have their relationships legally recognised as 'civil partnerships'.	No	
Pregnancy and maternity Pregnancy is the condition of being pregnant or expecting a baby. Maternity refers to the period after the birth and is linked to maternity leave in the employment context. In the non-work context, protection against	No	

maternity discrimination is for 26 weeks after giving birth, and this includes treating a woman unfavourably because she is breastfeeding.		
Race Refers to the protected characteristic of race. It refers to a group of people defined by their race, colour and nationality (including citizenship) ethnic or national origins.	No	
Religion or belief Religion refers to any religion, including a lack of religion. Belief refers to any religious or philosophical belief and includes a lack of belief. Generally, a belief should affect your life choices or the way you live for it to be included in the definition.	No	
Sex A man or a woman.	No	
Sexual orientation Whether a person's sexual attraction is towards their own sex, the opposite sex, to both sexes or none.	No	
Carers Individuals within the ICB which may have carer responsibilities.	No	

Please summarise the improvements which this policy offers compared to the previous version or position.
This policy has been written to ensure that BLMK Integrated Care Board (ICB) is working in line with the National Framework for Children and Young People's Continuing Care (2016) and is an updated version. This is not a change in practice, neither in service delivery that would impact cohorts of children and young people within the BLMK locality, in a different way. The policy is a positive step forward to ensure equity and proportionality for Children and Young People's Continuing Care across BLMK landscape and will provide clarity for those working for and in collaboration with, BLMK ICB.
Has potential disadvantage for some groups been identified which require mitigation?
Yes / **No** – (If there are significant impacts and issues identified a full Equality / Quality Impact Assessment (EQIA) must be undertaken.)

Appendix 2 - Data Protection Impact Assessment Initial Screening

Name of Policy:	Children and Young People's Continuing Care Operational Policy
Date of assessment:	2/6/2025
Screening undertaken by:	AACC Quality & Assurance Manager

Stage 1 – DPIA form **please answer 'Yes' or 'No'**

1.	**Will the policy result in the processing of personal identifiable information / data?** This includes information about living or deceased individuals, including their name, address postcode, email address, telephone number, payroll number etc.	Yes
2.	**Will the policy result in the processing of sensitive information / data?** This includes for living or deceased individuals, including their physical health, mental health, sexuality, sexual orientation, religious belief, National Insurance No., political interest etc.	Yes
3.	**Will the policy involve the sharing of identifiers which are unique to an individual or household?** e.g., Hospital Number, NHS Number, National Insurance Number, Payroll Number etc.	Yes
4.	**Will the policy result in the processing of pseudonymised information by organisations who have the key / ability to reidentify the information?** **Pseudonymised data -** where all identifiers have been removed and replaced with alternative identifiers that do not identify any individual. Re-identification can only be achieved with knowledge of the re-identification key. **Anonymised data -** data where all identifiers have been removed and data left does not identify any patients. Re-identification is remotely possible, but very unlikely.	Yes
5.	**Will the policy result in organisations or people having access to information they do not currently have access to?**	No
6.	**Will the policy result in an organisation using information it already holds or has access to, but for a different purpose?**	No
7.	**Does the policy result in the use of technology which might be perceived as being privacy intruding?** e.g., biometrics, facial recognition, CCTV, audio recording etc.	No
8.	**Will the policy result in decisions being made or action being taken against individuals in ways which could have a significant impact on them?** Including profiling and automated decision making. (This is automated processing of personal data to evaluate certain things about an individual i.e., diagnosis and then making a decision solely by automated means - without any human involvement)	Yes
9.	**Will the policy result in the collection of additional information about individuals in addition to what is already collected / held?**	No
10.	**Will the policy require individuals to be contacted in ways which they may not be aware of and may find intrusive?** e.g., personal email, text message etc.	No