



**Nottingham and
Nottinghamshire**
Integrated Care Board

Children and Young People's Continuing Care Commissioning Policy

March 2024 – September 2025

CONTROL RECORD			
Reference COM-006	Version 2.0	Status Final	Author Assistant Director of Nursing and Quality (CHC) Sponsor Chief Nurse Team Nursing and Quality
Title	Children and Young People's Continuing Care Commissioning Policy		
Amendments	The CYP CC Commissioning Policy is a new policy. The previous policy containing Adults and Children has been split following the advice of Capsticks to split the CHC Commissioning Policy into two – one for Adults and one for Children and Young People.		
Purpose	To ensure the quality of care delivered within the limitations of the Integrated Care Board's available financial resources and to support consistency and equity of access to services for all individuals assessed as eligible for Children and Young People's Continuing Care, whether fully funded by the ICB or part-funded in partnership with the Local Authority.		
Superseded Documents	Continuing Healthcare (Adults and Children) Policy v1.1		
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1. Introduction

- 1.1. This policy applies to the NHS Nottingham and Nottinghamshire Integrated Care Board, hereafter referred to as “the ICB”.
- 1.2. The NHS exists to serve the needs of all alongside its statutory duty to financially break even (National Health Service Act 2006). ICBs have a responsibility to provide health benefits for the whole of their population, whilst commissioning appropriate care to meet the clinical needs of individual patients.
- 1.3. This policy covers those Children and Young people (“CYP”) aged 17 or under for whom the ICB is the responsible commissioner and are eligible for funding in accordance with the National Framework for Children and Young People’s Continuing Care. This policy covers both full ICB funding and ICB contributions to joint funded packages of care.
- 1.4. The ICB has established this commissioning policy to ensure the best use of NHS resources, providing a level of service that is sustainable and equitable (fair) to the health and well-being of the children and young people within the ICB footprint.
- 1.5. A Continuing Care (“CC”) 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. These needs may be so complex that they cannot be met by the services which are universal services commissioned in the usual way either in hospital or in the community. A package of additional health support may be needed which is known as CC.
- 1.6. CC is not needed by CYP whose needs can be met appropriately through existing universal or specialist services through a case management approach.
- 1.7. Agencies working together and in partnership with the child and parent should bring together a single set of outcomes. The arrangements for children with special educational needs or disability (“SEND”) provides a framework for outcomes-focused joint assessments (Education, Health and Care Plan, (“EHCP”)) involving different partners across Education, Health and Local Authority Support. There may be common elements to both the CC assessment and the EHCP and where appropriate the single set of outcomes identified within the EHCP may be duplicated or further detailed within the child or young persons’ Care and Support Plan (“CASP”).

2. Purpose

- 2.1. The purpose of this policy is to ensure that high-quality, cost-effective care is delivered, and to support consistency and equity of access to services for individuals assessed as eligible for CC.

- 2.2. All NHS organisations have a duty to operate within its financial framework which must be considered in addition to the Human Rights Act. The ICB also has an obligation of equality under the Public Sector Equality Duty (“PSED”) of the Equality Act 2010.
- 2.3. This policy should be read in conjunction with the Children and Young Person’s Continuing Care National Framework (2016 and any subsequent updates).
- 2.4. The principles of this policy also apply to the provision of Personal Health Budgets (“PHB”). All CYP who are eligible for CC and have home based care will have a right to have a PHB if they wish to do so. They or the person with parental responsibility can choose not to have the option of a PHB and still have their assessed care needs delivered. All guidance in relation to PHBs and integrated budgets (for joint funded support) can be found in the ICB’s PHB guidance.

3. Scope

- 3.1. This policy applies to all ICB staff, CC delivery team staff and CYP in receipt of CC funding plus their representatives.

4. Roles and Responsibilities

Roles	Responsibilities
Directors	Directors have overall accountability for all aspects of an individual’s safety within the ICB and to ensure appropriate care is delivered. The ICB’s Directors are responsible for the implementation of all relevant policies and arrangements within their areas of control and to lead their managers and staff in proactive and effective risk management.
Chief Nurse	The Chief Nurse leads on Children and Young People’s Continuing Care and has a consultative and advisory role in clinical and operational aspects within the team. The Chief Nurse ensures that the ICB has met its responsibilities as set out in the National Health Service Regulations 2012.
Assistant Director, Heads of CHC and Case Managers	Responsible for ensuring that the CHC team work to the National Framework and the ICB’s policies related to Children and Young People’s Continuing Care and for ensuring the delivery of best possible health and well-being outcomes, as well as working to promote equality, and achieving this with the best use of available resources.
CHC Delivery Unit staff	All members of CHC staff have a responsibility to familiarise themselves with the contents of the Policy.

5. Principles

- 5.1. When commissioning services for people, we will prioritise the achievement of outcomes, and value for money, over purely the level of choice available.
- 5.2. The funding made available to support an individual will be determined by the most cost-effective care package that meets the individual's assessed needs, based on the local care market, the availability of local care providers and the cost of community based and residential or nursing care.
- 5.3. All CYP living at home will have their care delivered through person-centred care and a CASP will be developed reflecting clear outcomes aiming to maximise independence and control over their health and care outcomes. The CASP should reflect the CYP's EHCP and vice versa. The care can be funded by a PHB, either notional, third party or via a direct payment, this will be discussed with the CYP and their family to ensure the most suitable option.
- 5.4. The ICB also has a responsibility to promote a comprehensive health service on behalf of the Secretary of State and to offer individual choice within the constraints of the resources available to it.
- 5.5. The balance between cost and individual choice should be applied consistently and equitably across all individuals eligible for CC and this policy sets out the principles which will be applied to all decisions.
- 5.6. It is the responsibility of the NHS to make reasonable offers of services to individuals eligible for CC to meet their assessed needs. If offers of reasonable services are made to individuals to meet their assessed needs and are refused, the ICB has discharged its legal duty to those individuals.
- 5.7. The ICB will always aim to integrate commissioning with partners across the Integrated Care System ("ICS").

6. Parental Responsibility

- 6.1. The ICB appreciates that at times people with parental responsibility will want to leave the home and will require childcare for the child. As a health care commissioner we only commission health care services. This means that the ICB is unable to ask a care agency to provide "childcare" duties. If the care agency is prepared to undertake these tasks then family members should make separate arrangements with them.

7. Safer Patients, Safer Cultures and Safer Systems

- 7.1. The ICB is continuously working to improve patient safety. Patient safety will always remain paramount in planning a care package and will not be compromised.
- 7.2. The ICB will only commission packages of care where the care can be delivered safely without undue risk to the individual, the staff or other members of the household (if a domiciliary package) and the level of risk is acceptable. This decision will be made in discussion with:
- The care provider and the person/people with parental responsibility for CYP aged under 16 years, including the views of the CYP as appropriate;
 - The young person, if aged 16 or over, with mental capacity, including the views of the people/person with parental responsibility; or
 - The CYP and person/people with parental responsibility if the individual is 16 years or over and lacks capacity to make a decision regarding risk, following the ICB's policy on decision-making under the Mental Capacity Act 2005.
- 7.3. It is vital that the CASP and EHCP capture the complexity of the CYP's needs, providing the necessary evidence that the needs are of such a level which warrants the requested care package. This will enable the ICB to better understand, better commission and effectively manage the needs of individuals within the population they serve.
- 7.4. For assessed needs to be approved by the ICB, they must be identified and detailed in the person centred CASP and must be:
- **Lawful:** The proposed package of care should be legitimately within the scope of the funds and resources that will be used. The package of care must be lawful and regulatory requirements relating to specific measures proposed must be addressed.
 - **Effective:** The proposals must meet the person's assessed eligible needs and support the person's independence, health and well-being. A risk assessment must be carried out and any risks identified that might jeopardise the effectiveness of the plan or threaten the safety or well-being of the person or others must be addressed. The proposals must make effective use of the funds and resources available in accordance with the principle of best value.
 - **Affordable:** All costs have been identified and can realistically be met within the budget. In deciding whether the support plan is affordable it must show that it is within the indicative budget or, if the indicative budget is exceeded, a clear and reasoned explanation is provided to justify the additional spend.
 - **Appropriate:** The CASP should not include the purchase of items or services

that are inappropriate for the NHS to fund or that would bring the NHS into disrepute. The CASP must have clear and strong links to a health outcomes.

- 7.5. There may be circumstances where concerns are raised about the quality of care from a provider. Where necessary, the ICB will work with individuals and their families to commission an alternative package of care whilst quality concerns are investigated.
- 7.6. In all cases, the ICB will work with the CYP and parents to ensure that the CASP and care provision is managed on an individual basis and responsive to their changing needs and circumstances.
- 7.7. The ICB is committed to ensuring that a high quality, person-centred approach is at the heart of everything it does, whilst remaining focused on safe and effective care.

8. Assessment and Decision-Making

- 8.1. The process of assessment and decision making should be person-centred. This means ensuring the CYP's, and parental perception of the CYP's, support needs, and preferred models of support are at the heart of the assessment and care planning process. The assessment process will follow the National Framework for Children and Young People's Continuing Care.
- 8.2. When deciding on how their needs are met, the individual's wishes and expectations of how and where the care is delivered, along with the risks of different types of provision and access to resources should be documented and taken into account. This should ensure that the CYP's voice is heard as much as possible, even when they are unable to communicate verbally.
- 8.3. The need to balance the CYP and parental choice alongside safety and value for money means the ICB has to ensure consistent decision-making providing transparency so that decisions are:
 - Person-centred;
 - Robust, fair, consistent and transparent;
 - Based on objective assessment of the individual's clinical need, safety and best interests;
 - Have regard for the safety and appropriateness of care to the individual and those involved in care delivery;
 - Made collaboratively and involve the individual and their parent/carer/appointed representative wherever this is possible and appropriate;
 - Take into account the need for the ICB to allocate resources in the most cost effective way;
 - Support choice to the greatest extent possible in the light of the above factors.

- 8.4. The CC should be part of a wider package of care agreed and delivered by collaboration between Health, Education and Local Authority Support and therefore decisions are made by the ICB in consultation with Education and Local Authority representatives.
- 8.5. The final decision regarding whether a child is eligible for CC will be made at the multi-agency Children's Continuing Care Panel ("CCCP"). The multi-agency panel consists of representatives from the ICB, including a Children's Clinician, the Local Authority (both social care and education) and a senior Nurse from the ICB's community services.
- 8.6. Decisions must be demonstrably fair, equitable and impartial: other professionals, legal representatives or parents are therefore not able to attend panel with the exception of observation for training purposes.
- 8.7. CC eligibility is determined by the presenting health needs, their level of complexity, and whether existing services can meet the identified outcomes. The nature of the health need can be varied or multiple e.g., physical health, mental health, disability. The DST, including child and parent comment, will be used to support decision-making.
- 8.8. In accordance with the CC National Framework Decision Support Tool, a child is likely to have continuing care needs if assessed as having a severe or priority need in at least one domain of care, or a high need in at least three domains of care within the DST.
- 8.9. The CCCP members will not make decisions on how care is to be provided until CC need and eligibility is confirmed. The Panel decision will be one of the following options:
- **CC need determined (eligible)** which requires a package of care/support. This policy is not prescriptive regarding the type of care that can be provided but can typically include support in the CYP's home, support in a residential home and support in an educational setting;
 - **CC need not determined (not eligible)**, and no additional package of care/support is required from NHS Continuing Care;
 - **Continuing Care need not determined but a well-managed need is evidenced.** CCCP agree that the evidence (specialist assessment/review, behavioural plans, and planned outcomes) demonstrate a well-managed need. Joint arrangements will continue until further review shows the provision and support required has reduced enough to consider transfer to a setting 'less intensive/complex' or health and behavioural support has reduced to a level to warrant less support within placement

- 8.10. A CC decision will include agreement as to which commissioner (i.e., ICB or Local Authority) has responsibility for commissioning the different elements of the care package to meet the identified outcomes. This will be recorded in the CASP **and may include provision identified in the EHCP.**
- 8.11. A decision about eligibility should be made and communicated to the child and parent within 6 weeks of referral. The proposed date of decision-making and any revision of this date must be advised to referrer, child and parent by the CCCS and a rationale and new timescale provided. CCCS will also advise the referrer, child and parent of the decision and rationale verbally and in writing within 5 days of it being made. This advice should also include information about how to complain or appeal and, where eligible, how to contact their allocated CCCS case manager.
- 8.12. CC funding will commence from the date of the Panel decision or on day 43 following the date of acceptance of the referral, whichever is the earliest.
- 8.13. Decisions will be reported via panel members to their respective agencies and through their appropriate governance route. Local Authority representatives will follow the local authority internal process to seek approval for any Local Authority and educational care elements of the proposed package.
- 8.14. In cases where waiting for decision-making through the usual process could cause significant harm, the CCCS Case Manager can consider if a child or young person meets eligibility for Continuing Care services and ask the ICB for an 'Out of Panel' decision. These decisions should then be presented at the next CCCP for ratification.

9. Commissioning Packages of Care

- 9.1. The ICB is obliged to meet the health needs of individuals who are eligible for CC. However, guidance does not prescribe the type of healthcare required to meet the need. The ICB has discretion as to the manner of the provision of CC services and must exercise reasonable judgment to provide the most appropriate, cost-effective care. The ICB uses a Resource Allocation Tool (see Appendix A) for this purpose.
- 9.2. CYP should be jointly assessed to determine what package of care is required to meet their health and social care needs. The ICB will provide care to meet assessed health needs in line with the Resource Allocation Tool. It is the ICB's responsibility to determine what this appropriate health funded package should be, involving the wishes of the individual and their family in every step where possible.
- 9.3. In line with the ICB's responsibilities around use of public funds, the ICB's care package offer will be the most cost-effective way of meeting the CYP's health needs and outcomes and any care package will be reviewed at least annually or where there are significant changes to the individual's need.

- 9.4. Whilst there is provision for consideration of exceptional circumstances in relation to all of the matters listed below the ICB does not routinely fund:
- Care at home when a risk assessment identifies risks that cannot be safely managed in the community;
 - Care at home when the child or young person requires 24-hour oversight by a registered nurse or registered Mental Health Nurse due to their health needs;
 - Ongoing payment for care packages where the child or young person is in hospital, unless it is essential that the existing carers must be retained to support the child or young person on discharge. In such cases a suitable retainer fee may be agreed with the provider;
 - The cost of rent, food and utility bills;
 - Transport to and from education settings as this is the responsibility of the education authority;
 - Short breaks/respite as this is the responsibility of the local authority; or
 - Voids in children's care homes.
- 9.5. The ICB will only fund packages detailed above in exceptional circumstances, taking into account the following considerations:
- Likely impact on the individual of any potential move, including psychological and emotional impact;
 - Suitability and/or availability of alternative arrangements;
 - Risks involved to the individual and others;
 - The individual's views and those of their family and other carers;
 - Whether there are any creative alternatives available to enable the best use of resources available and to enable the individual's choice to be realised;
 - The ICB's obligation in relation to equality and the PSED; and
 - If the weekly cost of care increases, the care package will be reviewed to ensure high quality and cost-effective care is given. Other options may be explored. This excludes single periods of cost increase to cover an acute episode and end of life care where the individual is in the terminal stage and hospital admission can be prevented.
- 9.6. It is expected that care agencies will provide trained carers who have the necessary knowledge and skills to care for the CYP. There may be occasions when shadow shifts are required for a new carer to receive their training and achieve the necessary competencies. On such occasions the ICB will commission an agreed number of hours per carer to allow them to shadow and watch and observe and sign off any competencies necessary, the hours could be utilised in any way the agency deems appropriate. The Children's Case Manager will recommend the number of shadow hours depending on the child or young person's needs. Shadow shifts are at 75% of the standard AQP Framework carer rate.

- 9.7. It is expected that care agencies deliver 100% of the commissioned care package. All PHB should have a contingency plan recorded in the care and support plan which is reflected in the commissioned care package and supports delivery of 100% of the commissioned care package. If there are unexpected reasons when the agency is unable to deliver 100% then contact must be made with the CCCS as soon as possible to advise of the situation, reasons, and to enable a risk assessment to be carried out. The risk assessment will consider whether a safeguarding referral and/or a referral to the CQC should be initiated and will be shared with the registered manager and the ICB and retained in SystemOne.
- 9.8. Where family/parental choice is cited as a reason for an unfilled shift, it must be clear that it is a genuine choice provided by the family/ parent and a written record of the discussion, made by the agency, should be shared with the CCCS who will make a recommendation to the ICB in relation to whether there is a need to fill the gaps in the package and the appropriate level of skill required.
- 9.9. There may be times when a carer is the right person but none is available, and the family are unable to support. In these circumstances:
- i. Where between 80-99% of a commissioned care package is delivered as commissioned, it is considered reasonable for the parents to provide the remaining care as part of parental responsibilities; or
 - ii. Exceptionally, following assessment and identification of high levels of risk to a child or where less than 80% of a commissioned care package is delivered, the care provider, under the terms of the AQP contract will be asked to cover the shift(s) with a registered nurse. The care provider is expected to meet the difference in cost between the ICB's funding for a carer and the cost of a registered nurse.

10. Commissioning Care away from usual residence

- 10.1. Where a CYP, in receipt of CC funding, needs to be away from their normal residence to receive NHS approved and funded treatment, through either ICB commissioned services or as approved by the Individual Funding Requests (IFR) Panel, the ICB will continue to fund the usual commissioned care package so that carers may accompany the individual for the treatment. In addition, the ICB will fund reasonable quoted costs for the carer accommodation and carer mileage costs within the United Kingdom. This is for a maximum period of 3 weeks in a financial year. A request for more than 3 weeks would be reviewed by the ICB at the Complex Care Quality Assurance Panel ("CCQA") and a response returned to the family once a decision has been made.
- 10.2. Reasonable accommodation costs are considered to be equivalent to budget hotel prices for the area. Mileage costs are capped at 45p per mile. Train fare will be funded if the total cost is equivalent or less than mileage costs. Ferry crossings or flights to Northern Ireland or other UK islands, funding will be at the lowest price sourced.

- 10.3. When funding for carer accommodation and carer travel costs are approved, the ICB will set a ceiling price on the cost in line with the original quote received with the request. Any subsequent changes to arrangements which incur a higher cost will only be funded up to the original price approved.
- 10.4. The ICB will not fund carer accommodation, mileage or other travel costs for any treatment, whether NHS approved or otherwise, being delivered outside of the United Kingdom. The ICB will not fund carer accommodation, mileage or other travel costs for any treatment that has not been approved by the NHS, either through ICB commissioned services or through the Individual Funding Requests Panel.
- 10.5. NHS funding cannot be used to fund a person's and/or their family's holiday. Where a person wishes to go on holiday and take their employed personal assistant ("PA") or staff from a commissioned provider, they must formally request this through the CYP Continuing Care Case Manager who will liaise with the ICB. The ICB will only normally agree to pay for the staff for the current hours of support that are already agreed in the care and support plan.

The ICB will not cover the following costs:

- Flights for the person, their family or staff;
- Hire vehicles;
- Food and beverages for the person, their family or staff; or
- Any other request which is not directly related to a person's health and well-being.

The ICB can:

- Cover the additional cost of carer accommodation; and
- Fuel costs where a carer is expected to use their own vehicle to provide care and support to a person on their holiday. This excludes fuel costs outside of the UK.

Funding for holiday support may be requested for up to a maximum of 3 weeks per financial year.

- 10.6. The ICB will require additional assurance, for example with complex care packages where:
- The cost of care exceeds £5,000 per week;
 - The case is contentious irrespective of its cost – such cases are defined as those that fall outside the scope of this policy or where there is significant concern or complexity around the package of care and funding requested; or
 - The provision of a PHB to support care at home is significantly more than the cost of care in a residential setting.

- 10.7. The CCQA Panel process aims to ensure that these requests are considered in a fair and transparent way, with decisions based on the best available evidence and in accordance with the ICB's policies.

When considering a request, in addition to the principles outlined in section 7 of this policy the Panel will also ensure that decisions:

- Comply with relevant national policies or local policies and priorities that have been adopted by the ICB concerning specific conditions or treatments.
- Are based on the available evidence concerning the clinical and cost effectiveness of the proposed care package or placement.
- Address any contractual, CQC or safeguarding issues.
- Are taken without undue delay; a pragmatic approach may need to be taken when dealing with urgent requests i.e., where a delay in reaching a decision to fund adversely affects the clinical outcome.

11. One-to-One (1-1) in Care Homes

- 11.1. The ICB will contribute to One to One ("1:1") provision for CYP eligible for CC in a CYP residential home where the following is evidenced: :
- The providers has accessed NHS universal services prior to requesting 1:1;
 - 1:1 requests in a care home adhere to the National Framework for Children & Young People's Continuing Care which stipulates the elements of a good multidisciplinary assessment of needs; and
 - 1:1 funding will not be paid when the CYP is in hospital unless the member of staff is present at hospital and prior approval has been gained from the ICB.

12. Fast Track Packages for Children and Young People

- 12.1. End of life care refers to a child or young person whose condition is deteriorating rapidly, characterised by an increasing level of dependency and where a lifespan is thought to be days or weeks rather than months or years. The aim of the fast-track pathway is to ensure individuals with a rapidly deteriorating condition that may be entering a terminal phase of life are supported in the preferred place of care as quickly as possible. (Department of Health 2012). A referral for a fast-track end-of-life request must be consultant led.
- 12.2. Cases who are being 'fast tracked' for end-of-life care are not required to have a full assessment. In these cases, a Children's Fast Track request must be completed and signed and sent to the Children's Continuing Care service.
- 12.3. Where an urgent decision on fast-track funding is required, the ICB will make an out of panel decision, and then bring that decision to the next Panel for information.

13. Transport And Fuel

- 13.1. The ICB will only pay for the individual's assessed needs or services as outlined and agreed in their CASP, which may include identified provision in an EHCP, and not available for funding via alternative routes such as local authority school transport between home and school.
- 13.2. Provision of transport to and from school is the responsibility of the Local Authority Education Department. However, the ICB may support with funding training for escorts to support a child or young person in line with their assessed health needs.

14. Equipment

- 14.1. In line with the National Framework, equipment should be available to recipients of Children's Continuing Care. The ICB has an Integrated Community Equipment Loans ("ICEL") Service which will provide the majority of equipment required for children and young people.
- 14.2. Some individuals in receipt of CC will require bespoke equipment to meet specific assessed needs. The ICB and Local Authority will joint fund the provision of such equipment in accordance with agreed funding responsibilities. The Local Authority is responsible for arranging assessment for and provision of such equipment. This includes responsibility for any essential servicing and repair that might be required.
- 14.3. Where specialist medical equipment is required, and this is not available from ICEL the ICB has developed guidance at Appendix B of this document.

15. Private Funding of Care

- 15.1. The decision to purchase private care services should always be a voluntary one and not imposed upon individuals.

16. Mental Capacity

- 16.1. The Mental Capacity Act applies to those aged 16 years and over.
- 16.2. People aged 16 or over are entitled to make decisions provided they have the mental capacity to make the particular decision. This can only be overruled in exceptional circumstances where there is evidence that they do not have the mental capacity to make this decision.
- 16.3. Children under the age of 16 can consent if they're believed that they have sufficient intelligence and understanding to be capable of making up their own mind on the matter requiring a decision. This is known as being Gillick competent. Otherwise,

someone with parental responsibility can consent for them if the decision falls within the zone of parental responsibility.

- 16.4. These principles are also applied to involvement in the CC process and wherever possible, even if they are not competent to give full consent, the voice of every child should be sought regarding their needs and care preferences.

17. Reviews

- 17.1. All CYP in receipt of CC will be reviewed to ensure that the CASP continues to meet the individual's needs, the package of care that they are receiving remains appropriate, the PHB is being managed appropriately and whether or not the individual still has CC needs.
- 17.2. For CC funding, reviews are carried out in line with the Children and Young Person's Continuing Care Framework. This means that there is an initial review at 3 months and then annually.
- 17.3. Reviews may need to take place sooner or more frequently if the ICB becomes aware that the health needs of the individual have changed significantly, for example the EHCP has changed, or if it becomes apparent that the care plan is not being followed or expected health outcomes are not being met.
- 17.4. The individual and care providers should update the ICB if care needs reduce or increase so further assessment can be made to ensure the individual continues to receive the most clinically effective services and to ensure effective use of NHS resources.
- 17.5. In the event that a review of an individual establishes that their condition has improved or stabilised to such an extent that they no longer meet the eligibility criteria for CC, the ICB will no longer be required to fund their care. Such decisions will take account of well managed needs in accordance with the National Framework for CC.
- 17.6. The ICB will provide written notice of cessation of funding to the individual and the local authority from the date of the ICB's decision. The notice period is 14 days for patients registered in.

18. Family or Individual Dissatisfaction with Package Offer

- 18.1. Where a family or individual is not satisfied with the choices offered to them or believes that because of exceptional circumstances some or all of the principles in this policy are not applicable in their case, they may submit a complaint in writing to the ICB. Exceptionality is determined on a case-by-case basis and will require a clear clinical rationale and agreement by CCQA Panel.
- 18.2. Where the ICB, having applied the criteria set out in this policy, decides to fund care which is not agreed by the recipient (either because of type, volume or

location of care) and the individual makes a complaint against this decision, the ICB will offer an appropriate interim offer taking account of the individual's safety as the over-riding factor. For these purposes, "interim" refers to the time between the complaint being received and then considered and communicated by the ICB.

- 18.3. The ICB's original decision will be effective until the outcome of the complaint. If the complaint is successful, arrangements will then be made to revise the care package provided in consultation with the individual.
- 18.4. If, during the interim, the individual refuses the ICB's offer of a care package, they may arrange and fund their own package of care. If the ICB's original decision is upheld, the ICB will again offer the individual an appropriate care package that meets the criteria set out in this policy and their assessed needs, in line with the previous package of care. If the care package is still not acceptable to the individual, they may continue to arrange and fund their own package of care.
- 18.5. If the original care package offer proposed by the ICB is upheld, the individual will be advised of their right to complain to the Parliamentary and Health Service Ombudsman.

19. Article 8 of the Human Rights Act

- 19.1. The Human Rights Act means an individual can take action in the UK courts if their human rights have been breached.
- 19.2. However, Article 8 of the Human Rights Act is qualified; this means rights can be restricted in specific situations. To prove objective justification for qualification of the right, the aim must be a real objective consideration and not in itself discriminatory. For example, ensuring the health and safety of others would be a legitimate aim. Other examples of legitimate aim include the protection of other people's rights, the health, safety and welfare of individuals, running an efficient service, etc.

20. Equality and Diversity Statement

- 20.1. Nottingham and Nottinghamshire ICB pay due regard to the requirements of the PSED in policy development and implementation as a commissioner and provider of services as well as an employer.
- 20.2. The ICB is committed to ensuring that the way we provide services to the public and the experiences of our staff does not discriminate against any individuals or groups on the basis of their age, disability, gender identity (trans, non-binary), marriage or civil partnership status, pregnancy or maternity, race, religion or belief, gender or sexual orientation.

- 20.3. The ICB is committed to ensuring that our activities also consider the disadvantages that some people in our diverse population experience when accessing health services. Such disadvantaged groups include people experiencing economic and social deprivation, carers, refugees and asylum seekers, people who are homeless, workers in stigmatised occupations, people who are geographically isolated, Gypsies, Roma and Travellers.
- 20.4. As an employer, the ICB is committed to promoting equality of opportunity in recruitment, training and career progression and to valuing and increasing diversity within our workforce.
- 20.5. To help ensure that these commitments are embedded in the ICB's day-to-day working practices, an Equality Impact Assessment has been completed for, and is attached to, this policy.

21. Communication, Monitoring and Review

- 21.1. The ICB will establish effective arrangements for communicating the requirements of this policy and will provide guidance and support to line management in relation to their responsibilities.
- 21.2. This policy will be audited as to effectiveness of ensuring choice and equity in the delivery of CC across the ICB.
- 21.3. This policy will be reviewed every three years, or if there are changes in national guidance on individual choice or CC and will be approved by the ICB's Strategic Planning and Integration Committee.
- 21.4. An audit of cases will be undertaken annually by the Head of Continuing Healthcare and the CHC Lead Nurse – this will check that the CC process has been followed in terms of decision making, issue of decision letter to the child, young person and family and the commissioned care package is line with this policy and has been approved as per the ICB delegated limits. Corrective actions will be taken. The audit findings will be presented to the Assistant Director of Nursing and Personalisation and the Deputy Chief Nurse.
- 21.5. Any individual who has queries regarding the content of the Policy, or has difficulty understanding how this relates to their role, should contact the ICB's Continuing Healthcare Team via email: nnicb-nn.chcteam@nhs.net

22. Staff Training

- 22.1 Awareness of this policy will be proactively undertaken throughout the ICB and ongoing support will be provided to individuals to enable them to discharge their responsibilities. The core training that all CHC staff will undertake in addition to mandatory training will be personalised care training including personal health budgets. The assessment teams will undertake CHC specific training including the NHSE CHC e-learning.

23. Interaction with other Policies

- 23.1 The policy should be read in conjunction with the Children and Young Person's Continuing Care National Framework.

24. References

- ICB Commissioning Strategy: [Commissioning Strategy 2020-2022](#)
- ICB Financial Strategy: [Financial Strategy 2019-20 to 2023-34](#)
- ICB Safeguarding Policy: [QUAL-001 Safeguarding Policy \(inc LAC, PREVENT and Safeguarding Training Strategy\) v2 \(kinstacdn.com\)](#)
- Equality, Diversity and Inclusion (EDI) Policy 2020-2023 [Equality Diversity and Inclusion Policy \(nottscg.nhs.uk\)](#)
- Delayed Discharges Directions:
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/784710/Delayed Discharges Continuing Care Directions 2013.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/784710/Delayed_Discharges_Continuing_Care_Directions_2013.pdf) and
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/784711/Delayed Discharges Continuing Care Amendment Directions 2018.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/784711/Delayed_Discharges_Continuing_Care_Amendment_Directions_2018.pdf)
- Direct Payment: <https://www.england.nhs.uk/wp-content/uploads/2017/06/guid-direct-paymnt.pdf>
- Human Rights Act 1998, Citizens Advice Bureau & Equality and Human Rights Commission: <https://www.equalityhumanrights.com/en/advice-and-guidance/public-sector-equality-duty>
- Mental Capacity Act 2005: www.legislation.gov.uk/ukpga/2005/9/contents
- Motability Scheme: <https://www.motability.co.uk/about/how-the-scheme-works/how-your-vehicle-can-be-used/>
- NHS Choices Framework (2019): <https://www.gov.uk/government/publications/the-nhs-choice-framework/the-nhs-choice-framework-what-choices-are-available-to-me-in-the-nhs>
- NHS Constitution: <https://www.gov.uk/government/publications/the-nhs-constitution-for-england>
- Patient Safety Strategy: <https://improvement.nhs.uk/resources/patient-safety-strategy/>
- ICB Children and Young People's Continuing Care Policy 2022-2025

25. Equality Impact Assessment

Overall Impact on: Equality, Inclusion and Human Rights [Select one option]	Positive <input type="checkbox"/> Neutral <input checked="" type="checkbox"/> Negative <input type="checkbox"/> Undetermined <input type="checkbox"/>
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Name of Policy, Process, Strategy or Service Change	Children & Young People’s Continuing Care Commissioning Policy	Date of Completion	8 February 2024
EIA Responsible Person Include name, job role and contact details.	Jane Godden, Head of Continuing Healthcare Email: nnicb-nn.chcteam@nhs.net		
EIA Group Include the name and position of all members of the EIA Group.	Nicola Ryan, Deputy Chief Nurse Sally Dore, Assistant Director of Nursing Heather Woods, CHC Lead Nurse		
Summary of Evidence Provide an overview of any evidence (both internal and external) that you utilised to formulate the EIA. E.g., other policies, Acts, patient feedback, etc.	<ul style="list-style-type: none"> • Equality Act 2010 (inc. the PSED) • Human Rights Act 1998 • Mental Health Act 1983 • Gender Recognition Act 2004 • Mental Capacity Act 2005 (inc. DOLS) • Down Syndrome Act 2022 • Children’s Act 1989 and 2004 (where applicable) 		

<p>For the policy, process, strategy or service change, and its implementation, please answer the following questions against each of the Protected Characteristics, Human Rights and health groups:</p>	<p>What are the actual, expected or potential positive impacts of the policy, process, strategy or service change?</p>	<p>What are the actual, expected or potential negative impacts of the policy, process, strategy or service change?</p>	<p>What actions have been taken to address the actual or potential positive and negative impacts of the policy, process, strategy or service change?</p>	<p>What, if any, additional actions should be considered to ensure the policy, process, strategy or service change is as inclusive as possible? Include the name and contact details of the person responsible for the actions.</p>	<p>Impact Score</p>
<p>Age</p>	<p>A person-centred approach will achieve better outcomes by promoting health, well-being and independence through choice and control. This policy will include people from birth to 18.</p> <p>For children eligible for children's continuing care and those who have a legal right to a personal health budget there will be no age exclusion for being able to ask for a personal health budget.</p>	<p>The policy is for young people up to and including 17-year-olds. Anyone aged 18 years or old is covered by the Adult CHC Policy. There is no consideration for the transition of the care of young people into adult services.</p>		<p>None</p>	<p>2</p>
<p>Disability¹ (Including: mental, physical, learning, intellectual and neurodivergent)</p>	<p>A person-centred approach will achieve better outcomes by promoting health, well-being and independence through choice and control. Children with a disability who meet the criteria for children's continuing care will receive the care and support they have been clinically assessed for to meet their level of disability</p>	<p>A personalised approach may not always be achieved due to controls within the ICB's available resources.</p> <p>There is a potential impact on young people who do not have capacity to make decisions and choices about their care.</p> <p>The policy may impact on people with physical or learning disabilities</p>	<p>The ICB will support an individual's communication needs by providing an interpreter and or easy read, large print or recordings to ensure the person is provided with the information they require to be fully involved in the care and support planning process.</p>	<p>None</p>	<p>2</p>

	<p>Children’s assessors are fully trained in use of the Mental Capacity Act and will work with fellow professionals and families to make best interest decisions where required.</p> <p>The ICB will work with children and families to find the most appropriate way to meet identified needs. The ICB will be responsive to changing needs and circumstances.</p>	<p>when the person’s preference is for a package of care at home which is high cost due to complexity and intensity of needs. There is an expectation that CHC Case Managers will ensure that those people who have specific communication needs and will make this available in time for any DST assessment/ meetings with the individual, family and carers. This should not cause delays.</p>			
<p>Gender² (Including: trans, non-binary and gender reassignment)</p>	<p>Decisions regarding how care is delivered will be based on their needs, and the child or young person’s gender identity is not a determinant of whether they receive care.</p>	<p>The Policy does not make allowances for individual choice regarding the gender of the caregiver, and requires a clinical reason for challenging the delivery of care. The gender identity of children and young people is not considered in the macro or individualised planning of CHC services.</p>	None	None	2
<p>Marriage and Civil Partnership</p>	<p>Young people from the age of 16 are able to marry within England.</p> <p>Whilst the Policy does not specifically mention marriage and civil partnership, it does discuss “family” in relation to decision-making.</p>	<p>There are no perceived negative impacts for this protected characteristic.</p>	None	None	3

	The next of kin of all children and young people will be included wherever possible, and consent is given or it's in their best interests, in the planning and decisions regarding care.				
Pregnancy and Maternity Status	<p>Whilst the Policy does not specifically mention pregnancy and maternity, it does discuss "family" concerning decision-making.</p> <p>In the application of the policy, the ICB and providers should work together to ensure the best care package for the individual.</p>	There are no actual or expected negative impacts on the characteristic of Pregnancy and Maternity Status.	None	None	3
Race³	<p>The ICB will endeavour to meet all cultural needs of individuals, recognising personal choice. Part of the care and support planning process will recognise cultural sensitivities.</p> <p>Interpreters and information in other languages will be provided upon request.</p>	<p>The Policy does not specifically mention cultural considerations as part of the assessment and planning process to enable a person-centred approach to care delivery.</p> <p>The Policy is applicable equally across all areas of Nottingham and Nottinghamshire, that individual and community needs are not given full consideration.</p>	Mechanisms are in place via the Communications and Engagement Team to provide information in a range of languages, and in a range of accessible formats. .	None	2
Religion and Belief⁴	Part of the care planning process considers religious needs and preferences, taking into account the personalised approach.	The Policy does not specifically mention religious or belief impacts when undertaking the assessment and planning process to enable a person-centred approach to care delivery.	A personalised approach is offered through individual choice and control within the ICB's available resources.	None	2

		The Policy is applicable equally across all areas of Nottingham and Nottinghamshire, that individual and community needs are not given full consideration.	The ICB will work with patients and families to find the most appropriate way to meet identified needs.		
Sex⁵	Decisions regarding how care is delivered will be based on their needs, and the child or young person's sex is not a determinant of whether they receive care.	The sex of children and young people is not considered in the macro or individualised planning of CHC services.	None	None	3
Sexual Orientation⁶	Decisions regarding how care is delivered will be based on their needs, and the child or young person's sexual orientation is not a determinant of whether they receive care.	The sexual orientation of children and young people is not considered in the macro or individualised planning of CHC services.	None	None	3
Human Rights⁷	The care and support planning process will have due regard to the Human Rights Act 1998, with specific due regard to Articles 2, 3, 5, 8, and 14.	There are no actual or expected negative impacts on the characteristic of Human Rights	None	None	3
Community Cohesion and Social Inclusion⁸	During the care and support planning process, individuals are given the opportunity to explore methods to assist them with accessing the local community and activities. If the individual/parents chooses to receive their continuing care package via a personal health budget it allows more creative	There are no actual or expected negative impacts on the characteristic of Community Cohesion and Social Inclusion	None	None	4

	solutions to remove any barriers that may have prevented community access previously.				
Safeguarding⁹ (Including: adults, children, Looked After Children and adults at risk or who lack capacity)	Care givers/ professionals will undertake Children's Safeguarding and Capacity Training in accordance with best practices.		The ICB will work with fellow professionals and families to make best interest decisions where required.	Support from the ICB safeguarding team	3
Other Groups at Risk¹⁰ of Stigmatisation, Discrimination or Disadvantage	It is recognised that Nottingham and Nottinghamshire communities are diverse in their makeup, and therefore, children and young people from a diverse range of backgrounds, family structures, and identities will likely access CHC services.	The policy may not always support the recognition of structural barriers to how the most vulnerable access inclusive care services.	None	None	2

<h3>Additional Narrative</h3> <p>Provide additional evidence and narrative about the positive, negative, and neutral impacts of the proposal on the equality, inclusion and human rights elements detailed above.</p> <p>You should consider:</p> <ul style="list-style-type: none"> • Three elements of Quality (safety, experience and effectiveness) • Intersectionality • Impact of COVID-19 • Access to Services <ul style="list-style-type: none"> ○ Physical ○ Written communication ○ Verbal communication • Digital Poverty • Safeguarding • Dignity and Respect • Person-centred Care 	<p>Here you should add additional detail or explanation around the positive, negative, and neutral impact of the proposals on the above protected characteristic and health inclusion groups. To address this, you should consider the barriers to accessing or using the service, including the mitigations to respond to these.</p> <p>The provision of a CHC package will likely positively impact not only the child or young person but also their wider family and support network.</p>	<p>4</p>
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Positive Impact	Neutral Impact	Negative Impact	Undetermined Impact	<p>Equality Impact Score Total</p>	<p>38</p>
56 to 50	49 to 36	35 to 22	21 to 14		

Positive	Neutral	Negative	Undetermined
4	3	2	1

1. **Disability** refers to anyone who has: "...a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities..." (Equality Act 2010 definition). This includes, but is not limited to: mental health conditions, learning disabilities, intellectual disabilities, neurodivergent conditions (such as dyslexia, dyspraxia and dyscalculia), autism, many physical conditions (including HIV, AIDS and cancer), and communication difficulties (including d/Deaf and blind people).
2. **Gender**, in terms of a Protected Characteristic within the Equality Act 2010, refers to: "A person has the protected characteristic of gender reassignment if the person is proposing to undergo, is undergoing or has undergone a process (or part of a process) for the purpose of reassigning the person's sex by changing physiological or other attributes of sex."
3. **Race**, in terms of a Protected Characteristic within the Equality Act 2010, refers to: A person's colour, nationality, or ethnic or national origins. This also includes people whose first spoken language is not English, and/or those who have a limited understanding of written and spoken English due to English not being their first language.
4. **Religion and Belief**, in terms of a Protected Characteristic within the Equality Act 2010, refers to: Religion means any religion and a reference to religion includes a reference to a lack of religion. Belief means any religious or philosophical belief and a reference to belief includes a reference to a lack of belief.
5. **Sex**, in terms of a Protected Characteristic within the Equality Act 2010, refers to: A reference to a person who has a particular protected characteristic and is a reference to a man or to a woman.
6. **Sexual Orientation**, in terms of a Protected Characteristic within the Equality Act 2010, refers to: Sexual orientation means a person's sexual orientation towards persons of the same sex, persons of the opposite sex or persons of either sex.
7. The **Human Rights Act 1998** sets out the fundamental areas that everyone and every organisation must adhere to. In relation to health and care, the most commonly applicable of the Articles within the Human Rights Act 1998 include: Article 2 Right to Life, Article 5 Right to Liberty and Security, Article 8 Right to Respect of Private and Family Life, and Article 9 Freedom of Thought, Conscience and Religion.
8. **Community Cohesion** is having a shared sense of belonging for all groups in society. It relies on criteria such as: the presence of a shared vision, inclusion of those with diverse backgrounds, equal opportunity, and supportive relationships between individuals. **Social Inclusion** is defined as the process of improving the terms of participation in society, particularly for people who are disadvantaged, through enhancing opportunities, access to resources, voice and respect for rights (United Nations definition). For the EQIA process, we should note any positive or negative impacts on certain groups being excluded or not included within a community or societal area. For example, people who are homeless, those from different socioeconomic groups, people of colour or those from certain age groups.
9. **Safeguarding** means: "...protecting a citizen's health, wellbeing and human rights; enabling them to live free from harm, abuse and neglect. It is an integral part of providing high-quality health care. Safeguarding children, young people and adults is a collective responsibility" (NHS England definition). Those most in need of protection are children, looked after children, and adults at risk (such as those receiving care, those under a DoLS or LPS Order, and those with a mental, intellectual or physical disability). In addition to the ten types of abuse set out in the Health and Care Act 2022, this section of the EQIA should also consider PREVENT, radicalisation and counterterrorism.
10. **Other Groups** refers to anyone else that could be positively or negatively impacted by the policy, process, strategy or service change. This could include, but is not limited to: carers, refugees and asylum seekers, people who are homeless, gypsy, Roma and traveller communities, people living with an addiction (e.g., alcohol, drugs or gambling), people experiencing social or economic deprivation, and people in stigmatised occupations (e.g., sex workers).

Appendix A

Resource Allocation Tool

Criteria for Allocation of Health Support for Children who are Eligible for Continuing Care Services			
Level	Criteria	Comments	Indicative hours per week
4a	Ventilation Invasive 24 hour Night time only	24 hour invasive ventilation can be increased up to 105 hour per week in the school holidays for children at school. Enhanced allocation takes into account factors in the criteria for enhanced respite and discussion with parents.	24 hour Usual allocation Pre-school - Up to 95 School age - Up to 85 24 hour Enhanced allocation Up to 105 hours per week Night time Enhanced allocation up to 80 Usual allocation up to 70
4b	Non-invasive 24 hour Night time only	Non-invasive. life supportive. 24 hour ventilation can be allocated at level 4a de.pendant on a risk assessment. Enhanced allocation takes into account factors listed in criteria for enhanced respite and discussion with parents.	24 hour Enhanced allocation up to 40 Usual allocation up to 30 Night time Enhanced allocation up to 30 Usual allocation up to 20
3	End of Life Care <i>[Short term intensive respite subject to review]</i>		Enhanced allocation up to 60 Usual allocation up to 50
2	Continuously unstable. condition defined by nursing assessment and requiring nursing interventions to respond to: e.g. apnoea, irregular breathing, unstable airway, dropping heart rate, fluctuating O2 saturations despite O2.		Enhanced allocation up to 50 Usual allocation up to 40
1	Children who meet the continuing care criteria, whose condition remains largely unchanging, but who may have episodes of acute illness or instability, (e.g. chest infections managed by antibiotics, increased need for suction, episodes of increased fitting, short term increase in waking interventions) which may temporarily increase the need for nursing interventions. (Nursing interventions as identified by the nursing assessment)		Enhanced allocation up to 30 Usual allocation up to 20
CRITERIA FOR ENHANCED RESPITE - <i>If a child no longer meets the enhancement criteria, the usual allocation will apply and the hours reduced accordingly</i> <ul style="list-style-type: none"> • High level health needs in a foster placement, as identified by multidisciplinary meeting. • Waking 4 or more times a night for necessary nursing interventions, as identified by overnight nursing assessment. • Child not receiving regular schooling due to high level health needs and receiving home tuition, confirmed by consultant letter. • Deteriorating condition as identified by consultant letter and nursing assessment. 			

Appendix B

Funding for Equipment

This guidance has been developed to manage requests received by the ICB for funding equipment for individuals who are eligible for CC

The provision of community equipment falls within the remit of ICELS (Integrated Community Equipment Loan Service). All requests for community equipment should be directed to ICELS by contacting the team via icesteam@nottsc.gov.uk in the first instance who will give guidance and support.

However, ICELS will not fund certain medical/nursing type items, usually the higher end medical/nursing aids to support the management of 'life threatening conditions. These are items which are often complex, address a 24 hour need and are usually looked after via the acute hospital MESU arrangements such as

- Cough Assist Machines
- Vibrating Vests
- Nebulisers
- Suction Machines
- Heated Dehumidifiers
- Drip stands/trolleys

Any requests for respiratory equipment, eg Cough Assists, Nippys, should be directed to the Respiratory Services at the relevant acute hospital – the majority of such requests will be dealt with by this service.

Any other request for such medical items can be made by the CC Case Manager to the CHC Team by contacting the team on nnicb-nn.chcteam@nhs.net with a completed "Change of Package" form giving details of who the equipment is for (must be eligible for CC), rationale for the requirement of the equipment, details of who will be responsible for purchasing the equipment, owning the equipment, responsibility for servicing and repairs and responsibility for training the carers to use the equipment. The request should also be accompanied by a minimum of two up-to-date quotes.

Once a request has been received the CHC team will escalate through the appropriate approval channels for authorisation.

All equipment will normally be purchased by the Provider (i.e., the acute or community trust) who will own the equipment. The initial purchase should include a warranty to cover maintenance and servicing. The ICB will reimburse costs to the Provider for the purchase and warranty costs on receipt of an invoice. For an individual living at home with a PHB, provision for servicing and repairs following expiry of the warranty should

be included in the budget and documented in the care and support plan, along with details regarding training for using the equipment.

The CC Case Manager will be responsible for arranging training for the individual's care team to use the equipment. Any practitioner who provides the training will be accountable for the appropriateness of the training and ensuring that the person who does the work is able to do it to the required standard.

There may be exceptional circumstances when the ICB would need to purchase the equipment. In this case the equipment would be purchased through Arden and GEM Commissioning and Support Unit and the quotation should include a warranty within the purchase price. The ICB will be responsible for arranging the required servicing (at the necessary intervals) and any repairs. Therefore, if possible, the ICB should arrange for MESU to carry out the servicing and arrange the relevant service visits/recalls.

Longer term it is anticipated that the ICB will come to an arrangement with ICELs to purchase medical type equipment and loan the items to individuals, thus responsibility for servicing and repairs to sit with ICELs.