Policy for Children’s Continuing Healthcare

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## DOCUMENT CONTROL

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<td>For discussion at the policy development meeting</td>
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<td>Final sign off and agreement</td>
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<td>Added contents page, definitions used, also headings for training, dissemination, implementation, monitoring and review.</td>
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### Appendices

Appendix A

**Policy Guideline on CHC for Children and Young People** | 10-17
1. Introduction

1.1 This policy describes the way in which the five (CCG s) in North Central London will make provision for the care of children and young people (CYP) who have been assessed as eligible to receive funding for NHS continuing healthcare.

2. Policies statement

2.1 The policy describes the process, led by the CCG, of assessing, deciding and agreeing young people’s and children’s continuing care needs and bespoke packages of care. The policy has been produced in consultation with a wide number of stakeholders, including commissioners, providers and parent/carers.

2.2 The policy sets out to ensure that decisions will:

- be robust, fair, consistent and transparent,
- be based on the objective assessment of the patient’s clinical need, safety and best interests,
- have regard for the safety and appropriateness of care packages
- involve the child/young person, wherever possible, and their parents/carers
- take into account the need for the CCG to allocate its financial resources in the most cost effective way,
- support choice to the extent possible in the light of the above factors
- be consistent with the principles and values of the NHS Constitution
- take into account an individual’s needs for both their health and their wellbeing including safeguarding

2.3 This policy and the Continuing Health Care Guidelines (Appendix A) form the continuing care policy framework. This document should be read in conjunction with:

- National Framework for Children and Young People’s Continuing Care
- CCG Health and Safety Policies
- Policy and Procedure for Safeguarding Children
- The NHS Constitution

The responsible commissioner guidance, who pays should also be seen as a key document.

3. Scope of this policy

3.1 In March 2010 the Department of Health published the ‘National Framework for Children and Young People’s Continuing Care’. The National Framework sets out a process for assessment and agreement of eligibility for continuing care. All health professionals working directly with children and young people should ensure that safeguarding and promoting their welfare forms an integral part of all elements of the care they offer (Working Together, 2013).

4. Who this policy applies to

4.1 All staff involved in the assessment, commissioning and delivery of Continuing Healthcare with Children and Young People across Barnet, Enfield, Haringey, Camden and Islington.

5. Recommendations for independent contractors

5.1 Not applicable
6. Definitions used in this policy

i. Clinical Commissioning Group (CCG)
ii. Continuing Healthcare (CHC)
iii. National Healthcare Service (NHS)
iv. Lasting Power of Attorney (LPA)
v. Child or Young Person (CYP)
vi. Parliamentary and Health Service Ombudsman’ (PHSO)
vii. Patient Advocacy Service (PALS)

7. Roles and Responsibilities

i. The National Framework for Young People and Children’s Continuing Care (2010) defines continuing care as, ‘A package of care 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. Continuing care does not cover children and young people with care needs that may be met appropriately through existing universal or specialist health services.’

ii. The CCG is required to secure and fund a continuing care package to meet the reasonable needs of children and young people aged 0-18 years of age, as assessed by the relevant professionals. Such needs will be identified through the use of a full continuing healthcare assessment.

iii. Continuing health care is generally provided through bespoke care packages at home to children and young people (aged 0-18), but at times may include hospice, or additional care in a hospital or residential setting.

iv. Continuing Care Guidelines, (Appendix A) describes the process of assessing continuing care eligibility in detail. When the decision on eligibility is agreed, the Continuing Health Care Nurse, will identify establishments or organisations, including the private sector and NHS Provider Trusts which are capable of meeting the assessed needs.

8. Provision of Continuing Healthcare

i. The CCG aims to commission care provision which meets assessed needs. This assessment takes into account their needs for both their health and their general wellbeing, which falls outside this policy. The total costs of each package will be identified and assessed for overall cost effectiveness by the care management team and commissioners.

ii. If more than one suitable establishment or care package is available, or where there is a request for a care package which is not usually commissioned by the CCG, the total costs of each package will be identified and assessed for overall cost effectiveness by the care management team and commissioners.

iii. While there is no set upper limit on expenditure both deliverability and cost effectiveness will be taken into account. This is the most effective, fair and sustainable use of finite resources, as set out in the principles and values of the NHS Constitution.

iv. CCGs hold the responsibility to promote a comprehensive health service on behalf of the Secretary of State and to not exceed its financial allocations.
v. It is expected to take account choice, but must do so in the context of those two responsibilities.

Any assessment of need will include a review of the psychological and personal care needs, education and social care needs as well as the CYP healthcare needs.

Mental capacity
i. The Mental Capacity Act applies to those over the age of 16, and also children under the age of 16. The areas applying to children and young people are as follows:

   a. *Children under 16*
      - The Act does not generally apply to people under the age of 16.
      - There are two exceptions:
        - The Court of Protection can make decisions about a child’s property or finances (or appoint a deputy to make these decisions) if the child lacks capacity to make such decisions within section 2(1) of the Act and is likely to still lack capacity to make financial decisions when they reach the age of 18 (section 18(3)).
        - Offences of ill treatment or wilful neglect of a person who lacks capacity within section 2(1) can also apply to victims younger than 16 (section 44).

   b. *Young people aged 16–17 years*
      - Most of the Act applies to young people aged 16–17 years, who may lack capacity within section 2(1) to make specific decisions.
      - There are three exceptions:

        Only people aged 18 and over can make a Lasting Power of Attorney (LPA).217 Mental Capacity Act Code of Practice.

   c. Section 44 covers the offences of ill treatment or wilful neglect of a person who lacks capacity to make relevant decisions (see chapter 14). This section also applies to children under 16 and young people aged 16 or 17. But it only applies if the child’s lack of capacity to make a decision for themselves is caused by an impairment or disturbance that affects how their mind or brain works (see chapter 4). If the lack of capacity is solely the result of the child’s youth or immaturity, then the ill treatment or wilful neglect would be dealt with under the separate offences of child cruelty or neglect.

Receiving Continuing Health Care

i. The CCG is only obliged to provide services that meet the assessed needs. A parent however, has the right to decline NHS funded services and make their own private arrangements.

ii. Where a CYP is found eligible for continuing care, the CCG must provide any services that it is required free of charge. Equipment and medical equipment will also be provided free of charge and serviced as and when required.
iii. Not all of the five boroughs fund all home equipment, some will only nursing equipment and community equipment and adaptations will be funded through community health providers.

iv. The equipment will remain the property of the CCG and used for other CYP.

Continuing Healthcare Reviews

i. The CCG will ensure that the CHC Nurse is routinely reviewing packages of care. All CYP will have their care reviewed within the first three months of its start. Subsequent to any review, including this first, all CYP must be reviewed at least once every twelve (three monthly in Islington) months thereafter or sooner if their care needs indicate that this is necessary.

ii. CYP with palliative care needs will have their care reviewed more frequently in response to their medical condition. The review may result in either an increase or a decrease in support offered and will be based on the assessed need of the individual at that time. Reviews will include input from the parents/carers.

iii. Where the CYP is in receipt of a package and the assessment determines the need for a change, the package will alter accordingly and commissioning leads will need to be informed of the change. Prior approval should be sought for an increase in care package.

iv. This may result in care being offered from a hospital, residential setting or hospice, whichever best meets the CYP needs overall.

v. The appropriate care of children with profound multiple disabilities or chronic severe illness generally involves input from statutory agencies: health; social care and education, and the continuing care assessment and subsequent decision about packages of care, will take place around this context. A parent or carer may appeal the decision in writing within 28 days through the Continuing Healthcare lead, as described in Continuing Care Guidelines Appeals Policy (Appendix A). A parent or carer who is in disagreement with the change in care package following a review, may appeal the decision in writing within 28 days by contacting the CHC lead.

Transition

i. The final age for the transition of continuing care arrangements for all young people will be 18. Planning for the transition to adult services should however, commence at 14.

ii. A young person will be referred for formal screening by Adult Continuing Care services at 16 and by the age of 17 ½ an individual’s eligibility for Adult Continuing Care should have been decided in principle in order that packages of care can be commissioned in time for the individual’s 18th birthday. In Haringey and Islington those YP eligible for adult continuing healthcare can choose to have a personalised budget.

iii. Where a young person has an allocated social worker, the social worker will lead the transitions process working with the Transition Team. The adult continuing care process legally requires the involvement of both health and adult social care
assessment processes to determine eligibility, therefore a social worker will need to be allocated.

**Please refer to the CCG guidance and policy for adult continuing healthcare.**

9. **Training**
   None required by CCG. Provider services will ensure all staff are suitably qualified and trained to assess and/or provide continuing health care services.

10. **Dissemination and Implementation**
    This document will be shared with Quality /Governance Leads for all 5 North London CCG’s, the 5 Local Authorities, service users, parents/carers, NHS Community Health providers & other healthcare services.

11. **Monitoring**
    Each CCG will monitor implementation through quarterly performance meetings with its commissioned services.

12. **Review**
    Review date will be October 2015, or following any national/local changes. To include a focus group with families aiming to identify any improvements needed within the complaints/appeals process.

13. **References**

    The National Framework for Young People and Children’s Continuing Care, March (2010)

**APPENDIX A**

Policy Guideline on CHC for Children and Young People
1. Introduction
These guidelines provide information on the process from identifying a patient who may be eligible for CHC through to managing a CHC package of care.

The guidelines may also be read by parents and carers or representatives to support understanding of the process.


The National Framework is guidance and this guideline is in response to the principles within the National Framework, good practice from CCG policy and a result of consultation with Local Authority children’s services colleagues in Social Care, Education and with Parents.

All health professionals working directly with children and young people should ensure that safeguarding and promoting their welfare forms an integral part of all elements of the care they offer (Working Together, 2010). Staff must comply with the organisations safeguarding polices and procedures.

This guideline should be used in conjunction with Continuing Health Care Policy. Both documents should be read in conjunction with: National Framework for Children and Young People’s Continuing Care March 2010.

2. Background
The continuing care process is a three-phase activity which CCGs, local authorities and their partners undertake in order to deliver a continuing care pathway for children and young people with continuing care needs. The three phases are assessment, decision-making, and arrangement of provision, this is largely bespoke are packages provided in the child, or young persons home.

Continuing health care does not cover children and young people with care needs that may be met appropriately through existing universal or specialist health services. In this instance, their needs should be addressed using a case management approach.

The National Framework for Children and Young People’s Continuing Care March 2010 sets out an equitable, transparent and timely process for assessing, deciding and agreeing bespoke continuing care packages for children and young people whose needs in this area cannot be met by existing universal and specialist services. A continuing care package will be required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone.

The Framework provides a process for which, nominated healthcare assessors carry out holistic assessments of children and young people’s continuing care needs and any associated needs of their families, or carers. These needs can be from congenital conditions, long-term deteriorating conditions, accidents or the after effects of serious illness or injury. They may also be one or more of the following: challenging behaviour, communication, mobility, nutrition, continence or elimination, skin and tissue viability, breathing, drug therapies and medicines, psychological and emotional needs, or seizures.
The assessment and delivery of bespoke packages of care to meet these needs will be the focus of this guideline; these are delivered alongside services to meet other needs, including education and social care.

The Framework also provides guidance for further developments to improve the transition arrangements to adult continuing care, and needs to be seen in the context of ongoing work to streamline assessment arrangements for children and young people. This requires careful thought and planning amongst commissioners and practitioners across health, social care and education, and other provider agencies.

3. The Responsible Commissioner

The CCGs are responsible for those children and young people who have a General Practitioner (GP) at the time of assessment even if they do not reside in borough. If those CYP are looked after or have been placed out of borough, the CCGs will also be responsible irrespective of borough of placement by the Local Authority until such a time as they reach 18 years of age or they no longer meet the criteria for NHS CHC funding.

The responsibility for commissioning continuing health care post-18 years of age falls with Adult Services – see the CCG policy for Continuing Health Care for Adults.

4. Purpose

The purpose of this guideline is to establish responsibilities in meeting the continuing care needs of children and young people, and to clarify the process for assessment and eligibility of children and young people who may have continuing care needs.

5. Scope

This guideline applies to children and young people from 0-18 years (up to their eighteenth birthday) with complex health needs who are registered with a GP in the CCG area, or looked after and placed out of the area, and who may have continuing healthcare needs.

6. Definitions

For the purposes of this policy a child or young person is between 0-18 years of age.

The National Framework for Children’s and Young People’s Continuing Care defines continuing care as:

- ‘A package of care 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. Continuing care does not cover children and young people with care needs that may be met appropriately through existing universal or specialist health services.’

- 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.

- DST refers to the Decision Support Tool in the National Framework for Young People and Children’s Continuing Care (2010). The DST brings together all assessment information and evidence to inform the decision as to whether a continuing care package is provided.
7. Duties
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.

Parents have the primary responsibility for the care of their child with statutory agencies supporting them to meet the child’s identified needs.

CCG’s are responsible for leading the continuing care process, while recognising the individual may require services commissioned by the CCG, the Local Authority and other partners. Each agency is responsible for commissioning and funding their own contributions to the continuing care package, in line with their statutory functions. The co-ordination role of the CCG commissioners will ensure that all agencies work together to provide seamless care for a child and their family.

8. Continuing Care Process

One Point of Contact
All enquiries relating to children with complex needs, or continuing care needs, or referrals for continuing care assessment will be directed to the Continuing Health Care Nurse who will act as the one point of contact (National Framework for Children and Young People’s Continuing Care, DOH 2010).

Referrals:
Referrals will come from a range of services working with children and young people – most commonly this will be from Hospitals, Community NHS Trusts or Social Care.

Eligibility
Eligibility for NHS continuing healthcare is based on assessed health needs. The diagnosis of a particular disease or condition is not in itself a determinant of eligibility for NHS continuing healthcare.

Any baby, child or young person is entitled to a full CHC assessment if CHC assessors themselves consider that their needs may be sufficiently complex to warrant a full assessment. The National Framework for CHC, (DOH, 2010) provides a ‘Check List’ for CHC assessors.

This check list, as with all assessments in the CHC process should always be completed in conjunction with the child or young person and/or their parent or carer. The aim of this tool is to support a decision as to whether a full CHC assessment is required, or not. The assessment will be followed by a plan and recommendations including forming a key part of discharge pathway from hospital.

When a child or young person is not eligible for CHC, they will be signposted to alternative services that would be able to offer support.

Coordinating an assessment
Children or young people on can be identified for a full CHC assessment in a number of settings; Acute hospitals, hospice, residential care, the community or in their homes. Some
of these children or young people will already have allocated social workers. In these instances a comprehensive assessment will be required to assess for social care and respite needs.

For those children or young people who meet the threshold and have been assessed using the National Decision Support Tool (DST). The CHC Nurse is then required to make a recommendation to the CCG as to whether the individual is eligible for funding, including the reasons for making this recommendation. When completing the DST, it is essential wherever practicable to involve both the child and their parents/carers in the assessment process. CHC is a complex process and effective engagement throughout the process improves satisfaction and prevents undue appeals at a later stage.

The assessment process will consist of:
- Health assessments – coordination of existing nursing and medical information
- Coordination of social care and education assessments where appropriate
- Family and Child/Young Person’s views

This assessment information and documentation will be used to complete the Decision Support Tool (DST).

All assessment information including the DST will inform the decision making process. Health information must include written clinical guidelines and or protocols for use of technology dependence, medication, oxygen etc.

If a simplified fast track assessment has been undertaken for an urgent case such as end of life care, where appropriate, a retrospective full assessment must also be undertaken. Children and young people cannot be agreed for continuing care without a full or fast track assessment having taken place. All assessment documentation and correspondence including commissioning funding agreements will be retained in the child’s records held by the organisation employing the Continuing Health Care Nurse.

**Timescales**

Assessment and decision making in relation to additional needs will be completed where possible within 23 working days from receipt of referral. Urgent referrals for end of life care should be assessed and responded to appropriate to the need, but within 7 days. If more time is required to undertake this process, the referring party and the family will be informed of this extension, the reasons why and the proposed date of completion.

**9. CHC Funding/Decision- Making Processes:**

**Islington** - A final decision regarding eligibility for continuing care will be made for Islington by the multi-agency decision making forum. Each agency’s individual input to the package of care will be agreed, as with the funding. A review date will be set and the outcome of the review will be brought back to the decision making forum for discussion. The decision making forum will have representatives from Health, and partner agencies. The forum must be attended by at least one member from partner agencies and be a minimum of four members in total to be quorate the outcome of the decision making forum will be recorded.

**Camden** –

Assessments are conducted by the CHC team commissioned from Whittington Health. A final decision regarding eligibility for continuing care will be made for Camden by a multi-agency decision making forum. Each agency’s individual input to the package of care will
be agreed, as will the funding. A review date will be set and outcomes reported to the lead commissioner and/or decision-making fora as appropriate.

**Barnet-**
A continuing care group meets quarterly or as frequently as is required to make funding decisions. The Continuing Health Care Nurse is commissioned from CLCH as is the Complex care team leader. Representatives from partner agencies are invited including the paediatrician responsible for the case. We aim to ensure all funding decisions are met within the frameworks timetable.

**Enfield-**
Referrals are made through the multi-agency Early Support Resource Allocation Panel (ESRAP), which meets every fortnight, and where agreement is reached about the need for a continuing care assessment, the involvement of different agencies, and timescales and arrangements for review etc. Enfield Community Service is commissioned to carry out the assessments and co-ordinate the process on behalf of NHS Enfield. The assessment is carried out by the Continuing Health Care Nurse, and subsequent recommendation agreed with the relevant ECS Service Manager. A recommendation for NHS funding, together with options for meeting the proposed care package, is made direct to the responsible health commissioner, who will liaise with other agencies as necessary to agree funding splits. ECS are responsible for communicating the decision to the child/young person/family. Every attempt is made to meet recommended timescales. Appeals about the decision to be made in writing to the Joint Chief Commissioning Officer. The process is currently under review to ensure CCG involvement.

**Haringey-** the CHC Nurse discusses each CHC assessment directly with the Children’s Community nursing team manager as they are completed and a decision is reached on eligibility based on the nurse’s clinical assessment. Decisions around funding are based on the nurse’s recommendations obtained through a formal funding application to the responsible commissioner. Should the commissioner need additional clinical guidance on the recommendations they will seek this as appropriate. Sharing information with professionals involved in the child’s care about the outcome of these assessments and funding decisions is the responsibility of the CHC Nurse via Haringey’s Integrated Care Panel, attended by a mutt-disciplinary team, including a paediatrician. The decision will be communicated in writing to the child/young person, parents, carers and professionals involved in the process by the CHC Nurse within 5 working days of the funding decision being agreed by the commissioner. This notification will include details of the appeals, complaints process, and translation services.

Some children with complex difficulties including behavioural problems, whose needs cannot be met locally through continuing care processes, may be referred to the local multi-agency joint funding panels.

**10. Fast Track**
If a child’s condition is deteriorating very rapidly they may need to have a fast track assessment in order to agree CHC to enable them to be discharged from hospital and die at home. In these emergency cases each borough agrees that their commissioned CHC Nurse can agree CHC outside of any panel or decision making process with notification and discussion afterwards.

**11. Disputes, Appeals and Complaints Process**
The assessment, with its recommendations, should include enough information to enable the parents/carers to understand how the Decision Support Tool has been used and agreement on funding reached. If the recommendations indicate that continuing care is not required or the parent disagrees with the assessment then the carers/parent has the right to appeal and request a review of the decision.

This must be done within 10 days of receiving the assessment decision and recommendations. Details of how to do this and who to contact for a review should be included in the letter advising the parents of the assessment and recommendations. A copy of the NHS Trusts complaints procedure must also be made available to the relatives/carers, and contact details of any agencies who can offer translation services if required.

The CHC Nurse will be the first point of contact for all disagreements, disputes or appeals relating to decisions made in relation to eligibility for children’s continuing care and level of service provision.

If a resolution cannot be achieved informally with the CHC Nurse then the parent or CHC Nurse can refer the case to either the NHS Provider or organisations and formal complaints procedures must be followed with either organisation leading the response depending on the main concern. Each trust has a PALS department who can be will be the first point of contact for all disagreements, disputes or appeals relating to decisions made by the panel or responsible commissioner in relation to the level or funding of care packages that meet CHC criteria.

If the parents/carers are not satisfied with the PALS response they must ask the PALS department to request the commissioning CCG to review the case, this must be done within 10 working days.

In such cases the responsible commissioner will need to gather and scrutinise all assessments tools and decisions relating to the case in order to take into account the specific concerns raised by the parents/carers. For those boroughs with a panel process, a panel with the augmentation of an independent member from those who made the original decision will be formed to review the case. For those boroughs that make funding decisions through its responsible commissioner, the CYP’s safeguarding lead for that borough or quality lead will be involved in a review process. It may take up to 30 working days for the review to be held.

The decision of the review will be given to the parents/carers in writing, which will include a detailed rationale for how the decision was made. The letter should be sent within five working days of the review meeting/panel. The letter should give details of how to request an independent review by an out of area continuing care team if the parent/carer remains dissatisfied. An independent review should be sought within 10 working days on receipt of the CCG’s own internal review to be completed within 4 weeks.

12. Independent Review
The National Strategy for Continuing Care March 2010 does not contain a formal appeals process. This reflects the approach of the Adult Continuing Care Process where there is an independent review process.
Each CCG commissioner can ask another provider or CCG commissioning lead to look at the decision. If the CCG does choose to send the case to another organisation for an independent decision/second assessment then that from the originating CCG will review the information provided by that independent CCG. This process may take longer but it is the aim of the CCG to inform parents/carers of the decision within 30 days of referring the case to the independent CCG/health trust.

13. Ombudsman
Complainants who remain dissatisfied may contact the ‘Parliamentary and Health Service Ombudsman’ (PHSO), to request an independent review of their case. This must be done within a year after the day on which the person aggrieved first had notice of the matters alleged in the complaint, unless the PHSO considers that it is reasonable to review the complaint outside of this timescale. This request can be made in the following ways:
Contact the PHSO on 0345 015 4037, email at
Phso.enquiries@ombudsman.org.uk
Or write to them at:
The Parliamentary and Health Service Ombudsman
Millbank Towers
Millbank
London
SW1P 4QP
Visit their website at www.ombudsman.org.uk

Resolution of Disputes within Barnet

1. At times disputes may arise and the following dispute procedure should be followed.

   Between Agencies

2. Where funding for a particular care package cannot be agreed at a Joint Funding Panel the matter will be referred to the Integrated Governance Committee that meets between NHS Barnet and London Borough of Barnet (LBB). Cases will be presented from representatives from both NHS Barnet and LBB containing reasoned arguments for not funding part of all of a care package.

3. The referral to the panel will not delay the implementation of the care package. Where a provider needs reassurance from a commissioner that funding will be available, then that commissioner will give it. When a decision has been and there is a change in the commissioning arrangements, that commissioner should inform the provider.

4. Where funds have been committed by the commissioner before the decision and the decision has resulted in a change in commissioning then the “new” commissioner should repay these funds to the “old” commissioner.
By Parents of Care Packages
Where a family is unhappy with the care package that had been agreed at a panel then they should use the established complaints system for NHS Barnet and/or LBB dependant on the complaint.

Between NHS Barnet and Providers of Care
5. Where there is a dispute between NHS Barnet and the provider of the care, then the dispute procedure in the contract will be followed. The care package should be delivered and should not be affected by the dispute. Where there is a withdrawal of care from the provider without sufficient notice to commission an alternative provider, then the case will be subject to the fast track process.