

# **NORTH CENTRAL LONDON CHILDREN'S CONTINUING CARE POLICY**

1	<b>SUMMARY</b>	This policy describes the way in which the five Clinical Commissioning Groups (CCGs) in North Central London will make provision for the care of children and young people who are eligible to receive NHS Continuing Care Funding.			
2	<b>RESPONSIBLE PERSON:</b>	Responsible children's continuing care commissioning manager from Islington, Camden, Haringey, Barnet and Enfield			
3	<b>ACCOUNTABLE DIRECTOR:</b>	Accountable Commissioning Director from Islington, Camden, Haringey, Barnet and Enfield			
4	<b>APPLIES TO:</b>	Islington, Camden, Haringey, Barnet and Enfield NHS Commissioning, Patients, Parents, Public, Local Authorities, Provider Continuing Care Staff and Contracted Preferred Providers that deliver care.			
5	<b>GROUPS/INDIVIDUALS WHO HAVE OVERSEEN THE DEVELOPMENT OF THIS POLICY:</b>	Islington, Camden, Haringey, Barnet and Enfield responsible Children's Health Commissioning			
6	<b>GROUPS WHICH WERE CONSULTED AND HAVE GIVEN APPROVAL:</b>	Final agreement at the NCL Continuing Care Network 6 <sup>th</sup> December 2018			
7	<b>EQUALITY IMPACT ANALYSIS COMPLETED:</b>	Policy Screened	Yes	Template completed	August 2016
8	<b>RATIFYING COMMITTEE(S) &amp; DATE OF FINAL APPROVAL:</b>	09/08/18 Barnet Quality Committee – approved 28/08/18 Haringey and Islington Quality Committee – approved 12/09/18 Enfield Quality and Safety Committee – approved 17/09/18 - Camden Quality and Safety Committee.			
9	<b>VERSION:</b>	3.0			
10	<b>AVAILABLE ON:</b>	Intranet	Yes	Website	Yes
11	<b>RELATED DOCUMENTS:</b>	National Framework for Children and Young People's Continuing Care, Jan 2016 Policy for Adult Continuing Healthcare			
12	<b>DISSEMINATED TO:</b>				
13	<b>DATE OF IMPLEMENTATION:</b>	December 2018			
14	<b>DATE OF NEXT FORMAL REVIEW:</b>	Annual			

**DOCUMENT CONTROL**

<b>Date</b>	<b>Version</b>	<b>Action</b>	<b>Amendments</b>
05/06/2018	1.0	Approved by the North Central London (NCL) Children's Continuing Care Group	
30/07/2018	2.0		Edited by Haringey Head of Children's Commissioning following comments from the Haringey and Islington Quality Committee
11/12/18	3.0		Edited by Camden Children's commissioner following Camden Quality and Safety Committee

## CONTENTS

<b>1.0</b>	<b>INTRODUCTION</b>	<b>5</b>
<b>2.0</b>	<b>BACKGROUND</b>	<b>5</b>
<b>3.0</b>	<b>POLICY STATEMENT</b>	<b>6</b>
<b>4.0</b>	<b>SCOPE OF POLICY</b>	<b>6</b>
<b>5.0</b>	<b>CONTINUING CARE PROCESS</b>	<b>6</b>
<b>5.1</b>	<b>IDENTIFICATION</b>	<b>6</b>
<b>5.2</b>	<b>ASSESSMENT</b>	<b>7</b>
<b>5.3</b>	<b>CONSENT</b>	<b>8</b>
<b>5.4</b>	<b>FAST TRACK</b>	<b>8</b>
<b>5.5</b>	<b>RECOMMENDATION</b>	<b>8</b>
<b>5.6</b>	<b>DECISION</b>	<b>8</b>
<b>5.7</b>	<b>INFORM</b>	<b>9</b>
<b>5.8</b>	<b>ARRANGEMENT OF PROVISION</b>	<b>9</b>
<b>5.9</b>	<b>PERSONAL HEALTH BUDGETS</b>	<b>11</b>
<b>6.0</b>	<b>REVIEW</b>	<b>11</b>
<b>7.0</b>	<b>TRANSITION</b>	<b>12</b>
<b>8.0</b>	<b>GLOSSARY OF KEY TERMS</b>	<b>13</b>
	<b>APPENDIX A</b>	
	<b>Continuing Care Pathway</b>	<b>19</b>
	<b>Transition Pathway</b>	

## 1. INTRODUCTION

- 1.1 The Department of Health published the National Framework for Children and Young People's Continuing Care in March 2010, which has been updated in January 2016. The revision takes into account the new structures of NHS commissioning created by the Health and Social Care Act 2012 and the new integrated approach to the commissioning of services for children with Special Educational Needs and Disability (SEND) in the Children and Families Act 2014.
- 1.2 The Framework provides national guidance for Clinical Commissioning Groups (CCGs) and Local Authorities on the process for assessing, deciding and agreeing packages of continuing care for children and young people, whose needs cannot be met by universal or specialist services.
- 1.3 The Framework includes those children or young people with a Special Educational Need or Disability (SEND) and in receipt of an Education and Health Care plan (EHCP) and those eligible for continuing care funding who have the right to ask for a personal health budget (PHB).
- 1.4 This policy describes the way in which the five North Central London CCGs, Islington, Camden, Barnet, Enfield and Haringey will make provision for the care of children and young people who have been assessed as eligible to receive funding for NHS continuing care.

## 2. BACKGROUND

**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.**

*'National Framework for Children and Young People's Continuing care 2016'*

- 2.1 Some children and young people may have complex health needs as a result of congenital conditions, long-term or life-limiting or life-threatening conditions, disability, or the after effects of serious illness or injury. In some cases, these needs are so complex they cannot be met by the services that are routinely available from primary care, secondary care and other community services commissioned by the North Central London CCGs and NHS England.
- 2.2 NHS continuing care funding may therefore be required to ensure the child or young person's holistic health and wellbeing outcomes are met through bespoke packages of care from health; and where appropriate integrated with social care and education. The purpose of continuing care funding is to specifically meet the identified health needs of the child or young person.
- 2.3 Continuing care is usually provided through bespoke packages of care at home but the CCG will work in partnership with education and social care to ensure continuity of care, which may mean a jointly funded package is delivered across different settings, for example a nursery or school.

- 2.4 The North London CCGs 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. Commissioning responsibilities can be delegated when a joint package is agreed; in these circumstances a lead agency will be identified.
- 2.5 This policy sets out the process and responsibility of the North Central London CCGs of assessing, deciding, agreeing and commissioning bespoke continuing care packages for an eligible child or young person.

### **3. POLICY STATEMENT**

- 3.1 This policy is based on the Department of Health's National Framework for Children and Young People's Continuing Care (2016) and should be read in conjunction with this document.
- 3.2 This policy sets out the process led by the North Central London CCGs; Islington, Camden, Barnet, Enfield and Haringey, of assessing, deciding and agreeing continuing care bespoke packages of care.

### **4. SCOPE OF THIS POLICY**

- 4.1 This policy covers those children and young people, aged 0-17yrs (up to 18th birthday), who are already eligible for continuing care or are being assessed, who are registered with a North Central London GP or were registered at the point of being looked after and placed in care outside of the North Central London Boroughs.

### **5. CONTINUING CARE PROCESS**

#### **5.1 IDENTIFICATION**

- 5.1.1 The continuing care process begins when there is recognition that a child or young person may have needs that cannot be met by universal and specialist services and requires additional health services.
- 5.1.2 The child or young person must be referred by a professional from primary, secondary, tertiary or community services, Child and Adolescent Mental Health Services (CAMHS), education or social care.
- 5.1.3 The referring professional must submit the referral form and pre-assessment checklist along with supporting evidence to the appropriate continuing care nursing team. This is usually a paper based assessment and will give a suitable indication if the child or young person should proceed to full assessment.
- 5.1.4 Before sharing personal information, the referring professional must get explicit written consent from the parent, carer or young person, to share personal information with other professionals and organisations.

5.1.5 The receiving continuing care nursing team will decide whether the child or young person should proceed to a formal assessment. This decision must be made within 10 working days, be robust and fully documented and, when necessary, the responsible commissioner must be informed.

## 5.2 ASSESSMENT

5.2.1 Where the pre assessment checklist meets the criteria to move to full assessment, the nominated continuing care children and young people's health assessor (known as The Assessor) will lead the assessment phase of the continuing care process on behalf of the responsible Commissioner.

5.2.2 Where appropriate, the assessment should be a joint assessment with social care and education, which identifies the needs of the child or young person and their family. Their impact on daily living and quality of life is evaluated. There are four areas of evidence that should be considered in the assessment:

- A holistic assessment of the needs of the child or young person and their family
- Reports and risk assessments from a multidisciplinary team or evidence collated during the Education, Health and Care Plan (EHCP) assessment
- The Decision Support Tool (DST) from The National Framework
- The preferences of the child, or young person and their family.

5.2.3 If there is a CAMHS element to the child or young person's needs, the Assessor must request an assessment of domain 1 (challenging behaviour) and domain 9 (psychological and emotional) to be carried out jointly with a CAMHS practitioner.

5.2.4 As part of the assessment, if the Assessor identifies safeguarding concerns in relation to the parent/carer and or child, the Assessor will follow the appropriate local adult or child safeguarding policies. Likewise, if other needs are identified for example, the parent/carer may have mental health needs then the Assessor will ensure that the parent/carer is informed about the services/support available and where appropriate make a referral.

5.2.5 Where appropriate, the Assessor will work together with the local authority to ensure a holistic package of care without duplication of resource between all the agencies involved.

5.2.6 The Assessor must have the relevant skills and competencies to undertake the continuing care assessment. It is recognised that the Assessor may not have skills in all areas of the assessment and other professional expertise may be needed in some of the decision support tool's domains. For example, CAMHS professionals may need to assist in the challenging behaviour and the psychological and emotional domains.

5.2.7 The North Central London CCG's agreed assessment tools are the decision support tool (DST) and The Continuing Care Health Assessment Tool (CCHAT). This is a resource allocation tool. Further information about these can be obtained from The Assessor or The National Framework for Children and Young People's Continuing Care.

5.2.8 A copy of the assessment documentation must be given to the family on completion.

### **5.3 CONSENT**

5.3.1 The referrer must obtain explicit consent from the parent, carer or young person, before a referral is made to the continuing care team. The consent will encompass both the permission to undertake the assessment and permission to share information with relevant partners, such as social care and education.

5.3.2 Consent to undertake an assessment and share information is a requirement of the continuing care assessment process. Withdrawal of consent will affect the ability of the NHS to provide appropriate services to the child and will result in the CCG pursuing legal advice.

### **5.4 FAST TRACK**

5.4.1 Those children and young people with a rapidly deteriorating condition entering a terminal phase of their illness or those children and young people that were previously eligible for continuing care in the last 12 months may be fast tracked. In these cases, a package of care can be agreed outside of the decision making forum.

5.4.2 In the event that a child moves in to the Borough with continuing care needs and registers with a GP, these children will be fast tracked until a local continuing care assessment takes place.

### **5.5 RECOMMENDATION**

5.5.1 Following the completion of the assessment, the Assessor must produce recommendations for presentation at the appropriate responsible commissioning manager's multi-agency decision making forum.

5.5.2 The Assessor must provide all relevant documentation at the multi-agency decision making forum, including the decision support tool (DST) resource allocation tool (CCHAT) and supporting documentations from the multi-disciplinary team.

5.5.3 The multi-agency decision making forum must be independent from those involved in the assessment and involve key CCG and local authority professionals; and a clinician.

### **5.6 DECISION**

5.6.1 Following presentation at the multi-agency decision making forum, the responsible health commissioner will make a clinically led decision about the child or young person's eligibility and their recommended care package.

5.6.2 The North Central London CCGs should make a decision within 6 weeks of the commencement of the assessment.



5.6.3 If the decision making forum is not meeting within the necessary timescale, the health assessor must seek agreement with either a lead clinician or the designated medical officer (see glossary) and make the recommendations, along with the supporting paperwork to the responsible commissioner outside of decision making forum.

## 5.7 INFORM

5.7.1 Following the forum's decision, the child or young person and their family should be notified verbally by the Assessor to be followed by a clear written explanation for the decision from the responsible commissioner within 5 working days.

5.7.2 The CCGs have developed a Partnership Agreement, outlining roles and responsibilities of the CCG, families and the provider of care. This agreement will be sent with written confirmation to the family when the child or young person is eligible for NHS continuing care funding.

5.7.3 Key professionals, such as the referrer, the child's paediatrician, GP and other members of the child's multi-disciplinary team should be notified of the decision. In the event that the child has an Education, Health and Care Plan (EHCP), education should also be notified, to ensure the decision is incorporated into the EHCP.

**Resolving Disputes – See North Central London CCGs Appeals Policy**

## 5.8 ARRANGEMENT OF PROVISION

5.8.1 The assessment process will provide evidence to develop options for a care package. It is essential that the panel reaches a decision first on whether or not a child meets the continuing care eligibility criteria before potential packages of care are considered, to avoid a provision-led decision.

5.8.2 Multi-agency and/or multidisciplinary groups should work with the family to support the Assessor to produce the child or young person's continuing care options which are safe and effective, taking into account the child or young person's and their family's preferences and considering the delivery of the care package through a Personal Health Budget. Involvement of the family is essential, not least to discuss options in relation to the parental role as carers. However, the care package should not be driven by the family's preferences where this conflicts with the needs of the child or young person.

5.8.3 The domains of the decision support tool for children and young people allows consideration of actual needs, how these are being met, what is working and what interventions or referrals must be made to facilitate unmet needs. There is also scope for considering the workforce and training options, where these are necessary.

5.8.4 Where the child or young person has other care packages in place, the team must have due regard to these and seek to work with other professionals to ensure seamless care.

5.8.5 Joint commissioning, or tri-partite agreements may need to be arranged, to ensure health, social care and education needs are catered for in a package of care.

5.8.6 Care planning should begin early, consider discharge needs where appropriate, and be simplified to enable community-based services to provide home-based care wherever possible. Planning of the package of care should consider:

- the skill mix of staff, since this is a critical aspect of the care package in terms of quality and outcomes;
- staff competency and training of parents/carers, staff (including training costs);
- how continuing care integrates with SEND provision, and universal and specialist health provision;
- sustainability and long-term outcomes;
- a multi-professional approach, rather than one which focuses on venues of care;
- the child or young person's home as the focus of care;
- out of hours support;
- equipment.

5.8.7 Decisions about residential care and other social care support are made by the local authority, as the lead commissioner for social care. Health and Social care work together to identify how the child/young person's health needs can be met. If there are concerns about home care on grounds of care, risk or capacity, interventions should be planned which will enable home care to continue whilst addressing the care, risk or capacity issues (for example by implementing positive behaviour support for a child with severely challenging behaviour). Residential care should be used only when other interventions have failed and/or where there are safeguarding issues and it is judged in the best interests of the child.

5.8.8 Health commissioners and local authorities will need to make the necessary logistical, funding and, in some instances, contractual arrangements to initiate the delivery of the package of continuing care.

5.8.9 The CCG has a responsibility to ensure cost effectiveness when commissioning continuing care provision. This is the most effective, fair and sustainable use of finite resources, as set out in the principles and values of the NHS Constitution. For example, agency provision must be on the NHS Improvement agency pricing framework.

5.8.10 A package of continuing care should be put in place as soon as possible once the decision has been made, and the child or young person and their family has been informed. In some instances there may be an unavoidable delay in implementation, such as where time is needed to ensure the competence of the workforce, but health commissioners and local authorities should ensure that delays are avoided as far as is possible. As always, the child or young person and their family should be kept informed of progress and involved in implementation.

5.8.11 The purpose of the continuing care package is to specifically meet the identified health needs of the child or young person. Any provision delivered by a continuing care package does not replace parental responsibility; appropriate childcare cover will need to be provided by the family relevant to the developmental stage of the child.

## 5.9 PERSONAL HEALTH BUDGETS

5.9.1 Families of a child or young person eligible for continuing care have a 'right to have' a personal health budget, covering the part of their care package which would be provided by the NHS.

5.9.2 Where an eligible child or young person (or their family) requests a personal health budget, the responsible CCG must arrange for the provision of the personal health budget.

5.9.3 This can be achieved in one of several ways:

- a **direct payment** made to the young person or their family;
- the agreement of a **notional budget** to be spent by the CCG following discussions with the child or young person, and their family (or other representative) as to how best to secure the provision they need;
- a **third party** arrangement where the transfer of a budget, to a person or organisation which applies the money in a way agreed between the CCG and the child or young person, and their family.

5.9.4 North Central London CCG commissioners will publicise and promote the availability of personal health budgets to children and young people eligible for continuing care, and the Assessor will provide information, advice and other support to eligible families.

5.9.5 For further information, please see the local Personal Health Budget policy.

## 6. REVIEW

6.1 The child or young person's continuing care needs should be reviewed three months after the package of care has commenced, and then annually thereafter, or when a child or young person's health or function is known to have changed.

6.2 As with any commissioned service, the CCGs are responsible for regular contract review to ensure that service specifications are being met and that the service being provided is of the required level.

6.3 Reviews of a child or young person's continuing care should be an opportunity for assessment of needs and how they are being addressed by the care package. It should be made clear to the child or young person and their family that reviews are designed to ensure that the child or young person's continuing care needs are being met on an ongoing basis and that they are not financially motivated. Where a child or young person has SEND, professionals should work to synchronise the continuing care package review, and the regular review of an EHCP.

6.4 Any such review should be transparent and involve the child or young person and their family. Both verbal and written reports should be given to the child or young person and family as appropriate.

6.5 Reviews should be responsive to changes in a child or young person's fundamental need, as there will be cases where successful management of a condition has

permanently reduced or removed an ongoing need. The responsibility to commission care is not indefinite as needs may change and this should be made clear to the child or young person and their family. Equally, commissioners must guard against making changes to a package of care, where the child or young person's underlying needs have not changed. As always, transparency of process, and involvement of the child or young person and their family, will be essential to maintain the fairness and consistency of the review.

- 6.6 In the event that the continuing care package is being stopped or reduced, the changes to the package will take effect over an appropriate timeframe, usually between 2-4 weeks at the discretion of the responsible commissioner. For example, 2 weeks notice may be given to families and care agencies following the removal of a child's tracheostomy. However, it may take up to 4 weeks to allow for a care agency contract to be altered.
- 6.7 In instances where transition back into universal or specialist health services is appropriate, the child or young person and their family should be supported throughout this transition, ideally from within their existing care team. Early engagement with other services is essential for proactive planning and ensuring a smooth move to the other service.

## 7. **TRANSITION – See Transition pathway**

- 7.1 At **14** years of age, the young person should be brought to the attention of the CCG as likely to need an assessment for NHS Continuing Healthcare.
- 7.2 At **17** years of age, screening for NHS Continuing Healthcare should be undertaken using the adult screening tool, and an agreement in principle that the young person has a primary health need, and is therefore likely to need NHS Continuing Healthcare.
- 7.3 At **18** years of age, full transition to adult NHS Continuing Healthcare or to universal and specialist health services should have been made.

## 8. GLOSSARY OF KEY TERMS

### **Assessment**

A multi-agency process in which the needs of a child or young person and their family are identified and their impact on daily living and quality of life is evaluated. The nominated children and young people's health assessor (the Assessor) is responsible for undertaking a health assessment and collating existing assessments by local authority children's and young people's services on behalf of the commissioners to present a holistic picture of the child or young person's continuing care needs.

If there is no existing assessment, the Assessor should liaise with the appropriate professionals to instigate assessments by local authority children and young people's services on behalf of the commissioners and then use these reports to inform the holistic assessment of the child or young person's continuing care needs.

### **Challenging behaviour**

Defined by NICE as: "behaviour that is a result of the interaction between individual and environmental factors, and includes stereotypic behaviour (such as rocking or hand flapping), anger, aggression, self-injury, and disruptive or destructive behaviour. Such behaviour is seen as challenging when it affects the person's or other people's quality of life and/or jeopardises their safety."

### **Children and young people's continuing care**

A package of continuing care needed over an extended period of time for children or young people with continuing care needs that arise because of disability, accident or illness, which cannot be met by universal or specialist services alone. Children and young people's continuing care is likely to require services from health and the local authority children and young people's services.

### **Children's palliative care**

An active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

### **Consent**

If a child who is under 16 does not have the capacity to give consent, someone with parental responsibility can consent for them, but that person must have the capacity to give consent.

If one person with parental responsibility gives consent and another does not, the healthcare professionals can choose to accept the consent and perform the treatment in most cases. If the people with parental responsibility disagree about what is in the child's best interests, the courts can make a decision. If a parent refuses to give consent to a particular treatment, this decision can be overruled by the courts if treatment is thought to be in the best interests of the child.

If the local authority has reason to believe that the child is suffering or likely to suffer significant harm, they could apply to the court under the Children Act 1989 for either:

- an emergency protection order on the basis that the significant harm would occur should the child not receive care;
- an interim care order if the harm or likely harm could be attributed to the care given by the parents.

Young people with SEND have the right to make decisions for themselves, when they reach the end of the academic year in which they turn 16, rather than their parents making decisions for them (although their family can continue to provide support if the young person agrees). The right of young people to make a decision is subject to their capacity to do so, as set out in the Mental Capacity Act 2005.

### **Continuing care needs**

There are no clear definitions of continuing care needs but it is generally recognised that they include multiple health needs where care pathways require co-ordination because of the complexity of service provision and input from local authority children's and young people's services.

### **Decision Making Forum**

The Decision Making Forum is a multi-agency forum, bringing together health, education and social care, where based upon the assessed needs of the children presented, funding decisions are made.

### **North London Borough's Decision Making Forums:**

**Islington:** Education, Health and Care Needs Management Board (EHCMB)

**Camden:** Continuing Care Panel

**Haringey:** Integrated Additional Services Panel

**Barnet:** Continuing Care Panel

**Enfield:** Early Support Resource Allocation Panel 0-5yr and Specialist Children's Panel 5+yr

### **Designated Medical Officer (DMO) for Special Educational Needs and Disability (SEND)**

The purpose of the role is to co-ordinate and improve health SEND planning and practice within the local area. The post-holder is employed by the CCG and is usually a community paediatrician.

Duties of this function within the Code of Practice include:

1. To work closely with the paediatric multi-disciplinary team in supporting all activities necessary to ensure that the health provider services and CCG meet their responsibilities for children with SEND.
2. To provide overall strategic direction for the local health service in meeting statutory requirements for SEND, identifying priorities for development and facilitating improvement in implementation.

Please see the SEND Code of Practice for further information.

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/398815/SEND\\_Code\\_of\\_Practice\\_January\\_2015.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf)

## Education, health and care plan (EHCP)

At the heart of the new arrangements for children and young people with SEND introduced by the Children and Families Act 2014 is the concept of a single plan for each child with SEND, which covers their education, health and social care needs. A local authority must conduct an assessment of education, health and care needs when it considers that it may be necessary for special educational provision to be made for the child or young person.

CCGs and local authorities will work together to

- establish and record the views, interests and aspirations of the parents and child or young person
- provide a full description of the child or young person's special educational needs and any health and social care needs
- establish outcomes across education, health and social care based on the child or young person's needs and aspirations
- specify the provision required and how education, health and care services will work together to meet the child or young person's needs and support the achievement of the agreed outcomes.

The Code of Practice is the statutory guide to the EHCP process and covers all the legal requirements and important good practice.

### Lead professional

Where a child or young person with continuing care needs requires support from more than one practitioner, the lead professional is someone who:

- acts as a single point of contact for the child or young person and their family, serving as someone whom the child or young person and their family can trust, and who is able to support them in making choices and in navigating their way through the system
- ensures that they get appropriate interventions when needed, which are well planned, regularly reviewed and effectively delivered and
- reduces overlap and inconsistency among other practitioners.

### Mental Capacity Act

The Mental Capacity Act (MCA) is designed to protect and empower individuals who may lack the mental capacity to make their own decisions about their care and treatment. It is a law that applies to individuals aged 16 and over. All staff must follow the Mental Capacity Act Code of Conduct. The code of practice can be found at: <https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>

Before deciding that someone lacks capacity to make a particular decision, it is important to take all practical and appropriate steps to enable them to make that decision themselves. In addition, the Act underlines, the steps that must be taken in a way which reflects the person's individual circumstances and meets their particular needs

The MCA sets out a two-stage test of capacity.

- 1) Does the individual concerned have an impairment of, or a disturbance in the functioning of, their mind or brain, whether as a result of a condition, illness, or external factors such as alcohol or drug use?
- 2) Does the impairment or disturbance mean the individual is unable to make a specific decision when they need to? Individuals can lack capacity to make some decisions but have capacity to make others, so it is vital to consider whether the individual lacks capacity to make the specific decision.

Also, capacity can fluctuate with time – an individual may lack capacity at one point in time, but may be able to make the same decision at a later point in time. Where appropriate, individuals should be allowed the time to make a decision themselves.

In relation to the second question, the MCA says a person is unable to make a decision if they cannot:

- understand the information relevant to the decision
- retain that information
- use or weigh up that information as part of the process of making the decision.

If they are not able to do any of the above three things or communicate their decision (by talking, using sign language, or through any other means), the MCA says they will be treated as unable to make the specific decision in question.

### **NHS Continuing Healthcare**

A package of ongoing care that is arranged and funded solely by the NHS where the individual has been found to have a 'primary health need' as set out in the statutory guidance (as opposed to a need for local authority care). Such care is provided to an individual aged 18 or over, to meet needs that have arisen as a result of disability, accident or illness. Where an individual has a primary health need and is therefore eligible for NHS continuing healthcare, the NHS is responsible for providing all of that individual's assessed health and social care needs – including accommodation, if that is part of the overall need.

### **Nominated children and young people's health assessor (the Assessor)**

A health practitioner, experienced in children and young people's health and skilled in the health assessment of children, who leads on the assessment phase of the continuing care process. Following the completion of the assessment phase, the Assessor will produce recommendations for presentation to a multi-agency decision-making forum for them to reach a decision on whether continuing care is needed and, if so, what package of continuing care to provide. If a continuing care need is identified it is for health commissioners and the local authority to decide what services each will commission and fund.

### **North Central London CCGs**

North Central London include Haringey, Islington, Barnet, Enfield and Camden Clinical Commissioning Groups and Local Authorities. The North Central Boroughs work closely together with local NHS Providers to deliver the local Sustainability and Transformation Plan (STP); the STP sets out how the local health and care system will be transformed and made sustainable over the coming years. The name for this partnership is North London Partners in Health and Care.

### **Package of continuing care**

A combination of resources, planning, co-ordination and support designed to meet a child or young persons assessed needs for continuing care.

### **Parliamentary and Health Service Ombudsman**

The Parliamentary and Health Service Ombudsman makes final decisions on complaints that have not been resolved by the NHS in England and UK government departments. They do this fairly, without taking sides and their service is free.

They can be contacted via:

<https://www.ombudsman.org.uk>



## Parental responsibility

As defined by the Children Act 1989, a person with parental responsibility for a child could be:

- the child's parents
- the child's special guardian (under a special guardianship order)
- the child's legally appointed guardian
- a person named in a child arrangements order as a person with whom the child is to live
- a local authority designated to care for the child (under a care order) or
- a local authority or person with an emergency protection order for the child.

## Responsible commissioner

The organisation that discharges the statutory duty to secure care for an individual. For health services, the duty is that of Sections 3 to 6 of the NHS Act 2006, and accompanying regulations. Most health services for an individual are usually commissioned by the CCG of which their GP practice is a member, but specialised services and health care for some specific groups is commissioned by NHS England. Public health services are usually commissioned by local authorities or Public Health England.

## Special educational needs and disability (SEND)

The Children and Families Act 2014 states that a child or young person has SEND if he or she has a learning difficulty or disability which calls for special educational provision to be made for him or her. A child of compulsory school age or a young person has a learning difficulty or disability if he or she:

- has a significantly greater difficulty in learning than the majority of others of the same age or
- has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions.

A child *under* compulsory school age has a learning difficulty or disability if he or she is likely to be within the above categories (or would be likely to be if no special educational provision were made).

Post-16 institutions often use the term learning difficulties and disabilities (LDD). The term SEND is used in this Code across the 0-25 age range but includes LDD.

Section 3 of the Children and Families Act 2014 introduced from September 2014 a new statutory framework for how local authorities and CCGs should work together to ensure children and young people with SEND get the education, health and care services they need.

CCGs will work with their local authority, to develop and publish a Local Offer, setting out in one place information about the range of education, health and social care services available for children and young people in their area who have SEN or are disabled, including those who do not have EHC plans, and how they can be accessed. The published local offer should include details of continuing care services and how one accesses continuing care.

## Specialised services

Specialised services are those less common interventions needed by a relatively small group of patients, which require a clinical team with very specific training and often, equipment, which it would be impractical to commission or provide at a local level. These services are usually located in specialised hospital trusts that can recruit a team of staff with the appropriate expertise and enable them to develop their skills needed. Examples include Tier 4 Child & Adolescent Mental Health Services (CAMHS) and specialist neuroscience services for children and young people, including neurosurgery. Most specialised services are commissioned by NHS England directly, but some elements of a specialised service may be commissioned by local CCGs, or work closely with CCG commissioned services.



### **Universal services**



Health services which are available to all of the population of England from birth, including primary care provided by GP practices, health visiting for new born children, school nursing and Accident and Emergency services.

# **APPENDIX A**

## **Continuing Care Pathway Transition Pathway**




## CHILDREN'S CONTINUING CARE PATHWAY (excluding Fast Track)


PHASE	STEP	SUMMARY OF KEY ACTIONS	TIMESCALE
<b>IDENTIFICATION</b>	<b>PRE-IDENTIFICATION</b>	<ul style="list-style-type: none"> <li>Professional identifies that a child or young person's needs cannot be met by universal or specialist services.</li> <li>Professional refers the child or young person to the Continuing Care team, with the referral form, pre-assessment checklist and supporting evidence.</li> <li>The Matron will assess the referral and decide whether it meets the criteria to move to a full continuing care assessment.</li> <li>If the child or young person does not meet the criteria to move to full assessment, the Matron will notify the referrer and family.</li> <li>If the family appeal the decision, the North Central London Appeals Policy will come into effect.</li> </ul>	<b>2 WEEKS FROM ACCEPTED REFERRAL</b>  
	<b>IDENTIFY</b>	<ul style="list-style-type: none"> <li>If the child meets the criteria to move to full assessment, the Matron will nominate the lead health assessor (the Assessor) and proceed to the assessment phase. The Assessor is usually a continuing care nurse.</li> <li>The continuing care team will notify the responsible health commissioner.</li> </ul>	
<b>ASSESSMENT PHASE</b>	<b>ASSESS</b>	<ul style="list-style-type: none"> <li>The Assessor will lead the assessment on behalf of the responsible commissioner.</li> <li>If there is a CAMHS element to the child or young person's needs, the Assessor must complete domain 1 (challenging behaviour) and domain 9 (psychological and emotional) jointly with a CAMHS practitioner.</li> <li>At the start of the assessment, the Assessor will explain the process to the child or young person and their parent/carer. Information about how the service will be provided and personal health budgets (PHB) will be given at this time.</li> <li>The Assessor will undertake a continuing care needs assessment, including a holistic assessment of need, the preferences of the child or young person and their family and the decision support tool for children and young people.</li> <li>The Assessor must collate supporting information and assessments from relevant partners in health, social care and education.</li> <li>The Assessor must obtain explicit written consent to share the assessment with members of the decision making forum.</li> </ul>	<b>CLOCK STARTS</b>  

	<p><b>RECOMMEND</b></p>	<ul style="list-style-type: none"> <li>The Assessor completes the assessment phase and makes a recommendation; jointly with social care and education when appropriate.</li> <li>The Assessor provides a copy of the assessment to the family.</li> <li>The recommendation must be discussed with the child or young person and their parent/carer.</li> </ul>	 <p><b>6 WEEKS</b></p>
<p><b>DECISION MAKING PHASE</b></p>	<p><b>DECIDE</b></p>	<ul style="list-style-type: none"> <li>The continuing care matron/Assessor will present the assessment and recommendations at the decision making forum; jointly with social care and education when appropriate.</li> <li>If appropriate, assessments from social care and education will be presented at the same time as the health assessment.</li> <li>If a request for a PHB has been made, the decision making forum must be notified.</li> <li>A continuing care funding decision will be made at the decision making forum.</li> <li>If the decision making forum is not meeting within the necessary timescale, the Assessor must seek agreement from the designated medical officer in the Boroughs where this is in place, and make the recommendations, along with the supporting paperwork to the responsible commissioner outside of decision making forum. The assessment must then be presented at the next decision making forum.</li> </ul>	
<p><b>ARRANGEMENT OF PROVISION</b></p>	<p><b>INFORM</b></p>	<ul style="list-style-type: none"> <li>The Assessor must verbally inform the parent/carer of the continuing care funding decision.</li> <li>The responsible children's health commissioner will write a letter to the parent/carer within 5 working days of the funding decision and a copy will be sent to the continuing care matron.</li> <li>If the parent/carer wishes to appeal the funding decision they must inform the Assessor and write a letter of notification to the responsible health commissioner. Appeals must be in line with the North Central London Continuing Care Appeals Process, a copy of which should be given to the parent/carer.</li> <li>Any relevant partners in health, social care and education must also be notified about the decision.</li> </ul>	<p><b>1 WEEK</b></p> 
	<p><b>DELIVER</b></p>	<ul style="list-style-type: none"> <li>The continuing care provider commences delivery of the agreed provision, as soon as possible. In the event that the provision will be delayed the parent/carer and the responsible commissioner must be informed.</li> <li>If a PHB has been agreed and there is a delay in</li> </ul>	

		organising delivery of care, alternative provision may be offered.	
<b>REVIEW</b>	<b>REVIEW</b>	<ul style="list-style-type: none"> <li>Continuing care provision to be reviewed 3 months from commencement of the provision and thereafter annually, unless the child or young person's needs change or if the parent/carer requests an assessment.</li> <li>PHBs are to be reviewed every 3 months, reducing to 6 monthly and annually at the responsible commissioning managers discretion, unless the child or young person's needs change or the parent/carer requests an assessment.</li> </ul>	<b>ONGOING</b>

## CHILDREN'S CONTINUING CARE TRANSITION PATHWAY

PHASE	STEP	SUMMARY OF KEY ACTIONS	TIMESCALE
<b>ASSESSMENT PHASE</b>	<b>IDENTIFY</b>	<ul style="list-style-type: none"> <li>When a young person in receipt of children's continuing care funding reaches 14 years or above, partners in (adult) continuing healthcare (CHC) must be notified.</li> <li>When a young person in receipt of children's continuing care funding reaches 17 years of age partners in CHC must be notified and a date for a CHC checklist assessment will be arranged.</li> <li>If the checklist suggests progressing to a full CHC assessment, a date for a joint health and social care assessment will be arranged.</li> </ul>	<b>14 YEARS</b>  <b>17 YEARS</b>
	<b>ASSESS</b>	<ul style="list-style-type: none"> <li>When a young person in receipt of children's continuing care funding reaches 17 years of age and the CHC checklist indicates the young person can move to full assessment, an assessment must be carried out by the CHC assessor with the children's health assessor present.</li> <li>At the start of the assessment the children's health assessor and the CHC assessor must explain the transition process to the young person and their parent/carer.</li> <li>The CHC assessor will lead the coordination of the multi-disciplinary assessment.</li> <li>The CHC assessor must obtain consent to share the information.</li> </ul>	<b>CLOCK STARTS AT 17 YEARS</b> 
	<b>RECOMMEND</b>	<ul style="list-style-type: none"> <li>The multi-disciplinary team completes the assessment phase and makes a recommendation.</li> <li>The multi-disciplinary team must discuss the recommendations with the young person and their parent/carer.</li> </ul>	

<b>DECISION MAKING PHASE</b>	<b>DECIDE</b>	<ul style="list-style-type: none"> <li>The CHC assessor must present the checklist, London Health Needs Assessment and Decision Support Tool at the CHC panel for ratification.</li> <li>The continuing care health assessor must inform the children's Commissioner of the outcome of the CHC panel.</li> </ul>	
	<b>INFORM</b>	<ul style="list-style-type: none"> <li>The CHC assessor must inform the young person and the parent/carer of the CHC assessment outcome.</li> <li>If the parent/carer wishes to appeal they must follow the CHC appeals processes.</li> </ul>	
<b>ARRANGEMENT OF PROVISION</b>	<b>DELIVER</b>	<ul style="list-style-type: none"> <li>Transition preparation to take place up until the young person is 18 years, when the young person is 18 years the provision and funding will be transferred to CHC.</li> <li>In the event that CHC provision is delayed, the CHC commissioner must inform the responsible children's health commissioner. The CHC assessor must also inform the young person and parent/carer.</li> <li>In the event that CHC provision is delayed funding responsibility will continue to be transferred from children's health commissioning to adult health commissioning on the young person's 18<sup>th</sup> birthday.</li> <li>The Children's commissioner will have a verbal handover with the adult commissioner.</li> </ul>	<b>18 YEARS</b>
	<b>REVIEW</b>	<ul style="list-style-type: none"> <li>Suitability of provision to be reviewed in 3 months, to ensure needs are being met appropriately and then annually or if there is a change in condition.</li> <li>Ongoing eligibility for CHC to be reviewed as necessary</li> </ul>	<b>18 YEARS +</b>