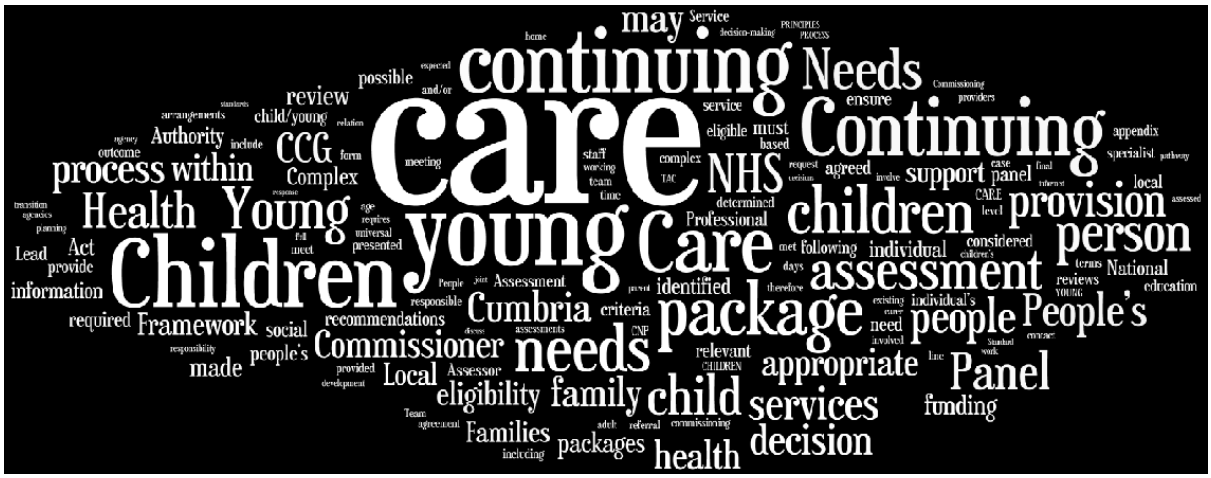
NHS
North Cumbria
Clinical Commissioning Group

Continuing Care for Children and Young People Policy



Summary:

This policy sets out the principles for operational management of Children and Young People's Continuing Care for North Cumbria Clinical Commissioning Group.

To be read in conjunction with all relevant policy and guidance, including the following:

- NHS Continuing Healthcare Joint Disputes Resolution Policy, 2018
- NHS Record Keeping Standards
- NMC Record Keeping Standards 2012
- NHS North Cumbria CCG PHB policy
- Cumbria Local Review Process
- Cumbria decision making policy
- National Framework for Children and Young People's Continuing Care (March 2016)
- The Children's Act 2014
- The National Service Framework for Children and Young People (2004)
- Haringey Judgement (2005)
- Every Child Matters (2005)
- Every Disabled Child Matters
- Together from the Start 2003
- Early Support Programme
- Gillick v West Norfolk and Wisbech Area Health Authority (1985)
- The National Health Service Act 2006
- The National Health Service (Nursing Care in Residential Accommodation) (Amendment)(England) Directions 2009
- The NHS Continuing Healthcare (Responsibilities) Directions 2009
- Coughlan Judgment (1999)
- NHS Constitution
- SEND Code of Practice
- Children and Families Act (2014)
- Transition Protocol (2018)

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CONTINUING CARE POLICY FOR CHILDREN AND YOUNG PEOPLE

INTRODUCTION

The purpose of this policy is to provide a statement of how North Cumbria Clinical Commissioning Group (CCG) will discharge its legal responsibilities for the assessment, provision and review of NHS funded continuing care for children and young people.

CONTEXT

WHAT IS CHILDREN AND YOUNG PEOPLE'S CONTINUING CARE?

Continuing Care is a general term that describes a tailor made package of care needed over an extended period of time for children with complex health needs which arise because of disability, accident or illness (including life limiting or life threatening conditions).

This is for children and young people whose health needs cannot be met by existing universal or specialist health services. The aim of the package is to support the child/young person's parents or carers to manage their child/young person's care at home and/or in other appropriate, specialist settings. It may be integrated with a range of services offered by the NHS, Local Authority or other independent organisations to enable the child and family to function in the community. The approved package does not affect existing access to specialist equipment.

Children and Young People's Continuing Care is different from NHS Continuing Healthcare for adults. It is care provided in a child and family centred way, either in the family home, at school or college, or in residential care settings, including residential special schools. The needs of children and young people are different to those of adults. This is because of their growing and developmental needs, the right to education for children of compulsory school age (0- 18 years old), and the dependency of children on their parents as carers. This means families will require support from education and social services provided through joint working between the agencies but with each agency being responsible for meeting the cost of their respective contribution to the care package.

Continuing Care for Children and Young People with complex needs, who are at home, is provided mainly by their parents and families. For some of these children/young people health input may be required either to support their families or to provide care under skilled supervision.

Social services for children and young peoples are provided under the Children Act 1989, following an assessment under the Framework for the Assessment of Children in Need and their Families. Each local authority providing children and young people services set its own eligibility criteria for social care and therefore, children and families experience different thresholds too. Both the Children's National Service Framework (NSF) (2004)[1], the

[1] DH (2004) National Service Framework for Children, Young People and Maternity Services: The mental health and psychological wellbeing of children and young people

Framework for the Assessment of Children in Need and more recently, guidance for children under 3 years old who are disabled or have complex health needs advocates multiagency comprehensive needs assessment and joint planning of care with integrated provision to help maximise children and young people's development and achievement in life. Likewise, the Disability Discrimination Act (2005) makes it unlawful to discriminate against disabled children with a physical or mental impairment where that has a substantial long-term adverse effect on their ability to carry out normal day-to-day activities.

Since the introduction of the Children and Families Act 2014, partners will want to take account of the full range of policies that affect the provision of education, health and social care services to children and young people with a Special Education Need and /or Disability (SEND) and how they overlap. This includes the early help assessments, the criteria for children's continuing care packages and Education, Health and Care Plans (EHCP), and wider duties for all partners to make reasonable adjustments under the 2010 Equality Act.

As established within the Children's and Young People's Continuing Care Framework (2016)[2] the NHS is responsible for leading the Children and Young Peoples continuing care process. North Cumbria CCG is therefore responsible for the establishment and management of governance which facilitates the commissioning of bespoke clinical packages of care with the Local Authority and other partners. NHS commissioners are responsible for ensuring that resources are turned into service provision in a flexible way. Bespoke provision is dependent on the partnership of services to enable the child or young person to function optimally within their family, community or care setting with each partner organisation funding their agreed contribution as in line with their statutory functions.

THE NATIONAL FRAMEWORK

The National Framework for Children and Young People's Continuing Care was published by the Department of Health in March 2010, reviewed and updated in 2016 to provide guidance on dealing with the continuing care needs of children and young people who are under the age of 18 (up until their 18th birthday). This framework sets out an equitable and transparent process for assessing, deciding and agreeing bespoke packages of care.

PRINCIPLES

The principles and core values guiding the assessment of children and young people's continuing care are:

1. Children and young people's continuing care assessments and subsequent decisions about care are needs led, not based on diagnosis alone, and acknowledge layers of complexity.
2. A comprehensive, multi professional assessment and subsequent decisions about provision of care are made in context of the child's or young person's social care, education and family needs and are as joined up as possible.
3. Care planning and provision of continuing care for children and young people considers applicable safeguarding policies, best practice standards and legislation.

[2] DH (2016) National Framework for Children and Young People's Continuing Care

4. Assessment of children and young people's needs for continuing care considers whether there is further potential for rehabilitation and how the outcome of any treatments or medication may affect on-going needs.
5. The risks and benefits to the child or young person of a change of location or support (including funding implications) that is based on assessed need are considered carefully before any move or change is confirmed.
6. Decisions about continuing care are fair, culturally sensitive, and client-centred. They should result in care that supports and enhances the care that parents/family are giving already and enables the child or young person to develop meaningful relationships with the whole family through provision of consistent and skilled support taking account of the family circumstances and preferences.
7. Regular reviews are built into the process.
8. There will be equity of access to care.
9. NHS resources will be utilised effectively and efficiently to commission care services which are affordable and meet the individual's reasonable needs
10. The assessment, verification and decision making process will be undertaken as speedily as possible, so as not to cause delay to the delivery of appropriate care, consistent with the individual's assessed needs.

The National Framework reinforces the fact that:

- NHS continuing care for children and young people may be for a finite period as a person's condition may alter over time.
- Regular reviews are therefore built into the process to ensure that the care package continues to meet the individual's needs.
- The reasons given for a decision on eligibility should not be based on:

    - The setting of the care
    - The ability of the care provider to manage care
    - The use (or not) of NHS employed staff to provide care
    - The need for / presence of 'specialist' staff in care delivery
    - The existence of other NHS-funded care, or
    - Any other input-related (rather than needs-related) rationale.
    - Existing support or packages of care provided by universal services

- Eligibility must be based on the level of need.
- Local Authorities should not be required to provide services beyond those they can legally provide under Section 21 of the National Assistance Act 1948.

Continuing Care eligibility is determined by the needs identified in the continuing care assessment and whether the child or young person meets the required threshold. Packages of support are determined by the services on offer, if the identified need can be met by universal services then they should be. However, in circumstances where care needs cannot be met appropriately through existing universal or specialist health services alternative provision should be provided, where appropriate.

Individuals and their family/carers need to understand the process for assessment and provision of continuing care and to participate wherever possible.

EDUCATION HEALTH AND CARE PLANS

In September 1 2014, a new framework for children and young people (up to age 25) with SEND was introduced and the core element to these new arrangements is an integrated Education, Health and Care plan (EHC plan).

The EHC plan process is a co-ordinated assessment of a child or young person's needs, based on multi-professional input, and focused on the outcomes which make the most difference to the child or young person and their family. The views and aspirations of the child or young person, and of their family, are central to developing a holistic view of the child's needs.

Given the elements common to both the EHC plan assessment, and the continuing care process North Cumbria CCG recognise there may be an overlap in the collation of information and assessments.

Where possible, the CCG and Local Authority will work together to ensure the two processes and information fit together to result in a coherent package of care across health, education and social care for children who are eligible for children and young people's continuing care.

ROLES & RESPONSIBILITIES

North Cumbria CCG - Where North Cumbria CCG is determined as the 'Responsible Health Commissioner '[3] it is accountable for establishing and managing governance arrangements for the children and young people's continuing care process. It has an obligation to meet the assessed health care needs of eligible children and young people in a way that is considered to be reasonable and affordable.

To ensure appropriate provision in line with the Department of Health's framework North Cumbria CCG have an identified Children and Families Commissioner to have overall responsibility for commissioning of services for children and young people who are eligible for continuing care. There will also be a named first point of contact for commissioning of continuing care. The role of the named individual in North Cumbria CCG's Children's & Families team who is to act as a point of contact for professionals from the community, acute or tertiary settings wishing to discuss a child or young person with possible continuing care needs. The named point of contact should hold contact details for all local nominated children and young people's health assessors.

Cumbria Partnership Foundation Trust (CPFT) - The Trust is commissioned to conduct continuing care assessments and associated reviews which should take place in a consistent and open manner as guided by the Framework document. Where relevant, such

assessments and reviews should be considered by the Team Around the Child before submission to the Commissioner, eligibility panel and the Complex Needs Panel.

The Framework document requires that providers share contact details for all local nominated children and young people's health assessors.

CHILDREN AND YOUNG PEOPLE'S CONTINUING CARE PATHWAY

The delivery of Children and Young People's Continuing Care is delivered through a three phased process defined as; **assessment**, **decision-making** and **arrangement of provision** as set out in the National Framework. The North Cumbria Children and Young People's Continuing Care decision pathway is illustrated in **Appendix 1.**

The full process (Standard Operating Procedure) of arrangements for continuing care would include:

- How to make a Referral to North Cumbria CCG
- How the assessor is allocated (TAC meeting called, pre-assessment checklist completed, lead professional identified)
- Process by which North Cumbria CCG is informed whether a full assessment will go ahead
- Process by which the CCG identifies continuing care health lead
- Full assessment completed, including relevant forms and recording process
- Recommendation given to eligibility panel whether the referral is, or is not, eligible
- Eligibility decision made and the criteria for doing so
- When it is needed to make a further referral to CNP for joint packages
- How the Family is informed of the outcome of the process

REFERRAL ELIGIBILITY CRITERIA

Any professional working with a child or young person can alert North Cumbria CCG of an additional health need that may require an onward referral for the provision of Continuing Care. Eligibility will be determined by a multi-agency eligibility panel. The provision of Continuing Care for children and young people is dependent on the individual meeting the identified eligibility criteria. These are detailed as:

- The child or young person is under the age of 18 years
- The child or young person has complex health needs that could include behavioural, emotional, mental health, physical disabilities.
- The child or young person has identified health needs which cannot be met by existing universal and specialist local health services.
- The child or young person has a rapidly deteriorating condition which requires a care package to support end of life care.

North Cumbria CCG has adopted a Pre-Assessment Checklist (**Appendix** 2) to determine the appropriateness of referrals. If the checklist indicates the above criteria are likely to be met, a full assessment of need will be progressed.

A full assessment should be completed prior to submission to the Eligibility Panel, which will inform panel members of the needs of the child or young person. If a child or young person is considered as meeting the eligibility criteria, a referral to CNP can be made to determine the appropriate package of support. The expectation is that the Children's Eligibility Panel will convene every 4-6 weeks; however, this will be determined by need.

MULTI-DISCIPLINARY TEAM (MDT)/TEAM AROUND THE CHILD (TAC)

The MDT/TAC should include an appropriate mix of clinicians and practitioners representing health and social care interests relevant to the individual's circumstances, notifying the Lead Professional where further input is identified as necessary in order to comprehensively complete the assessment. Members of the team are responsible for submitting reports and risk assessments as part of the assessment process.

The TAC will be the preferred forum to complete the initial Pre Assessment Checklist and determine who will take the role of lead professional.

The referrer may act as the Lead Professional in terms of collation of information from the team and submission of the final documents to the Commissioner, Eligibility and Complex Needs Panels. However, the full assessment must be completed by an identified health lead such as a community nurse or other member of the CPFT. The Lead Professional will be responsible for submitting the collated referral to the Eligibility & Complex Needs Panels. The Lead Professional is responsible for sharing the decision from the Commissioner/Eligibility Panel/Complex Needs Panel with the child, family and the remainder of the Team Around the Child.

ASSESSMENT

The assessment phase is the next stage of the continuing care process and is led by the Children and Young People's Continuing Care Health Needs Assessors. Children and Young People's Continuing Care Health Needs Assessors should comply with para 71 of the National Framework. Such Assessors should be readily identifiable within the Trust.

The assessment phase should be a holistic assessment of the child's needs and involve the collation of all current and pertinent assessments/information from key individuals who are highlighted as being involved in an individual's care. Part of the assessment will include the completion of the DST (**Appendix 3**). The collation of this information serves to provide a holistic and objective health needs assessment which incorporates the views of the child, young person and their family. This information is used to complete the 'Children and Young People's Continuing Care Health Needs Assessment' forms

Consent to request and share information is obtained from the child or young person and their parent/carer before proceeding (Consent Letter, **Appendix 4**). Requests for information are made in writing and/or by telephone to facilitate a timely response to the process (Request for Information Letter, **Appendix 5**). This information may require current providers to complete an assessment in relation to current care needs and activity. This information is collated to specifically reflect the core values and principles outlined within

the Children and Young People's Continuing Care Framework and to formulate a comprehensive multidisciplinary assessment.

Assessments and the consideration of eligibility for Continuing Care for Children and Young People should be planned so that the family understands the process and the child or young person is included as far as possible. Decisions and rationales relating to eligibility should be transparent from the outset to members of the multi-disciplinary team, families and their children and young people wherever possible. Written information relating to the Continuing Care Process including Personal Health Budgets should be provided as a routine.

All assessment paperwork should be collected by the Children and Young People's Health Needs Assessor for collation in a timely manner. The collated information will then be reviewed by the Children and Young People's Continuing Care health Needs Assessor for the development of a holistic assessment defined by the 'Decision Support Tool' framework.

Establishing that a child or young person meets criteria to be eligible for Continuing Care funding requires a clear, reasoned decision based on evidenced needs. Children and Young People that have been referred for continuing care will only meet criteria to be funded by North Cumbria CCG if the child or young person has identified health needs that can be considered as complex health needs by reference to the Decision Support Tool (DST) within the Children and Young People's Continuing Care Framework. This tool proposes as a general guide that the achievement of at least 3 x High or 1 x Priority or Severe levels attained on the DST makes an individual eligible for Children and Young people's continuing care.

Any child/young person who is deemed eligible for continuing care on the basis of challenging behaviour or psychological and emotional needs will prompt a discussion with the Local Authority about joint responsibility for related service provision (Joint decision to be made by CCC & NC CCG in CNP).

On completion of the Health Needs Assessment the report and recommendations are shared with the TAC (which includes the child or young person and their family). This provides opportunity for the child/young person and/or family to contribute further to the report and respond to the recommendations made. The recommendations of the TAC will be recorded in the minutes of the relevant meeting.

The outcome of the assessment phase will be the recommendation that the child or young person is or is not eligible for Children and Young People's Continuing Care. This will be presented to the eligibility panel who make final decision. If eligibility is confirmed and it is determined that the identified need cannot be met by existing universal or specialist services then arrangements are made for presentation of the continuing care Health Needs Assessment and recommendations to the CNP.

In cases where the subject of the assessment is receiving (or should be receiving) services from another agency and they have been assessed as eligible for Continuing Care, decision-making on the totality of support available to the child and family should be referred to the Complex Needs Panel (CNP Referral Form, **Appendix 6**). All relevant documents must be

submitted electronically by 10 working days prior to the panel date to allow the panel members to prepare adequately. All documentation presented to the panel must have been approved and signed by the appropriate line manager in the lead agency.

Where a child is assessed as ineligible for Continuing Care, it may still be appropriate to propose a request to fund a package of support if the child is deemed to have needs that are unable to be met by standard service provision. In such a case, it is advised that the Lead Professional contacts the Commissioning Manager (Continuing Care and Complex Needs) at North Cumbria CCG to discuss the appropriate mechanism by which the case may be considered.

Where a child or young person has a rapidly deteriorating condition which requires a care package to support end of life care formal assessment is not a pre-requisite to access the care that is required and can be deferred until a suitable time. Proposals for such packages should be addressed to the Children and Families Commissioner. North Cumbria CCG will make a decision on proposed fast-tracked care packages and seek ratification at the CNP at the earliest opportunity.

DECISION PHASE

The Eligibility Panel will be independent from those involved in the assessment process, and include key CCG and local authority professionals, and at least one clinician.

The nurse assessor will carry out the required assessment that will be presented to the panel with supporting evidence. The panel will then decide whether they agree with the recommendation or not.

COMPLEX NEEDS PANEL

Children and Young People's Continuing Care funding is provided for identified needs that cannot be met by universal and specialist services and where need is considered to be long term. It is therefore expected that an individual's bespoke care package may involve a number of agencies with health contributing funding in part for the assessed level of health needs. Children and Young People's Continuing Care is not appropriate for short periods of convalescence / recovery following an operation and cannot be implemented with the main aim of allowing parents or carers to go to work or short term to support post-operative rehabilitation.

After a child has met the eligibility criteria from the eligibility panel they will be referred to the CNP. The purpose of the Complex Needs Panel is to determine joint funding contributions to packages of care and/or residential placements. Additionally, any solely funded health packages will also be presented for ratification and transparency at CNP.

The Complex Needs Panel is a decision-making panel which has the following aims:

- To ensure the best possible outcomes for children and young people with complex needs by bringing agencies together to support and promote effective planning and provision within a tripartite funding arrangement.
- To inform commissioning decisions of service/provision needs in North Cumbria.
- To monitor and review outcomes for children and young people placed through the complex needs panel process.

The panel is comprised of Commissioners from the Local Authority and NHS. The scope of the Panel is to support the needs of children and young people with complex learning and/or physical disabilities where a strong multi agency team around the child is in operation or children and young people eligible for Continuing Care provision. The Panel provides an opportunity for consistency and transparency with regard to the provision of support packages to children and young people across Cumbria. Individual cases where it is appropriate are jointly presented to the Panel by the Lead Professional and relevant health, education and social care professionals. Assessed need and service gaps with respective costed care package options are then considered to determine an appropriate multi-agency package of support.

In instances where a continuing care need is identified, the CNP should consider the preferences of the child or young person and their family when deciding on packages of care. It is important that CCGs and local authorities plan the co-ordination of their care and support, taking into account local authority children's and young people's services' requirements.

NHS funding for packages are authorised by the Children and Families Commissioner. Where such funding would be regarded as a high-cost package i.e. greater than £75,000pa, North Cumbria CCG requires that the case is considered internally prior to funding approval being given.

Once a decision has been made at CNP, the child or young person and their family should be informed of the decision within five working days usually via the Lead Professional (CNP Decision Support Proforma, see **Appendix 7**). Packages of continuing care should be recorded in a care plan and worded so they are understandable to the child or young person, their family and the different agencies involved in the decision-making process and/or the continuing care of the child or young person.

The Commissioner is committed to ensuring that decisions are made as per the Continuing Care eligibility criteria and based on the recommendations of MDT's or clinician's reviews.

This will include:

- taking into account all relevant factors
- reviewing the standards of information presented;
- auditing and reviewing patterns of recommendations separate to the decision making process to ensure consistency of standards of application;

- to ensure the time that elapses between referral to outcome is within the 28 days for DST and 24 hours for Fast Track; and
- comply with relevant and applicable legislation (such as Mental Capacity Act and the Disability Discrimination Act).

If a package of care is agreed it is the responsibility of the Lead Professional to facilitate arrangement of the agreed provision. This provision may involve commissioning on behalf of social care and education where joint funding has been recommended. If a Personal Health Budget is requested as part of this process (which may occur at the initial submission or, more likely, subsequent to the decision by the Panel confirming eligibility), the Lead Professional should liaise with the Children and Families Team, CCG, to arrange appropriate support for the family and practitioners.

An indicative budget will be articulated by the Commissioner and a support plan developed by the TAC (it is anticipated that the TAC will work closely with the Children and Families team in refining a package of care to be proposed). The resultant support plan and final budget will be presented to the Children and Families Commissioner and CNP for final approval.

PROVISION PHASE

Following an approval, the Children and Families Commissioner will 'plan and commission' services as agreed in line with the National Service Framework for Children, Young people.

The Commissioner will ensure the:

- implementation and maintenance of good practice;
- quality standards are met and sustained;
- provision of training and development opportunities for practitioners, including supervision;
- identification and action on issues arising in the provision of children and young people's continuing care; promoting awareness of the Framework; and
- flexibility to shape strategic commissioning arrangements and the design of services in instances where a consistent and transparent children and young people's continuing care process highlights repeated issues, e.g. several children with the same continuing care needs.

Implementation time frame for each care package will be dependent on the specific needs of the individual, the level of care required and the bespoke training needs of the child/young person. All providers identified to deliver care packages, will be expected to demonstrate their ability to manage the following aspects of care effectively and within the financial constraints placed upon them:

- Implementation time
- Training requirements of staff
- Sustainability of staffing
- Value for money

At this stage it may be appropriate to involve the child/young person and their family/carers so that they have choice over which care provider to commission. Personal Health Budgets exist to provide a greater sense of control for patients and so some aspects of provision may be overseen entirely by the family once a PHB has been agreed.

Parents, carers, children and young people will need to be informed and work in partnership with the identified providers in order to implement the determined package of care. This involvement may include participation in recruitment and training of staff where appropriate.

If a child has been deemed eligible for continuing care and a suggested package of care agreed by the CCG, this can be offered to the family directly. If it is to be a joint funded package of care, it should then be brought to the CNP for a final joint funding decision.

The commissioned care package will aim to meet the standard outcomes specifically referred to in the care package referral form.

- Joint/partnership working between parents/guardians/guardians of the child or young person and other agencies to provide the best possible service together for the benefit of the patient.

- To support the parents/guardians of the child or young person with complex health needs enabling the patient to live at home with his/her family and within the wider community.

- Care packages must be delivered within a safe environment by provision of experienced and appropriately trained staff

- Risk minimisation so far as is reasonably practical, of all known risks whilst undergoing a change of environment (outside of the home).

- Access to mainstream services and specialist services as appropriate

- Achievement of developmental milestones

- To maintain social contact, friends and relationships within the community

- To live with a sense of security

PROVIDER

Providers are required to submit sufficient evidence of their capacity to undertake a package of care as described in the specification, following the agreement of the CNP of the appropriate package of care. Such evidence should include accreditation with regulatory bodies (i.e. CQC or Ofsted), reference to previous similar service provisions (where applicable), workforce descriptions, transparency related to costs and any relevant contingency planning required.

Once a package is allocated to a provider, the terms of the provision will be confirmed either using the NHS Standard Contract or an agreed Service Level Agreement. Providers will be expected to report their activity as specified in the terms. Funding arrangements vary but may include direct invoicing to NHS, Personal Health Budgets (PHB) or recharges to NHS via an existing Local Authority Direct Payment.

Providers would be expected to comply with Continuing Care review processes. Terms of service de-commissioning will be negotiated between the Provider and Commissioner according to the circumstances of each case but as a default will allow at least a one month notice period.

TIME LINE

North Cumbria CCG will ensure there is a clear timeline against which progress is measured. Clear information will be available to the child or young person and their family on the process, the roles of the nominated children and young people's health assessor and multi-agency decision-making forum. There will be a process of regular updates, so that the child or young person and their family know what point has been reached in the process.
It is important that a decision on whether or not a child or young person has a continuing care need can be made in a timely way. The clock starts at the point of recognition that a child or young person should have a full continuing care assessment (i.e. following the completion of the pre-assessment checklist and confirmation from the CCG to proceed to a full assessment).

The pathway will aim for a decision to be given to the child or young person and their family within 6 weeks. However, given the complexity and variety of needs which North Cumbria CCG may be assessing, there should be scope for flexibility – where it is not contrary to the best interests of the child or young person. For example, if an assessment is being made pending a child's discharge from hospital which is not planned for several months, other assessments may be reasonably given priority. In cases of very complex needs, there may be a number of professionals involved. As outlined above, there may also be a need for a simultaneous social care assessment.

A continuing care assessment should not however be delayed in order to fit within the timescale for an EHC plan assessment. A decision on whether or not a child has a continuing care need can be made by the panel, and notified to the local authority SEND co-ordinator, as part of the health advice, with the package of care developed as part of the planning process, which would provide a basis for determining which commissioner is responsible for what types of care, and reaching bipartite decisions. Timescales and deadlines should always be discussed with the child or young person (where appropriate) and their family.

If the child or young person is being discharged from acute care or tertiary care adherence to a clear timetable increases the likelihood of the child or young person being discharged in a timely manner and reduces potential for a delayed discharge. Children and young people who require fast-track assessment because of the nature of their needs (such as a palliative care need) will be identified early and the child or young person's needs met as quickly as possible. The continuing care process should not restrict access to end-of-life care for

children and young people who require immediate support over a shorter period, and should not result in any delay to appropriate treatment or care being put in place.

REVIEWS OF CARE

All children and young people receiving continuing care packages must have a specified review date of which parents/carers are made aware. For all new packages of care a review must take place 3 months following initial agreement. This review is undertaken by the Children and Young People's Continuing Care Health Needs Assessor and should be evidenced to Children and Families Commissioning at regular monitoring meetings.

The purpose of this review is to ensure that the package has been implemented as envisaged in the terms of the Panel decision. Following initial review at 3 months, review dates are set at 6 month intervals from the Panel decision (with Complex Needs Panel related package reviews being presented at the relevant scheduled Panel meetings). All review material presented to the Commissioner should also be presented at the next available Complex Needs Panel, if they are to be jointly funded. However, health funded only cases can be decided by North Cumbria CCG.

Whilst the Framework stipulates a minimum of annual review, in North Cumbria it is desirable that a 'mini-review' is conducted in the intervening 6 month interval. Whilst this review should be based on the domains of assessment, it may be acceptable to document an uncomplicated analysis in narrative form.

Parents/carers must be made aware that they can request a review of the package at any time by requesting the lead professional to call a TAC meeting. If the decision is made that a change in package is required the case will be brought back to CNP.

On review of a care package and where a potential change in provision is considered a full Health Needs Assessment must be completed. If it is determined that a continuing care package is no longer required, a multi-agency meeting may be necessary to consider whether to reconfigure the package or to decommission the entire package.

At any assessment/ review/ transition assessment, if it is identified that the child/young person does not meet the criteria then the following actions will be taken:

- The family are informed of the outcome in writing and are advised of their right to appeal against this decision.
- The family are advised that the ineligibility for continuing care does not affect eligibility for assessment for universal, specialist or Local Authority services for help with meeting needs.
- The Children and Families Commissioner will direct the child, young person, family or key worker to appropriate service provision as required.
- The decision to withdraw from a package of support will be brought to the CNP for discussion.

MONITORING OF CARE PROVIDERS

In addition to the formal individual review process each package of care, solely funded by health, should be monitored to identify whether providers are delivering in accordance with the NHS Standard Contract agreement. In appropriate cases, providers may be asked to submit more frequent situation reports. Where packages are being delivered outside of the terms of the NHS Standard Contract (such as via local authority direct payments), the terms and conditions of the provision should be explicitly stated and accountable to the funders of the service.

Failure to comply with any standard set out within the contract will initiate a comprehensive performance review which will be issued as a contract query.

It is recognised that the facilitation of home care provision may result in complications which impinge on the delivery of a care package agreed by the Children and Families Commissioner. In the event of such difficulties it is expected that the Commissioner will be notified promptly and, where appropriate, offer resolution guidance. In the unlikely event that concerns are not managed it may be necessary to involve a third party such as an advocate, Patient Advisory Liaison Service, safeguarding.

CHALLENGES AND DISPUTES

There are two different kinds of dispute that may arise in relation to NHS Continuing Care agreements/outcomes (NHS Continuing Healthcare Joint Disputes Resolution Policy, 2018):

1. Disputes between the CCG and LA regarding eligibility
2. Challenges (include requests for reviews) by the individual or their representative in relation to the process or decisions made.

Continuing care arrangements, in relation to health, social care and education have the capacity to generate disagreements about agency responsibilities and funding, which may be complicated further by the right to education for children aged 5-16 years old (with additional entitlement in specific circumstances) and the duty of local authorities to make it available for all children of these ages. The growth of children and young people is one of rapidly changing physical, intellectual and emotional maturation in the context of social and educational development. Their continuing care needs are therefore best addressed holistically, and on a joint basis where agencies are involved in providing them with public services or care.

KEY PRINCIPLES

The following principles apply:-

• The development of a culture of problem solving and partnership should be fostered.
• Formal disputes should be the last resort and should seldom be necessary.
• Multi-Disciplinary staff should endeavour to resolve issues at the frontline wherever possible and should not be encouraged by either party to elevate the decision-making to

more senior people with less knowledge and understanding about the individual's care needs.
• When staff are unable to reach an agreement they will have timely and ready access to senior decision makers (members of the Complex Needs Panel) who are expected to agree a resolution of the issue with their counterparts.
• The child/young person should not become involved in the dispute in any way. In these cases, the child/young person should be informed that a decision will take a little longer than usual and be advised of the likely timescale.
• Children/ young people should always be cared for in an appropriate environment throughout the process.

ORGANISATIONAL DISPUTES PROCESS

Where organisation disputes over care provision arise the mechanism for resolving disputes between Cumbria CCG and the Local Authority (LA) are facilitated with the key objective being to ensure that an individual's potential eligibility for continuing care is correctly determined and that an appropriate package of care is agreed and commissioned.

The process of considering and deciding eligibility for continuing care must not delay treatment or appropriate care being put in place. The agreed arrangements will therefore be based on the following principles and where it is determined that North Cumbria CCG are the responsible commissioner:-

• Neither North Cumbria CCG nor the Local Authority will unilaterally withdraw from funding an existing package.
• The child/young person will be discharged from hospital as soon as it is appropriate to do so (to their own home, nursing/residential care etc.)
• The Local Authority and North Cumbria CCG will work together to agree case management arrangements to ensure the child/young person continues to receive the appropriate standard of care.
• The placement will be funded without prejudice to the final decision (reimbursement will be paid if required).
• Responsibility and disaggregation of funding will be based on the Continuing Care and Local Authority Community Care assessments.

CHILDREN, YOUNG PEOPLE AND THEIR PARENT/CARERS APPEAL PROCESS

Appeals Procedure:

Parents and carers of children and young people undergoing assessment for continuing care have a right to be informed about the outcome of the assessment for eligibility and care package agreement. This includes the outcome of applying the Decision Support Tool and the decision made by the Children and Young People's Continuing Care Health Needs Assessor, Commissioner or Complex Needs Panel.

Where it is possible, parents/carers and individuals should be given the opportunity to be involved in discussions about eligibility for continuing care and they should be central to and involved in all assessments contributing to the Decision Support Tool.

In addition, in line with the Children and Young People continuing care pathway, every effort should be made by the continuing care Health Needs Assessor to involve the parent/carer/individual in the development of the Health Needs assessments where recommendations on the level of care package required are identified. The emphasis of the pathway is full participation of the parent/ carer and individual at all times to ensure that all significant factors are taken into account and will ensure there is a good understanding of the criteria for eligibility and allocation of packages of care. Parent's inability or refusal to be involved with this pathway cannot be the single rationale for not making recommendations about a care package.

Parents/carers and individuals should be given clear written information stating whether they meet the criteria, the package of care awarded or an explanation of why the criteria was not met. Disputes frequently occur because people are not made aware of the criteria and are not able to understand why they do not qualify or do not understand why a certain level of care package was awarded.

The process for appeal should be clearly identified within the written information provided to the family.

The stages of the Appeals process are summarised as follows:-

Stage 1: Informal procedure

In the first instance the parent/carer should contact the Continuing Care Health Needs Assessor and/or key member of the child's multi- agency team to discuss their concerns/issues. These concerns may be in relation to the continuing care assessment, and /or the outcome of the assessment in terms of whether or not their child meets ` criteria and/ or the outcome of the allocation panel in terms of the level of care package awarded.

If they remain not satisfied, then they should be directed to appeal in writing to the Children and Families Commissioner (who has a responsibility to share this with the Chair of the Complex Needs Panel if the case has presented at Panel). Responsibility for an appeal will not be accepted until notification is received in writing from the parent / carer/ child or young person.

Stage 2: Local Panel response

Following receipt of an appeal the **Senior Commissioning Manager** in partnership with the Panel Chair will determine the level of response required.

Level of response:

- Formal response letter

- The convening of a local appeals panel within 30 days. Written communication to parent / carer with explanation of local panel findings and recommendations would then follow.

A Local Appeals Panel should not proceed if the parent/ carer, and where appropriate the individual concerned, has not had the opportunity of an informal discussion and also where that individual has not undergone a full assessment in line with the standards of the local Children and young people continuing care pathway.

Written confirmation that a Local Panel will be convened should be forwarded to the parent/ carer and the child/young person where appropriate with an explanation of the process. The Local Panel will consist of at least three staff to include one each of senior clinicians/managers/ commissioners. The outcome of the Local Panel's decision should be communicated in writing to the parent/ carer and individual within 7 working days of the decision being made by the chair of the panel.

TRANSITION TO ADULT SERVICES

PRINCIPLES AND PROCESS

Planning for transition from children's services to adult services should begin at the age of 14 years (Year 9). All young people aged 14 or above, will have interventions planned which work towards fostering independence within the family unit , this will involve the child/ young person assuming responsibility for decision making wherever this is feasible. Consideration needs to be given to young people with a learning disability who are entitled yearly health checks from the age of 14.

Discussions around transition of continuing care needs will comply with relevant transition protocols (Transition Protocol, **Appendix 8**) that apply to the child or young person as well as 'Who Pays' guidance.

The issue of funding and access to equipment must also be addressed within the transition planning process.

In line with the recommendations within the National Framework, Adult Continuing Health Care services must screen young people who are receiving continuing care at age 16. Therefore the children's continuing care lead will formally refer the young person to the adult NHS continuing healthcare team at the relevant NHS commissioner. The Commissioning Manager (Continuing Care) at North Cumbria CCG will notify the CHC Team Lead of young people awaiting an indication of eligibility for transition purposes when they reach 16.5 years of age.

By the age of 17, an individual's eligibility for adult NHS continuing healthcare should be decided in principle in order that, where applicable, effective packages of care can be commissioned in time for the individual's 18th birthday. Therefore the continuing care lead will formally request a decision in principle in relation to the eligibility of the individual for continuing health care on their 17th birthday.

Where a young person is found not to be eligible for adult continuing healthcare, then children's and adult services should work together to ensure that transition from children's services to adult services acknowledge individual need.

Appendices	Document
1. Continuing Care Pathway	Children and Young People's Continuing C
2. Pre-Assessment Checklist	Pre. Assessment Checklist v.2.doc
3. Decision Support Tool	Childrens Continuing Care Decision Suppor
4. Consent Form	Continuing Care Consent Form.doc
5. Request for Information	Request for Information.doc
6. Complex Needs Panel (CNP) Referral Form	CNP Referral Form.docx
7. Complex Needs Panel Decision Proforma	CNP Decision Pro Forma.docx
8. Transition Protocol	Cumbria Transition Protocol Final.docx