NHS
Lancashire and South Cumbria
Integrated Care Board

Children and Young Peoples' Continuing Care and Complex Care Protocol

Lancashire and South Cumbria Integrated Care Board

Document Tracking

Document Reference:	CYP_CCP_LSCHCP
Document Title:	Children and Young People' Continuing Care and Complex Care Protocol, Lancashire and South Cumbria Health and Care Partnership
Version:	1.8
Version Superseded:	1.7
Author:	
Authors Designation:	Multiple Health and Care Authors
Consultation Group:	Children and Young People IPA Group
Date Ratified:	1st March 2022
Review Date:	1st March 2023
Updated date:	3rd April 2025 (**note** this is an interim update only whilst policy undergoes a full review. Blue highlighted text indicates organisational changes red highlighted text indicates the process no longer exists)

Version Control

Version	Date	Author	Status	Comment / Details of Amendments
1.5	February 2022	MLCSU, CCGs, in Collaboration with System Wide Partners	Draft	Completed protocol to submit to FCIB for ratification
1.6	February 2022	Samantha Vos, ICB Funded Care Programme	Draft	Formatting amendments, ICS branding applied, version control and document tracking amendments before submitting to FCIB
1.7	February 2022	Julie Beech, Project Manager Support	Final	Amending words in the main document. Finalising formatting.
1.8	April 2025	Sue Mounsey HoS CYPCC	Interim version pending full review	Updated during review period to reflect organisational changes in Oct 2023 – i.e. CYPCC Service Tupe into LSC ICB

Protocol Development Process

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Children and Young People Group	Delivery Group reporting to All Age IPA Board	N/A
ICB Commissioners	Commissioners responsible for children's services	N/A
LSC ICB	Lancashire & South Cumbria Integrated Care Board (LSC ICB) Children's IPA Continuing Care/CYPCC Team	N/A
Local Authorities	Blackburn with Darwen Cumbria Lancashire Blackpool	N/A

Abbreviations used in Protocol

CAMHS	Child and Adolescent Mental Health Service
CC/CC	Continuing Care/Complex Care (Children's)
CHC	Continuing Health Care (Adult)
CCNT	Children's Community Nursing Team
CHC	Continuing Health Care
CCCAT	Children & Young People's Continuing Care Assessment Team
CYPCC NA	Children & Young People's Continuing Care Nurse Assessor
CYPCC Team	Children & Young People's Continuing Care Team
LSC ICB	Lancashire & South Cumbria Integrated Care Board (LSC ICB)
DOH	Department of Health
EHCP EHC Plan	Education Health Care Plan The plan for children and young people aged up to 25 years old, who need more support than is available through special educational needs support. This plan identifies the educational, health and social needs that are required and sets out the additional support to meet those needs.
FNC	Funded Nursing Care
Health Needs Assessment	Health Needs Assessment (Assessment carried out to establish what needs a child or young person has, at that moment in time.)
HV	Health Visitor
LD	Learning Disability
MDT	Multi-Disciplinary Team (group of professionals who provide support to child/young person and to parents)
PHB	Personal Health Budget
SEND	Special Educational Needs and Disabilities

Table of Contents

1. Introduction

1.1. Background

1.1.1. This protocol is written in the context of a range of national policy, guidance and local system approach, to ensure consistent delivery across the footprint of Lancashire and South Cumbria

1.1.2. It relates to Individual Patient Activity (IPA) concerning children and young people, including NHS continuing care and complex care

1.1.3. It formalises the joint local approach to the implementation of continuing care and complex care working arrangements in Lancashire including Blackburn and Darwin and South Cumbria, delivered by Lancashire & South Cumbria Integrated Care Board (LSCICB) and local authorities (LAs) described in the 'Scope' section of this protocol.

- **PLACES**
- Blackburn with Darwen

  Blackpool (informal joint working arrangements, as of January 2024)

  Lancashire

  South Cumbria

LOCAL AUTHORITIES

- Blackburn with Darwen Council
- Blackpool Council (informal joint working arrangements, as of January 2024)
- Lancashire County Council
- Westmorland and Furness County Council (as per organisational changes in April 2023, previously Cumbria Council)

1.1.4. Continuing care/complex care for children and young people applies from birth to the 18th birthday, with the NHS Continuing Healthcare Framework (CHC) applying thereafter. The frameworks each reflect the specific contexts and needs of children and of adults, using appropriate criteria to gauge eligibility.

1.1.5. The children's framework recognises the complexity of needs of some children and a child who has complex health needs can be considered for assessment using the National Framework for Children and Young People's Continuing Care (Department of Health 2016). This framework is designed to support Integrated Care Boards (ICB) in determining if those health needs are so complex, that they require additional support alongside local NHS services (core/universal, targeted or specialist), routinely available in the community, in hospitals or from GP practices, which are normally commissioned by ICBs. This additional type of support from continuing care/complex care is known as a

package of care, or care package. continuing care/complex care describes the additional package of support that may be needed. Decisions regarding funding for additional support are to be based on the assessed need of the child or young person, following a holistic health needs assessment. (See Appendix 3).

1.1.6. Where a child or young person has Special Educational Needs and Disabilities, the ICB and LAs endeavour to coordinate the assessment and agreement of the package of continuing care/complex care, as part of the process to develop the child's Education, Health and Care Plan. Whilst a child or young person may be identified as having continuing health and care needs, it is important to note that most have a combination of health, education and social care needs that require joint assessment, planning and coordination.

1.2. Definition

1.2.1. Continuing care/complex care are general terms that describes a tailor-made package of care, needed over an extended period for a child or young person to meet their complex health needs as defined through an assessment process. The package of care may be integrated with a range of services offered locally or nationally by the NHS, Local Authority, or other independent organisations to enable the child and family to function in the community.

1.2.2. **Continuing care is described in the framework as follows:**

"Some children and young people may have very complex health needs. These may be the result of congenital conditions, long-term or life-limiting or life-threatening conditions, disability, or the after-effects of serious illness or injury."

"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."

1.2.3. **Complex Care definition is as follows:**

"A complex care package will be required when a child or young person, does not meet eligibility criterion for continuing care, but has recognized needs which impact on each other making the overall presentation more complex, which still can't be met by existing universal or specialist services alone. The overall complex presentation may have an impact of how the family are able to provide support to the child or young person"

1.2.4. This applies to children and young people aged between 0-17 years, who may have one or a combination of physical disability, mental health needs, learning disability, end of life needs, and where these needs are not being met through the commissioning of universal and targeted services. In some cases, the child or young person will have been placed, or requires placement in a residential or therapeutic setting, and has complex needs which require a healthcare planned approach and management of the same. In these instances, specialist healthcare professionals are expected to provide input to the care planned approach, via

specialised health case assessment. (See Appendices 16 and 17).

1.2.5. It is important to note that a diagnosis of a particular disease, or condition is not in itself a determinant for a child or young person to receive support from continuing care/complex care. It is the role of the Multi-Disciplinary Team (MDT), and parents/carers, child/young person to collectively agree that this approach should be considered via assessment. The guidance around continuing care/complex care, including how a child or young person should be assessed is described within the National Framework.

1.2.6. Commissioned activity that LSC ICB provides, and which falls outside of the remit of continuing care/complex care is called Individual Patient Activity (IPA). The children and young people IPA activities are covered as a spoke of the All-Age IPA 'hub and spoke' model and related arrangements (where commissioned) and include:

- Bespoke packages of care for children and young people who do not meet continuing care/complex care eligibility. These are packages of care, or elements of support that cannot be managed by core locally commissioned NHS services and are additionally outside the remit of social care and education provision.
- Arrangement and management of Personal Health Budget's (PHB) for children and young people who are eligible for continuing care/complex care, or which the ICB identify as requiring a PHB within the scope of IPA.
- Vehicle for funding of specialist and non-specialist equipment and consumables that cannot be accessed from Community Equipment Stores i.e., Nottingham Rehab Services, Mediquip, and maintaining accurate records of funding release related to this activity (responsibility retained by referrer in relation to purchased items via LSC ICB).
- Integral assurances of clinical governance, quality, and safety across the remit of responsibilities.

1.3. Purpose of the Protocol

The purpose of this protocol is to:

- Describe the continuing care/complex care process for the Lancashire (excluding Blackpool) and South Cumbria health and social care economy Integrated Care System (ICS). (See Appendices 9 and 10).
- Describe the joint and consistent approach to assessing and responding to children and young people, who have a complex physical health, mental health or learning disability need, or an end-of-life need, and who require a package of care and where relevant support linked to the Education Health and Care Plan (EHCP), or an Individual Care Plan (ICP). The Children & Young People's Continuing Care Nurse Assessor (from either the CYPCC Team or CCCAT) will liaise with the Designated Clinical Officer/plan writers with regards to the details regarding provision of support.
- Describe the roles and responsibilities of the key people and agencies involved in the process.
- Equip local practitioners with the knowledge and tools to follow the process.

- Describe the remit and responsibilities of the panels involved in the process.
- Describe the process for appeals by children, young people, or their families, including disputes between agencies.
- Describe local funding arrangements.
- Describe the local approach to commissioning support packages.
- Describe local arrangements for transitioning children and young people with continuing care/complex care needs to adult services. (See Appendix 23).
- Describe the current local approach to PHB's (See Appendix 15).

1.4. Scope of the Protocol

1.4.1. This protocol sets out the principles for the operational management of Children and Young People's Continuing Care/Complex Care by LSC ICB.

1.4.2. The local authorities that are within scope of this protocol with regards to social care and education are Lancashire County Council, Westmorland and Furness Council and Blackburn with Darwen Council. Blackpool Council has been part of the consultation process and are shadowing the approaches taken for continuing care/complex care but are not currently included within the scope of the protocol. Note: Since Blackpool place became integrated with LSCICB in October 2023, there are informal joint working arrangements with Blackpool Council that largely follow the principles for managing CYPCC/Complex Care, as set out within this protocol.

1.4.3. LSC ICB is responsible for ensuring that the process of continuing care/ complex care is undertaken in an effective, timely and safe manner. The LSC ICB CYPCC Team will commission the necessary homecare services, whilst understanding the child and young person's needs and their views around care package arrangement. Their parents and families will be integral to this along with partner agencies, core services and commissioned providers. Residential provision is sourced by the relevant LA.

1.4.4. There should be an MDT holistic approach, with shared responsibility throughout the continuing care/complex care process. The MDT approach should include health, education, and social care professionals representing their services or who know the child, as well as other services who are involved.

2. Leadership and Accountability for the Continuing Care/Complex Care Process

2.1. Roles and Responsibilities

2.1.1. The roles that support the children's continuing care/complex care process are:

- LSC ICB
- CYPCC Team (LSC ICB)
- Nurse or other health professional leading on checklist or Health Needs Assessment

completion (Children's Continuing Care and Assessment Team/Children's Community Nursing Team/ Learning Disability Team/Child and Adolescent Mental Health Service Practitioner/ Child in our care Nurse/ School Nurse – This is not an exhaustive list)

- Continuing care/complex care multi-agency panel
- Child or young person (CYP)
- Parents/Carers
- Other involved Health Care professionals i.e., Consultants
- Social Care practitioners
- Education professionals

2.1.2. CYPCC team at LSCICB is responsible for agreeing and managing appropriate governance arrangements

2.1.3. Removed, not relevant – referred to MLCSU contractual arrangements

2.1.4. The CYPCC team sits within the All Age Continuing Care & IPA Service at LSCICB. The CYPCC team co-ordinates the continuing care/complex care process throughout from receipt of the completed Checklist/and or Health Needs Assessment. Continuing Care Assessments are undertaken by a CYPCC Nurse Assessor (NA) when there is no nominated CCCAT Nurse Assessor for that geographical area, namely, Chorley & south Ribble, Blackpool, Fylde & Wyre, Lancaster, Morecombe and South Cumbria. The CYPCC NA will also undertake checklists and assessments, reviews/re-assessments where there are delays or barriers.

Their work includes:

- Receipt of checklist for audit and data purposes (for those that do not proceed to a Health Needs Assessment)
- Quality assuring the Health Needs Assessment and all supporting information (See Appendix 5)
- Undertaking checklists and Health Needs Assessments (as outlined above in section 2.1.4)
- Presenting assessments to the continuing care/complex care multi-agency panel
- Leading on the sourcing and procuring of home care packages,
- Supporting the MDT of professionals, including the responsible LA, in relation to the Complex Cases process
- Reporting to the multi-agency panel where there is a delay and/or difficulty in putting a package of care in place.
- Prompt community teams to perform reviews and receive completed reviews to quality assure and present to panel.
- Undertake reviews/re-assessments (as outlined above in section 2.1.4)
- Presenting to the multi-agency panel any further recommendations that are made by the Nurse leading assessment with regard to a package of care.
- Co-ordinating and delivering the training (where feasible with Local Authority

colleagues), support professionals in relation to continuing care/complex care and processes.

- Liaise with the child/young person and parents, multi-agencies, third party organisations, acute and community sector and other related agencies.
- Keep and maintain records for data and reporting purposes. Sharing in accordance with data sharing agreements.
- Individual agencies are responsible for ensuring that the most up to date agreed records are held locally.

2.1.5. It is the responsibility of the NHS provider services, who may be known as the lead health professional, and multi-agency team supporting the child/young person to complete a checklist (see Appendix 4) and Health Needs Assessment (see Appendix 3). The MDT will need to determine if a checklist is required to aid their understanding of the child and young person's needs (the checklist can be used to determine if a Health Needs Assessment is required). The MDT can complete a Health Needs Assessment without completing a checklist if they agree to this. Any checklists completed and not progressed onto a Health Needs Assessment will need to be sent to the CYPCC team for audit purposes. (note, as outlined in section 2.1.4, some checklists and assessments will be led by a CYPCC Nurse Assessor)

2.1.6. The **health provider service/nurse** leading on completion of the checklist/Health Needs Assessment should have experience of both caring for children with complex needs and of assessing health need (there is a requirement for multi-agency staff to attend training to ensure checklists and Health Needs Assessments are completed to a sufficient standard. It is expected that those present at the checklist/health needs assessment stage remain where feasible as part of the MDT throughout the continuing care/complex care process (inclusive of the review process and other relevant stages). They will ensure that all relevant and requested supporting evidence is provided alongside the Health Needs Assessment to LSC ICB. Should there be no current health professional involved then a referral to the appropriate core commissioned services should be explored prior to considering continuing care and complex care process if there remains an unmet health need.

2.1.7. Refer to crisis pathway (see Appendix 18) when dealing with emergency placement scenarios. In those cases where health professionals have no oversight on the individual case the LA must refer to the ICB for relevant involvement, to ensure any gaps in service are highlighted.

2.1.8. Lead Health Professional leading on the checklist/Health Needs Assessment completion (CYPCC Nurse Assessor/Children's Continuing Care and Assessment Team/Children's Community Nursing Team/Learning Disability/Child and Adolescent Mental Health Service/School Nurse/ Child in our Care Nurse etc)

- Point of contact with parents, children, and young people in the community setting
- Work alongside MDTs to consider if referral to continuing care/complex care is necessary
- Complete a checklist to determine if a Health Needs Assessment is required, with

MDT, parents, child/young person (as required) for those cases which relate to Complex Cases i.e., residential placement, or if the MDT are unsure about the complex health needs presented

- Note – CCNs will only complete checklist (as of June 2024) If a checklist is positive and HNA is indicated, this will be undertaken by a CYPCC NA.
- CCCAT will progress to HNA where indicated and submit to CYPCC team for quality assurance and progression to multi-agency panel.
- CYPCC Team to receive completed checklists from CCNs and progress to Health Needs Assessment if checklist is positive.
- CYPCC team at LSC ICB to receive negative checklists completed by MDT, which are not being progressed to Health Needs Assessment relating to both cohorts continuing care and complex cases. For recording, audit and reporting purposes, these are shared and discussed within multi-agency panel arrangement
- Nurse assessor is to make an appropriate recommendation for care required after collating the supporting evidence.
- Nurse Assessor sends the completed Health Needs Assessment back to the MDT for review and forward thereafter to the CYPCC Team at LSC ICB for quality assurance.

2.1.9. Reviews/re-assessments are to be completed by the most appropriate professional from either the CYPCC team or CCCAT service. CCNs to be invoked in the review/re-assessment MDT, where appropriate.

2.1.10. The lead health professional will be responsible for submitting the checklist and/or Health Needs Assessment to the CYPCC Team at LSC ICB, but the completion of both documents should remain the responsibility of the agencies involved to ensure a holistic view of their needs is considered when understanding how their needs should be and can be met. Checklists submitted alongside Health Needs Assessment (for continuing care cases) to be managed by LSC ICB for audit, gap analysis and reporting.

2.1.11. The lead health professional in conjunction with partner agencies, may recognise that a children and young people may have needs that require additional health services that cannot be met by existing universal and specialist services. They have specific responsibilities identified under Sections 3.7 – 3.15 below, describing the referral process and the role of the referring professional – these sections are headed ‘Referral / Pre-Assessment Checklist’.

2.1.12. The continuing care/complex care multi-agency panel (referred to as the eligibility panel) is made up of key professionals from health, education, and social care, who hold delegated responsibility to act on behalf of their organisation with regards to financial decisions. The panel receives recommendations for a care package and will be responsible for reviewing and ratifying these recommendations, to determine the support required.

2.1.13. The CYPCC team will hold an internal decision-making panel to quality assure, review and make decisions with regards to eligibility and non-eligibility concerning continuing care and complex cases. Non-eligible, high cost and cases that are cause for concern will be presented to eligibility panel. Negative checklists will be tabled on agenda.

2.1.14. For home care packages of care the commissioning of the package of care is arranged

by the CYPCC team to ensure that the required support is commissioned. This may be through existing contracts with statutory or independent providers, or through individual agreements with specialist providers, including schools.

2.1.15. For residential packages of care the responsible **Local Authority,** with support from the MDT, will lead on sourcing an appropriate placement, (this may include the support from mental health and learning disability practitioners within the community or acute setting from an early stage within the process of continuing care, as well as MDT).

2.1.16. The preferences of the child or young person and their parents will need to be understood by the MDT and nurse leading the assessment, who will ensure these are taken into consideration when decisions are being made. Adjustments must be made, and aids used, to ensure the child/young person is able to express their views.

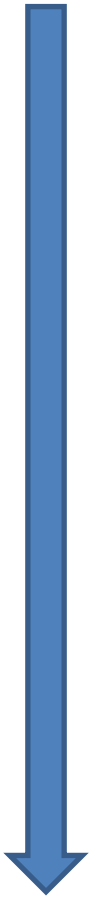
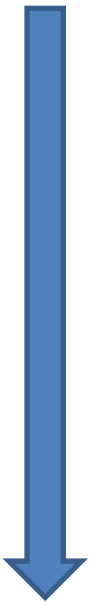
2.1.17. The NHS recognises that parents will take an active part in caring for their child, unless they can specifically evidence that they have exceptional circumstances that preclude them from providing a reasonable level of care, or are part or full the responsibility of the LA. The MDT will need to understand if the child or young person is under the care of the LA (known as a Child in our Care).

3. Children's Continuing Care/Complex Care Process Outline and Pathway

The continuing care/complex care process has five phases as indicated on the Pathway Outline utilising the National Framework as guidance table:

Pathway

Phase	Step	Summary of Key Actions	Responsible	Timescale
Identify	Identify/ refer	Lead health professional is nominated to lead on process, with Multi-Disciplinary Team (MDT) supporting. Checklist completed by MDT to determine whether to proceed to a full Health Needs Assessment for complex care cohort. Checklist may be used by MDT for continuing care cohort and sent alongside HNA or proceed straight to HNA.	Multi-Disciplinary Team and Lead Health Professional, ie CCCAT Nurse assessor, CCN or CYPCC Nurse Assessor. In instances where there is no known health professional involved, the Social worker or other non-health professional can lead on a checklist providing they have undergone	2 working days to complete and send the negative checklist to LSC ICB 6 weeks' timeframe from receipt of Health Needs Assessment completed by lead health professional and MDT, for ratification via

		If checklist is negative/not proceeding, then this must be sent to LSC ICB for recording/data purposes and presentation to multi-agency panel.	checklist training from the CYPCC team **and** had a pre-checklist triage conversation with a CYPCC Duty Nurse	multi-agency panel 
	Assess	The lead health professional (CCCAT Nurse/CYPCC Nurse Assessor) undertakes the Health Needs Assessment and completes the recommendation. (Supporting evidence will be referenced in the Health Needs Assessment and proforma submission). Lead health professional submits the HNA to CYPCC Team for quality assurance – CYPCC team allocate the HNA for QA to a CYPCC Nurse Assessor, if this was undertaken by the CCCAT service	Lead Health Professional	
	Recommend	If all supporting evidence has been received and quality assured, the recommendation is presented to the multi-agency panel based on the Health Needs Assessment and supporting evidence by the allocated CYPCC Nurse Assessor LSCICB	CYPCC Nurse Assessor	
Decision Making	Decide	The multi-agency panel considers the recommendations for those cases that are deemed eligible by the	Multi-agency panel	

		MDT and decides if the child or young person has continuing care/complex care needs that remain unmet following all core commissioned/universal services being exhausted.		
Arrangement of Provision	Inform	CYPCC team send outcome letter to the family, lead health professional and GP regarding panel outcome. Lead health professional to liaise with child or young person and their family and MDT	CYPCC team	Within 5 working days of panel
	Arrange	Pen picture of need sent to Dynamic Purchasing System (DPS) for tendering. A costed package of care is developed as a result. Where this is not possible, collaborative working may be required. Residential/educational placements sourced by responsible Local Authority. HNA to be completed in line with urgent decision-making process. See appendix 18 on page 34 Relevant organisations involved in the child or young person's care are notified.	CYPCC Nurse assessor (home care packages) MDT/LA with support from specialist health professionals (where feasible) CYPCC team – home care packages LA – residential/ educational placements	2-4 working days of panel outcome
	Deliver	Commission the package of care provision for the child or young person.	CYPCC team Home Care packages) MDT and	Home Care: Mobilisation of a package of care can take between 3-6 months

			responsible LA (Residential packages)	depending on the complexities of the child. A proposed timescale will be shared at time of package award. Residential: dependent upon placement availability
	Monitor	On-going monitoring and contract management of the commissioned service, and reporting	CYPCC team (Home care packages) Residential/ educational (LA) The specialist health professional (core and specialist NHS services) should provide oversight of care and support provided	12 months or change in needs occurs, in relation to care package provision/ eligibility (Home care and residential/ educational placement)
On-going	Review	Reassessment of the child or young person's continuing care/complex care needs as outlined in 3.8.12	Lead Health Professional (CCCAT or CYPCC Nurse Assessor)	Annual, or when a change in need occurs

The timescale to complete the process is within six weeks of receipt of the completed Health Needs Assessment, although it is recognised that there may be circumstances under which this may not always be possible due to the complexity of needs and/or the timings of scheduled panel meetings.

3.1.1. The assessment and associated process should not be delayed fitting within the timescales of Education Health Care Plan writing and assessments. A decision can be made outside of the Education Health Care Plan process and then shared with the education assessment team to inform Education Health Care Plan.

3.1.2. A fast-track process is used for urgent cases, concerning end of life care, to ensure decisions regarding packages of support can be agreed and procured without delay. This is described in Section 8 of this Protocol

3.1.3. Urgent residential/therapeutic placement of children and young people will be managed by the responsible LA in conjunction with the relevant health specialists within the community and/or acute setting i.e., mental health or learning disability team. The NHS

health specialists and CYPCC Nurse Assessor may provide advice and support in relation to the appropriateness of residential/therapeutic settings, within their limits of practice. The CYPCC team will support with the case upon receipt of the checklist or Health Needs Assessment and where feasible (within their levels of expertise and previous clinical knowledge), provide advice regarding suitability of placements. There is a separate Crisis Pathway for these cases to ensure timely decisions on funding.

3.2. Documentation

3.2.1. A range of documents support the continuing care and complex care process from end to end. These are embedded in the appendix to this protocol. These documents are updated as necessary, and the CYPCC team will circulate an updated version control document following each change. It is the responsibility of each individual/agency involved in the process to ensure that the most up-to-date versions of documentation are used, to ensure that there is no delay to the process.

3.2.2. The use of incorrect documentation, or the incorrect completion of document (including failure to provide other relevant and related supporting documentation) will result in the CYPCC team returning such documents to the lead health professional. A timely response to the request(s) is required to minimise delays in the process which will impact directly on the child or young person.

3.3. Referral / Pre-Assessment Checklist

3.3.1. The process for a continuing care/complex care assessment begins when there is recognition that a child or young person may have needs that require additional health services that cannot be met by existing core/universal, specialist and targeted services, referred to as ‘core services’ in the Health Needs Assessment document. These are referenced as ‘unmet needs.

3.3.2. Any professional can identify that a child or young person may benefit from being assessed for children’s continuing care/complex care and can ask for a MDT to be convened, to review the child’s needs. This includes (but is not limited to); a GP, Community Nurse, School Nurse, Dietician, Physiotherapist, Mental health Nurse, Learning Disability Nurse, Consultant, Social Care practitioners, Education professionals e.g., SENCO, teacher, headteacher. The members of the MDT must contribute towards the discussion, or at the least provide concise reports to evidence the needs. The multi-disciplinary members must maintain involvement throughout process.

3.3.3. The lead health professional, must carry out the following actions:

- Use the Pre-Assessment Pathway flowchart prior to checklist being completed (see Appendix 19) to ensure that all core/universal, specialist and targeted services have been accessed.
- Discuss the assessment process with parents, and the option of having a PHB. continuing care/complex care leaflets are available to share with families to give them more information. (See Appendices 9 and 12).

- Obtain consent for the continuing care/complex care referral and assessment using the consent form (See Appendix 3).
- Identify professionals who are involved in care for the children and young people.
- Arrange for a multi-agency meeting, referred to as an MDT. This could be combined with other MDT meetings, or it may be a newly established MDT that is used to hold the discussion. (See Appendix 20).
- Invite parents to the MDT meeting, where appropriate to do so.
- Ensure appropriate representation is present at the MDT across health and social care and education services i.e. therapies; community nursing; learning disability nursing; social care; educational psychologists; school; specialist advisory teachers; Children Looked After/Looked After Children; child protection; safeguarding; post adoption; children with disabilities; GP; paediatrician.
- Invite appropriate Voluntary Care Sector organisations (VCS).
- There is an approximate six to ten weeks timeframe for completion depending on factors such as panel date and other factors, of the pathway, from the point that the MDT collectively agree that a child or young person requires a Health Needs Assessment.

3.3.4. The CYPCC team will provide support where needed through the checklist and Health Needs Assessment completion, particularly when the MDT are unsure about the outcome of a checklist. Multi-agency teams are expected to attend training sessions on continuing care/complex care provided by the CYPCC team within LSC ICB.

3.3.5. Completion of the Checklist does not determine eligibility.

3.3.6. The MDT should complete a checklist if it is apparent that the child/young person has unmet needs (physical health, behavioural, emotional, learning disability) within 24/48 hours if this is indicated. If the MDT agree that a Health Needs Assessment is further indicated this should be completed either on that same day or within 2 weeks of the checklist being completed.

3.3.7. Completed checklists that do not proceed to Health Needs Assessment will be forwarded to the CYPCC team for recording and data purposes to capture trends. Checklists will be reviewed within eligibility panel as an agenda item.

3.3.8. Checklist and Health Needs Assessment are not required for those cases identified within the fast-track process. Refer to the fast-track process described in Section 8 of this Protocol.

3.3.9. The Lead Professional and MDT will use the Pre-Assessment Pathway to ensure it is appropriate to complete the Checklist. The Checklist is completed when:

- Relevant locally commissioned universal and specialist services (also referred to as ‘core services’) have identified that they cannot amend or alter the service they deliver which cannot meet needs by amending or altering, or
- Adjustments cannot be made to the planned care the children and young people is receiving, or
- The child or young person cannot be referred to other universal or specialist services

for assessment to meet the needs or

- a newly referred to service has provided strategies or implemented a change to the existing health care plan, but as a result has shown the needs remain. Consideration given to those cases where the child/young person/parents do not engage with the service and the strategies/plans being suggested
- the parents have accessed available training and support that subsequently has not met needs

3.4. Assessment using the Health Needs Assessment

3.4.1. Where a decision is made to proceed to complete a Health Needs Assessment, a lead health professional must be identified. The lead health professional is responsible for completing the Health Needs Assessment with input from the MDT. Where indicted this will be a CYPCC Nurse assessor (as outlined in section 2.1.4).

3.4.2. A key part of the holistic continuing care/complex care assessment process is the Health Needs Assessment, which is used to understand health needs across ten care domains.

3.4.3. The Health Needs Assessment considers, health, social and education assessments, and input from the family to ensure a holistic understanding of the child's and family's needs. The Health Needs Assessment consists of:

- Preferences of child or young person and their family
- Holistic assessment of need
- Reports from multi-agency MDT
- Supporting documentation from the range of other assessments that are identified in the Health Needs Assessment

3.4.4. The level of health needs detailed in the Health Needs Assessment does not in isolation determine eligibility. The entire assessment is considered, and review and discussions of all the elements of the assessment informs and identifies the care needs, which in turn informs the recommendations for how **unmet needs** might be addressed. The Lead Professional completing the assessment is responsible for making recommendations based upon all the information gathered.

3.4.5. The MDT meeting is convened and chaired by the relevant lead health professional for that case, and includes health, social care and where appropriate, education, the parents and the child or young person (where feasible). Health professionals should be involved for children and young people placed in residential settings, when they have recognised complex health needs. This meeting can take place remotely using MS Teams.

3.4.6. The lead health professional will submit the completed Health Needs Assessment and supporting documents to the CYPCC team at LSC ICB. The MDT present will need to understand what is being captured within the checklist and/or Health Needs Assessment, to ensure the information captured is agreed.

3.4.7. The allocated CYPCC Nurse Assessor checks and quality assures the Health Needs Assessment and supporting documentation to ensure all relevant information is available

for the eligibility panel. (See Appendix 5)

3.4.8. A Health Needs Assessment that is submitted to the CYPCC team at LSC ICB using incorrect documentation,-or with incomplete information or without the relevant supporting information and evidence will be returned to the lead health professional. These delays will need to be reported to the child/young person and their parents, as well as members of the MDT, and will have an impact upon the assessment process.

3.4.9. Review of the Health Needs Assessment, supporting documentation, and related discussions are used to identify any unmet care needs and to inform the recommendations as to how these might be addressed and if eligibility criteria is met.

3.4.10. The recommendations are compiled by the Lead Health professional, after reviewing the Health Needs Assessment and supporting information. The recommendations should outline what **health needs** a child or young person has, and how these are being met i.e., via core and specialist NHS services. In the instances of any **unmet health needs**, the views of the child/young person, parents and MDT will need to be considered as to how these can best be met via a package of care, or via additional specialist support (through residential or therapeutic placement).

3.4.11. The recommendations are presented to the eligibility panel by the children's continuing care/complex care.

3.4.12. For consistency purposes, there is a weighting process within the Health Needs Assessment process to indicate whether eligibility for either continuing care or complex cases is met. (See Appendix 22). This is based upon an individual's level of health needs across the 10 domains, and is neither prescriptive nor restrictive, and is a guide to understand what support is required to meet any unmet health needs. For example, where there are psychological or behavioural needs that are identified in the Health Needs Assessment as being high or severe it may be considered that having just one of these needs unmet is sufficient to determine that a package of care is required, if it is shown that NHS core and specialist services are providing what they should and cannot adjust or amend their provision in order to alleviate the needs.

3.4.13. Those children and young people who meet the criteria for **continuing care**, refer to weighting guide to eligibility, shown as **3 highs, 1 severe, or 1 priority** across the ten care domains of the Health Needs Assessment.

3.4.14. Those children and young people who meet the criteria for **complex care**: a suggested guide to eligibility is **2 highs or 1 High and 1 Moderate, or 3 or more moderate needs** across the 10 Health Needs Assessment care domains and includes either psychological or behavioural need domains (or both). This is based upon an individual's level of health needs across the 10 domains, and is neither prescriptive nor restrictive, and is a guide to understand what support is required to meet any unmet health needs.

3.4.15. Achieving the suggested guide of the levels of needs within the continuing care/complex care remit is not a determinant to receiving a commissioned bespoke care package of support, PHB arrangement or contribution towards a residential/therapeutic placement, consideration will be given in the first instance to understand what the core

and specialist NHS services are providing. In some instances, the support may be a social care or educational need and will be discussed within the Health Needs Assessment meeting between agencies.

3.4.16. Rationale and reasoning will be sent by the CYPCC team at LSC ICB for those cases where eligibility criterion is not met in relation to continuing care or complex cases. those cases will be progressed through process and sent where required to the eligibility panel. In these cases, the child or young person should have their needs met via NHS core/universal or specialist services and where applicable via the Local Authority offer. This will be articulated by the CYPCC Nurse Assessor to the CYP/family and Lead Professional with rationale.

3.4.17. In those instances where core and specialist services are engaged in support but are not accessed by the child/young person i.e., due to refusal, those existing services must continue to engage and provide support by working with the child/young person and their family, and not be referred to continuing care or complex cases. For those children and young people in residential settings if the universal or specialist services could meet their needs but not within required timescale, or the residential setting does not enable universal or specialist input, the MDT will need to liaise with the service and ICB in the first instance, prior to referral into Continuing Care/Complex Cases.

3.5. Decision-Making: Continuing care and complex care multi-agency panel

3.5.1. The purpose of the continuing care/complex care multi-agency panel is to discuss the case identifying what needs are not being met, and to ratify the recommendations made by the Lead Professional/CYPCC Nurse Assessor. (See Appendix 2).

3.5.2. Eligibility panel is held monthly unless periods of high demand necessitate additional panels. Eligibility panel management will be a shared arrangement between CYPCC team, LA, Nurse/Lead Health Professional

~~Clinical Commissioning Group's/LA Responsibility~~

- ~~Ratify/disagree with recommendations~~

CYPCC Clinical Lead or deputy responsibility

- Chair panel
- Support the CYPCC Commissioning support officer with their role in administration, including agenda setting, minute taking, recording checklists not progressed

CYPCC Nurse Assessor within LSC ICB

- Present cases inclusive of new referrals (continuing care, complex care), issues/concerns with existing cases, transition, end of life, request for PHB's,

safeguarding, provider concerns, care package breakdown, gap analysis (moved from above)

- Post panel communication, inclusive of correspondence and informing Nurse/Lead Health Professional of panel outcome (moved from above)
-

- Face to face/telephone update with parents regarding panel outcome
- The panel is attended by professionals from relevant partner agencies who hold delegated decision-making responsibility to act on behalf of their organisations. Where feasible senior health professionals/clinicians to attend panels as necessary. The panel members are independent from the individuals who completed the Heath Needs Assessment. *Will need to re-consider this with CYPCCs new role of undertaking assessments*
- The panel will either ratify the recommendations made by the Nurse/Lead health professional, or make alternative decisions such as:
- requesting further evidence/information to support the assessment recommendations, therefore deferring the decision
- recommending an alternate provision of support via other means than those suggested by the Nurse/Lead health professional.

3.5.3. The CYPCC Nurse Assessor ~~or Lead Health professional~~ will inform the child/young person and parents of the decision in writing within 5 working days of the panel convening.

3.5.4. Where applicable, the rationale for alternative decisions is noted during the panel meeting and is sent to parents and the MDT.

3.5.5. All decisions made during the panel meeting and/or processes followed within the panel setting are subject to challenge and scrutiny in accordance with appeal, dispute, Judicial Review or Parliamentary and Health Service Ombudsman Review.

3.5.6. The child/young person and parents will be informed of their rights to appeal through the appeals procedure by the CYPCC team via panel outcome letter and through front facing public information, if they do not agree with the decision.

3.6. Arrangement of Provision

3.6.1. Following the panel agreement of eligibility, and confirmation that the child/young person has a continuing care/complex care need that requires additional support over and above what has been commissioned as core/universal, specialist and targeted services, the CYPCC team will facilitate home care provision set up. The LA arrange residential/educational placement. Where feasible there will be joint working between the MDT and CYPCC Nurse Assessor to help identify placements, in relation to a child or young person's complex health needs.

3.6.2. Planning of the home care package begins as soon as the panel decision has been

made. The planning process covers:

- Communication of timescales for delivery with parents
- Involvement of child/young person/parents/Local Authority
- Appropriate and relevant health care provider/s
- The skill mix of staff required to deliver the care package
- Integration of continuing care/complex care with Special Educational Needs and Disabilities provision, universal and specialist health provision
- Sustainability
- A multi-professional approach
- The preferred place of care provision, considering other venues apart from home setting
- Out of hours support
- Staff training and competency including school and residential staff
- Training and competency of parents and foster carers
- Training and clinical governance costs
- Equipment and consumables (where not available via community stores)

3.6.3. Planning of Complex Cases care package provision begins as soon as the panel decision has been made. The planning process covers

3.6.4. The CYPCC team has a duty to ensure that clinical governance is maintained in all bespoke care package arrangements, with assurances gained from various sources to safeguard children and young people receiving health and behavioural support from NHS and independent agencies, the third sector and, where required, from health and social care providers.

Refer to Crisis Placement Pathway for those children and young people who are placed in urgent circumstances.

3.7. Personal Health Budgets (PHBs)

3.7.1. The process for PHBs will be included within the All-Age IPA hub and spoke model approach when this has been fully mobilised. At this point, PHBs will be the default offer. ~~In the meantime, the following process is used in relation to PHBs. LSC ICB will advise Clinical Commissioning Groups of any requests~~

3.7.2. The NHS Mandate, which ICBs must follow, contains a specific objective on supporting children and young people with SEN or disabilities, including the offer of personal budgets. The families of children and young people with continuing care/complex care needs have a ‘right to have’ a PHB, which may contain elements of education, social care and health funding, (NHS Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) (Amendment) Regulations 2013), Special Educational Needs and Disability Code of Practice (2015) and Special Educational Needs (Personal Budgets) Regulations (2014).

~~3.7.3.~~ Where a child or young person eligible for continuing care/complex care, or their family, requests a PHB the ICB will arrange for the provision of care through this means. ~~The Clinical Commissioning Groups are responsible for providing PHBs.~~

3.7.4. A PHB will be arranged in one of the following ways:

- a direct **payment** made to the young person or their family
- a notional **budget** to be spent by the ICBon care following discussions with the child or young person, and their family, on how best to meet their needs through provision of care
- The transfer of a **real budget (3rd Party budget arrangement)** agreed as above, to a person or organisation which provides the money in a way agreed between the Clinical Commissioning Group/LSC ICB and the child or young person and their family (or another representative)

3.7.5. The ICB will publicise and promote the availability of PHBs within the Local Offer and through the distribution of leaflets aimed at young people and their families, which have been developed by third sector partners in co-production with families. Awaiting new documentation

3.7.6. PHBs will also be offered to children and young people who have not been identified as having continuing care/complex care needs on a discretionary basis and as approved by the Chief Nurse or deputy i.e., long-term conditions. These PHB's will not be managed by the Children's Continuing Care/Complex Care Service. ??

3.8. Reviews

3.8.1. A review will be carried out at three months after the initial set up of the continuing care/complex care package. (See Appendix 7). This is to ensure the care package arrangement is safely meeting needs and is running smoothly.

3.8.2. The review is led by the Nurse/Lead Health Professional (CYPCC Nurse assessor where indicated) with relevant members of the MDT and will include the child/young person and parents. It would be encouraged for core commissioned services to remain involved with the child/young person.

3.8.3. Subsequent continuing care/complex care reviews are held annually and require completion of the Health Needs Assessment to establish whether the package of care continues to meet needs and is being delivered according to plan. See review/re-assessment flow chart

3.8.4. A child or young person or their parents can request a review of provision at any time. A request should be made by the Child or Young Pearson/or their family to the CYPCC team, or CCCAT service as appropriate

3.8.5. Reviews will also be held at any time that the child or young person's needs alter and require a change in provision, or if a professional requests a review for other circumstances. This might include

- changes to the package of care, such as change in the number of support hours

required

- changes to the package of care resulting from changes in health needs

3.8.6. The reviewer will ensure that the child or young person and parents understand that reviews are designed to confirm that continuing care/complex care needs are being met on an ongoing basis.

3.8.7. In the case of a child or young person having Special Educational Needs and Disabilities requirements, the review will ideally be prior to or at the time of the annual review of the Education Health Care Plan to inform the Education Health Care Plan of any changes. The Education Health Care Plan must be amended to take account of any changes in the care package arrangement via continuing care/complex care. a review of the Education Health Care Plan may be required prior to any reduction in provision.

3.8.8. Parents are informed at the checklist stage that the package of care is based upon unmet needs and that there is a review process that enables on-going assessment. They are also informed of any changes such as improvement or deterioration in the child/young person's health may result in a reduction or increase in continuing care/complex care provision.

3.8.9. In some cases, a review highlights that health or behavioural needs can be met by universal or specialist services, as their needs may have reduced. In this instance the child or young person may no longer meet criteria for eligibility. The Nurse/Lead health professional will convene a MDT meeting to confirm that universal or specialist service input will meet needs and agree how the continuing care/complex care package of care is to be stepped down to minimise the impact on the child/young person and parents.

3.8.10. A phased withdrawal should be agreed between the child/young person/parents and MDT, and consideration given to a timeframe of 6-8 weeks depending on circumstances. Individual circumstances may require a longer phased withdrawal and should be discussed as part of the process including risk mitigation. (See Appendix 1). The step-down should include social care and education individual assessments where necessary to consider any amendments to their input. The process will include a care plan that details how the child or young person's health needs are to be met, and by which service, when the continuing care/complex needs package has fully withdrawn, there should be coordination between services to ensure smooth transition.

3.8.11. In the case of a retrospective review being required as the result of a complaint, appeal or Ombudsman directive, the CYPCC team will follow the retrospective review process.

3.8.12. The allocated CYPCC Nurse Assessor will notify the Nurse/Lead Health Professional to carry out the review in line with the agreed timescales (or conduct this themselves, where indicated).

3.9. Funding

3.9.1. Funding arrangements are not part of the assessment or eligibility process and are not included within the recommendations.

3.9.2. The health care elements of traditional home care packages will be arranged by the CYPCC Team. Any social care-funded element will be directly invoiced to the relevant responsible LA. unless there are circumstances why this should not occur. CYPCC team will advise Independent providers of this arrangement. Residential placements will be managed under a separate arrangement and primarily sourced and funded by the LA. Contributions made towards Children in our Care, in residential or therapeutic settings will be provided via a re-charge from the relevant responsible LA to LSC ICB.

3.9.3. A funding split model has been agreed between the ICB and Local Authorities. (See Appendix 21).

3.9.4. The scope of the funding split model is intended to include:

- Children and young people up to 17 years
- New cases as at the date of the pilot, and those with a package of care that is amended to create a new package
- Implementation of the Health Needs Assessment to ensure that all necessary local arrangements are covered
- Implementation of the agreed funding model – a varied split for Lancashire and South Cumbria, including Blackburn with Darwen. ~~and a 3-way split for Blackburn with Darwen~~ (no longer applicable)

3.9.5. The cohort that the funding split pilot relates to is:

- Residential placements and homecare for all compulsory school age children, and for those outside of school age (pre-school and 16+ NEET) who meet eligibility for continuing care/complex needs due to unmet needs
- New cases, and those existing cases requiring a new package of care

3.9.6. The **varied split** allows for 100% of education costs to be met by education ~~within LCC or CCC~~, and for the remaining costs to be split as follows:

- For residential care, social care will meet 2/3rd of the remaining costs, and health will meet 1/3rd of the remaining costs
- For home care, social care will meet 1/3rd of the remaining costs, and health will meet 2/3rd of the remaining costs

3.9.7. For Residential Placements, there may be instances where the child or young person's identified health needs are considered as being met through the commissioned residential service however it is recognised that they may still need a funding contribution for the placement. See Section 5 below.

3.10. Children in our Care - in Residential or Therapeutic Settings

3.10.1. Children and young people are either placed or are about to be placed in a residential/therapeutic environment will need to be assessed for any additional support, above what has already been commissioned from core/universal and specialist/targeted services. If support is required that cannot be met by universal or specialist services consideration should be given within eligibility panel or Individual Funding for Treatments

(IFR) panel to meet these needs via an alternate route. (See Appendix 8).

3.10.2. Those children and young people who are entitled to Section 117 aftercare do not require assessment within the continuing care/complex care remit, as this follows a separate assessment. However, there may be cases where a child or young person requires support under S117 aftercare alongside continuing care/complex care.

3.10.3. The process of continuing care/complex care is followed for those children and young people who are placed, and recommendations made with regards to the type of placement, type of support received and what is needed to meet the child or young person's health and behavioural needs over and above what has already been commissioned as core/universal and specialist/targeted services, by specialist practitioners at the MDT meeting

3.10.4. For those children and young people who are going to be placed in a residential setting, the checklist and Health Needs Assessment should be completed when the child or young person is at an agreed time by the professionals involved in care and support i.e., when the child/young person is at a stable period of time and thought that their level of health can be accurately assessed. This may occur after a period of 'settling in' to the placement. ~~In some cases, the ICB may consider retrospective contribution from the date of commencement of placement if there is substantiated evidence of safe and appropriate provision and effective clinical governance in place. This is determinable on a case-by-case basis.~~ no longer applicable, the ICB have comminated their position on backdated payments to partners in November 2024, these will not be considered. The Crisis Pathway should be referred to in referred for urgent placement, in these cases retrospective funding will not be considered.

3.10.5. The CYPCC Team must be informed in advance or within 24 - 72 hours of any new placement and any significant issues occurring within that placement. The service will require new or revised plans of health/behavioural management and short/long term outcomes, to ensure safe and appropriate support is being provided. The residential setting will need to liaise with 'health/behavioural specialists' to ensure the needs are reviewed which may mean changes to provision of care/strategies.

3.10.6. The Local Authority will work closely with CYPCC Team to ensure the transfer of information within 5 working days of any new placement. This information includes but is not limited to:

- Staff ratios
- Care and support plans for health/behaviours
- Risk assessments (see Appendix 1)
- Incident report logs
- Any new review from NHS or other Specialist Services

3.10.7. Any revision to costings in relation to additional health or behavioural requirements within the placement setting will be discussed within panel

3.10.8. A child or young person may be placed in a therapeutic environment. A therapeutic

environment is defined as:

- Residential setting which provides access to therapeutic interventions focussed on developing more secure attachment and supporting children in working through trauma.
- An environment where therapeutic support is provided by a qualified professional registered with a recognised professional body
- A setting where all staff have an evidenced knowledge of attachment and trauma, and a therapeutic care model is in use that informs how care and parenting needs to be adapted for children who have insecure attachments and have experienced trauma – care focusses on initially building relationship rather than changing behaviours.

This list serves as a basic set of requirements to achieve the appropriate clinical governance required from a health perspective, and additional general governance from a children's social care requirement. Each Child and Young Person is considered as an individual with the specific therapeutic approach having been indicated by the Professional/Clinician treating the patient at time of referral, or at a time of crisis, or otherwise.

- Care staff have regular access to clinical supervision/consultation that has the aim of supporting the carer in providing the above in line with the Children's Home Regulations 2015
- Supervision records are kept
- Staff training requirements are met, and attendance is recorded in line with the Children's Home Regulations 2015
- There are individualised patient assessment and review reports, with health plans based on assessment of need with measurable outcomes.
- Daily logs of behavioural/mental health behaviours where escalation plans have been used, and their effectiveness
- Ofsted rating of Outstanding or Good
- CQC registration as appropriate
- Stability of staff team and residents

Funding start date will be from the date of receipt of **al**l costs and due diligence/clinical governance information (as communicated by the ICB in November 2024)

4. Risks in Relation to Care Package Provision

(Home care and residential/therapeutic/educational – denoted as placement)

4.1. All home care packages must have contingency plans in place, in the event of:

- Provider failure
- Sickness or incapacity that effects the person to exercise the Parental Responsibility

4.2. Contingency plans need to be established within plans of care and risk assessment, and agreed between parents, the child or young person, and multi-agencies. In exceptional circumstances other options are explored to provide care to the child or young person, which may include wider family members and friends or informal family support, or

network/commissioned providers.

4.3. The hospital setting is not seen as a contingency arrangement, unless the child or young person's health needs warrant hospital review or admission.

4.4. The CYPCC Team will endeavour to commission appropriate homecare packages in a timely manner. However, despite best efforts, there may be a delay, for example the inability to recruit care staff, or the inability to access specific training.

4.5. For those families who have significant gaps in provision from bespoke commissioned providers, interim alternative provider support will be considered on a case-by-case exceptional basis.

4.6. In the event of unforeseen circumstances, such as when the commissioned continuing care/complex care provider cancels a shift, the expectation is that parents/carers have the responsibility to ensure that the needs of their child/young person are met. It is therefore important that parents/carers maintain their own competencies to care for their child or young person 24 hours per day.

4.7. In circumstances of several missed shifts, the CYPCC team will discuss care package arrangements with the provider, and review sustainability of the provision. Steps may be taken to commission an interim provider due to significant gaps in care provision. This will be discussed and agreed on an individual basis.

4.8. In the case of residential/therapeutic placement breakdown, the CYPCC team will need to be informed of the new placement within 24 hours by social care. CYPCC team will request the necessary clinical governance/information for the new provider from the Lead Health Professional.

4.9. It is expected that the relevant information will be transferred within 5 working days of new placement. This information includes:

- Registration of the residential placement and inspection reports
- Staff ratios
- DBS checks
- Staff training and supervision
- Care and support plans
- Risk assessments
- Incident reports
- Education Health Care Plan

4.10. Placement cost will be required, although this is not a pre-determining factor for decision-making.

4.11. The updated information will be taken to the subsequent joint panel for discussion and ratification

5. Reporting and Gap Analysis

~~5.1. LSC ICB will provide monthly reports to the Clinical Commissioning Groups to identify type and amount of caseload pertinent to each Clinical Commissioning Group.~~

5.2. The MDT and/or the eligibility panel will identify gaps in service provision in relation to localised service commissioning, any gaps identified will be escalated to the ICB for further discussion. This might be where eligibility criteria are not met and there are demonstrable needs which cannot currently be met by universal or specialist services, nor can they be met through Local Authority provision.

6. Fast-track (End of Life)

6.1. If the child or young person has end of life needs that cannot be met by the routine services available, the fast-track process will be followed. (See Appendix 6). The request will be acted on normally within 24 hours of receipt of fast-track document and supporting information (during office working days).

6.2. Children or young people who meet the criteria for children's end of life/palliative care nursing should receive that service and do not need to go through the Health Needs Assessment process. In any circumstance continuing care/complex care should not replace existing NHS services that can meet a child or young person's end of life needs.

6.3. The fast-track document is completed by the Lead Health Professional working with the child/young person who they believe may have end of life needs. The Lead health professional should collate the relevant supporting evidence in relation to the end-of-life health care needs for the CYPCC team at LSC ICB to commission the appropriate support. This information includes an advanced care plan/Respect Document.

6.4. If the child or young person has needs that cannot be met by the available service, a Fast-Track continuing care process should be followed, and document completed.

6.5. The CYPCC team will collate the Fast-Track document and relevant information and seek an out of panel agreement (depending upon the costings and scheme of delegation) for an end-of-life care package, and thereafter place the case on the next panel agenda for update/review as required.

6.6. The CYPCC team will discuss jointly with Local Authority with regards to decision-making for those cases who are jointly managed.

6.7. Where possible a Health needs Assessment will require completion at 3 months after commencement of a fast-track package of support, to determine the ongoing care provision and remain under constant review by the Lead health professional/ MDT involved. This will be handled in a sensitive manner in consideration of the circumstances.

6.8. For those children and young people who are known to continuing care/complex care a Fast-Track document will not need completing, and a review of needs should describe the changes and what additional/alternate provision is required

6.9. Fast track cases will be standard agenda items on all panel meetings.

6.10. Universal/core and specialist services should be involved where necessary

7. Urgent Decision Making (Complex Cases Requiring Urgent Placement, Treatments and Therapies)

7.1. Decisions of an urgent nature in relation to a child or young person requiring residential placement, will be made in accordance with the presenting individual child or young person's needs, and the evidence of safe placement and clinical governance in place to support those needs.

7.2. A child or young person requiring urgent placement, treatments or therapies will follow the Decision-Making guidance (See Appendix 18)

~~7.3. In some cases, the responsible CCG will need to be consulted in line with the scheme of delegation to contribute towards residential placement on an urgent basis. In these circumstances the CCG (LSC ICB acting on their behalf) will still require the necessary quality assurances prior to contribution.~~ CCG is obsolete, no alternative process is agreed

7.4. Generally, treatments and therapies should not be required on an urgent basis. A proforma will require completion by an **NHS health professional** outlining the requirement for treatment or therapy. The proforma will be reviewed by the CYPCC Team, and process followed to agree funding (occurring within 5 days). Exceptionality will apply for cases that present in an unusual manner requiring urgent decisions, and where necessary escalated to the ICB Executives ~~responsible CCG~~ for advice.

~~7.5. In some circumstances the responsible CCG may be contacted prior to, and outside of the continuing care or complex care process being instigated, due to a lack of specialist health professionals involved in a child or young person's care. In these instances, the CCG may need to commission specialist health professionals separately, in order to provide specialist assessment of needs and provide plans and management of care, and where feasible support the LA in identifying appropriate placements, to meet the individual child or young person's needs.~~ CCG is obsolete, no alternative process is agreed

8. Special Educational Needs and Disabilities

8.1. The Education Health Care Plan 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.

8.2. Where possible the Education Health Care Plan assessment and continuing care/complex care assessment process will be brought together to identify needs and how the needs and related outcomes can be met. The health needs of children and young people should be reflected in the Education Health Care Plan. The same information should be utilised, and professionals should be involved in either or both processes, and it is recognised that there may be an overlap in the collation of information and assessments. Repetition should be avoided.

8.3. If a child or young person does not have an Education Health Care Plan, an Individual Care Plan (ICP) should be in place in the education setting, addressing, and providing plans of care for the health needs identified.

9. Transition

9.1. Lancashire and South Cumbria has a 'plan on a page' for the development of transition arrangements. This approach will be used for the process of transition from continuing care/complex (children's care) to continuing healthcare (adult care).

9.2. Transition arrangements should commence at the age of 14. Where a young person does not have a transition plan in place after their 15th birthday then arrangements will be put in place as quickly as possible, and no later than the next review of the package of care.

9.3. The case-holding nurse within the CYPCC team and relevant adult continuing health care CYPCC Nurse Assessor are responsible for the timely co-ordination of transition continuing care/complex care to adult continuing health care (CHC) and for inviting relevant professionals to the transition meetings.

9.4. Adult CHC nurses will be involved in the review of the package of care at the review of the package of care around the young person turning ~~14~~ 16 years of age, or at the next review.

9.5. At an appropriate time agreed with the young person and their family, and no later than the review of the package of care on or around the young person's 17th birthday, the Adult nurse completes the adult Decision Support Tool (DST) Health Needs Assessment in order to identify the required long-term planning.

9.6. If the young person does not meet eligibility for adult CHC nor is identified to require a 'joint funding arrangement' in adulthood, the CCNA will continue to work with children's health services to aid transition of the young person over to the universal and specialist services. It is the responsibility of children's services to liaise with the corresponding adult service to aid smooth transition into adult health services. The transition process will co-ordinate with education, utilising the young person's Education Health Care Plan (where applicable), and additionally have engagement from Social Care (where relevant), through the process. Each agency will be responsible for assessing needs moving into adulthood but working jointly to provide a seamless approach through process. The transition pathway commences at the age of 14.

9.7. At **14** years of age, the young person is brought to the attention of adult CHC as likely to need an assessment for NHS Continuing Healthcare.

9.8. At **16** -**17** years of age, screening for NHS Continuing Healthcare is 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 CHC.

9.9. From **17** years of age, all risk assessments, incident forms and behaviour plans are maintained to inform social care and subsequent CHC funding applications.

9.10. At **18** years of age, full transition is made to adult CHC or to universal and specialist health services, except in instances where this is not appropriate.

9.11. Future entitlement to adult CHC or 'joint funding arrangement' should be confirmed as early as possible in the transition planning process, especially if the young person's needs are likely to remain at a similar level until adulthood, and this should be accomplished by undertaking an initial screening for CHC at a suitable point around the time of the young person's 14th birthday, and again at the young person's 17th birthday.

9.12. It is recognised that many children and young people with continuing care/complex care needs are dependent on others for all their care throughout their lives. There are those, however, with the capacity to develop independence, and continuing care/complex care team will support this transition and preparation for adulthood, enabling the young person to manage their condition with a full understanding of its implications for their overall health and wellbeing.

9.13. A key aim of the management of the transition period is to ensure that a consistent package of support is provided during the years before and after transition to adulthood. The nature of the package may change because of the change in circumstances for the young person however, this change shouldn't occur purely because of a move from children to adult services. Where change is necessary, it will be carried out in a phased manner in full consultation with the young person or their advocate/parents.

9.14. Every young person with a package of continuing care/complex care who is approaching adulthood will have a multi-agency plan and/or an Education Health Care Plan. The documents will be used to detail their needs and expected outcomes throughout the transition pathway. Every effort is made by all agencies to identify young people who are potentially in need of on-going services in adulthood as early as possible. This includes children placed out of area in placements.

9.15. Where a young person is not in receipt of a continuing care/complex care package (not held within the caseload), usually because their needs are being met from within children's social care and it is believed that they may be eligible for CHC, then the young person's most appropriate health professional or social worker will refer the young person to the CHC Team.

9.16. From 17 years and 9 months, all new referrals that are not known to continuing care or complex cases will go directly to the CHC Team (unless exceptional circumstances prevail i.e., require a package of support prior to 18th birthday). For young people under the age of 17 years and 9 months a referral to the CYPCC Team will be appropriate.

9.17. Where a young person is referred to the CHC Team and is found to be eligible for CHC or joint funding, a retrospective payment may be considered from the age an adult Health Needs Assessment was completed. CHC has its own eligibility date criterion that needs adhering to. This section is not in line with Adult CHC policy

9.18. Transition plans will set out clearly who is responsible for what and why. In some cases, a service which is provided for children and young people may not be available from their 18th birthday. If this poses a risk to the young person who is reaching adulthood then the ICB will be informed, and the case will be addressed accordingly by them.

9.19. It is important that a child or young person is listened to, and all necessary steps are

taken to facilitate them in communicating their aspirations, views, and opinions with regards to their future. In those cases where the child is unable to express their views their parents or advocates must do this on their behalf, acting in their best interests. The principles of the Mental Capacity Act must be observed for those young people aged 16 and over, and where necessary the relevant assessments carried out by relevant member/s of the MDT.

10. Panel Member Disputes

10.1. Disputes between panel members are expected to be few in the context of this protocol, particularly in the context of full assessments being undertaken, and using the agreed funding split model.

10.2. The underlying principles of resolving inter-agency disputes are:

- Formal disputes should be the last resort and will seldom be necessary.
- The development of a culture of problem solving and partnership will be fostered.
- MDTs should endeavour to resolve issues at the frontline practitioner level wherever possible and should not be encouraged by either party to escalate the decision-making to more senior people who have 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 eligibility panel) who will work collaboratively to agree a resolution of the issue with their counterparts.
- The Child or Young Person or their family should not be involved in the dispute in any way. In cases of dispute, they will be informed that there is a delay and will be advised of the likely timescale.
- Children/ young people should always be cared for in a safe and appropriate environment throughout the process.

10.3. Where a dispute does arise between health and the local authority that cannot be resolved through discussion between the representatives on the eligibility panel, then the matter will be escalated utilising the agreed disputes process. (See appendix 14).

10.4. The dispute will not affect the provision of care for the Child or Young Person and their family, and the existing funding arrangement and support will continue to be provided until the dispute is resolved, and any recharge that is due to either agency will be made from a date that is agreed within the dispute process.

11. Clinical Governance (Training and Competency Oversight)

11.1. The CYPCC team will provide training for all relevant staff across the local authorities, and provider organisations who are involved in the process of delivering continuing care/complex care. This training is delivered at least once each month to those staff who require it.

11.2. The CYPCC team will have access to and full awareness of evidence-based training and

competency for carers (irrespective of speciality or setting) to ensure clinical governance is in place in relation to providers commissioned to deliver packages of care.

11.3. It is the responsibility of qualified health professionals to ensure that any delegated care tasks are safely delivered, by trained and competent care workers. Qualified nurses must adhere to relevant guidance and instruction i.e., Royal College of Nursing (Accountability and Delegation 2018), (Meeting health Needs in Education and other Community Setting 2018).

11.4. For practical purposes, ward-based staff should handover care of children with complex health needs to community nurses, ensuring that they are trained in the use of any medical equipment and are competent to meet the clinical need.

11.5. Community nursing teams or tertiary centres will ensure that parents and informal carers are trained and competent to provide the care assigned. The community nursing teams will also ensure that school staff based in education facilities have the appropriate training and are competent.

11.6. Where a package of support is purchased from an independent agency or NHS provider, it is the responsibility of that provider to ensure they have the facilities to provide training and deem competency. These measures will be sought during the procurement phase.

11.7. The parents of a Child/Young Person found to be at risk because of inadequate training by a care worker will be informed that the care worker will cease provision until such time as they are trained and competent. Additionally, if the parent or carer is not trained and competent in carrying out health tasks, an urgent referral will be made to secure training, and where appropriate safeguarding procedures instigated.

12. Complaints and Appeals

12.1. If the child/young person or parents wish to complain about the continuing care/complex care **process** (for example regarding the time taken to reach a decision or to deliver a community support package), rather than about the decision itself, the matter should be dealt with through the internal LSC ICB complaints process. The family are provided with details of how to appeal within the panel outcome letter, which also provides a timeframe to appeal within.

12.2. When the child/young person or parents wish to appeal the **decision** regarding continuing care/complex care provision or appeal against any other alternative decisions made in panel the internal LSC ICB complaints process will be followed. The family are provided with details of how to complain within correspondence sent from the CYPCC team at LSC ICB.

Appendices

Local Arrangements		Document
1	Equality impact risk assessment	Equality Impact Assessment V1.pdf
2	Terms of Reference continuing care/complex care multi-agency panel	CC Panel TOR 2022 v5.pdf
3	Health needs assessment and consent form	Children and Young People HNA v4.docx CONSENT FORM v2.docx
4	Pre-Assessment checklist	Children_and_Young _People_Checklist v4.(
5	New quality assurance form	CYP New Referral Quality Assurance For
6	Fast track document for end-of-life care	Children and Young People Fast Track v4.(
7	3 Month proforma review	3 Months Review Proforma BLANK 202
8	Treatments and therapies proforma	CYP Treatments & Therapies Requests Pı
9	Continuing care/complex care leaflet	Continuing Care Leaflet for parents.pdf
10	Continuing complex care flowchart	Contining_Complex Care Flowchart.pdf

11	Continuing care/complex care appeals/complaints leaflet	Complaints Flow Chart Lancs.pdf Continuing Care Appeal Leaflet Lancs.p
12	Continuing care/complex care local offer information	CYP Continuing Care Complex Care Local C
13	Appeals process	Local Appeal Process.pdf
14	Disputes resolution	Disputes Resolution Protocol V1.pdf Stages of Resolution.pdf
15	Clinical governance guidance for personal health budget arrangement	Personal Health Budgets.pdf
16	Clinical governance guidance for complex care, home and education settings	Clinical Governance Requirements for Con
17	Clinical governance guidance in residential placement	Clinical Governance Requirements Res_Th
18	Urgent decision-making guidance (Looked after Children in residential placement, and treatments and therapies)	
19	Pre-Assessment pathway flowchart	Pre-Assessment Pathway for CYP.pdf
20	Interagency pathway for children and young people's continuing care and complex care	Pathway for CYP.pdf
21	Funding split model	Funding Split.pdf
22	Weighting model	Weighting Model for the DST_HNA.pdf

23	Transition pathway flowchart	Transition Pathway flowchart v2.pdf
Statutory Documents/National Guidance/Local Documents		**Link to documents**
1	Children and Young People's Continuing Care Framework (2016)	**LINK**
2	Home to School Travel and Transport: Statutory Guide for Local Authorities 2014	**LINK**
3	Safeguarding Children and Young People: Roles and Competencies for Healthcare Staff Fourth edition 2019	**LINK**
4	Meeting Health Needs in Educational and other Community Settings: A guide for nurses caring for Children and Young People	**LINK**
5	Managing Bowel and Bladder Problems in School (2019)	**LINK**
6	Working Together to Safeguard Children 2018	**LINK**
7	Who Pays? Determining Responsibility for payments to Providers 2020	**LINK**
8	Delegation of healthcare tasks to personal Assistants within Personal health budgets and Integrated Personal Commissioning (2017)	**LINK**
9	Supporting pupils at school with medical conditions Statutory guidance for governing bodies of maintained schools and proprietors of academies in England (2015)	**LINK**
10	Guidelines for Nasopharyngeal Suction of a Child or Young Adult	**LINK**
11	Recommendations for Paediatric Respiratory Physiotherapy Care of the Complex Child in the Community	**LINK**
Local Documents/Processes/Guidance		

13	Direct Payments (Lancashire County Council)	LINK
14	Direct Payments (Blackburn with Darwen Borough Council)	LINK
15	Direct Payments (Cumbria County Council)	LINK
16	Transition Pathway, Preparing for Adulthood (Lancashire County Council)	LINK
17	Transition Pathway, Preparing for Adulthood (Blackburn with Darwen Borough Council)	LINK
18	Transition Pathway, Preparing for Adulthood (Cumbria County Council)	LINK
19	Personal Health Budgets (Lancashire County Council)	LINK
20	Personal Health Budgets (Blackburn with Darwen Borough Council)	LINK
21	Personal Health Budgets (Cumbria County Council)	LINK