



LINCOLNSHIRE

Children & Young People's

Continuing Care Policy 2020

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Continuing Healthcare Service

Date: 5th June 2020

V3 Final

Approval Date: 27/10/2020

Review Date: 27/10/2022

POLICY DEVELOPMENT PROCESS

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Policy Ratification

Committee/Group		Status
Children's Continuing Care Team		Complete
Executive Groups & Forums		Complete
CHC / PHB Programme Board		Complete
Quality and Safety Forum		Complete
Joint Children's Panel LCC / LCCG		Complete

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1.0 Introduction

- 1.1 In March 2010, the Department of Health published the Framework for Children and Young People's Continuing Care, which provides guidance for clinical commissioning groups (CCGs) when assessing the needs of children and young people whose complex needs cannot be met by universal or specialist health services.
- 1.2 The Guidance incorporated the new structures of NHS commissioning created by the Health and Social Care Act 2012, the new integrated approach to the commissioning of services for children with Special Educational Needs and Disability (SEND) which the Children and Families Act 2014 has introduced, and the changes to adult social care introduced by the Care Act 2014. The Guidance published and which all CCGs adhere to is the 'National Framework for Children and Young People's Continuing Care 2016' (referred to throughout this Policy as 'the Framework').

The Framework can be found at:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/499611/children_s_continuing_care_Fe_16.pdf

- 1.3 All health professionals working directly with children and young people should ensure that safeguarding and promoting their welfare forms an integral part of all elements of the care they offer (Working Together, 2018). Staff must comply with the organisations safeguarding policies and procedures.
- 1.4 The National Framework is intended to provide guidance for the CCG to help the children's continuing care service in meeting the complex health needs of children and young people. It includes the framework for assessing children and young people's continuing care needs, e.g. those which cannot be met by universal or specialist health services. It also provides advice more generally for commissioners on meeting the needs of children with physical or learning disabilities.
- 1.5 This document describes the Lincolnshire CCG's policy by which children and young people with complex health needs are assessed using the principles established in the Framework. It supports partnership working between

2 Purpose

The purpose of this policy is to establish the Lincolnshire CCG staffs responsibilities in meeting the continuing care needs of children and young people, and to set out the process for assessment and eligibility of children and young people who may have continuing care needs.

3 Scope

3.1 This policy applies to children and young people from birth up to their eighteenth birthday with complex health needs, who may require additional support that is not available through universal, targeted or specialist services and who are registered with a Lincolnshire GP. The policy has been developed in partnership with the Local Authority. Children and Young persons who have been fostered out of County and whose care remains under the Local Authority, responsibility will continue to be under Lincolnshire CCG.

3.2 This framework covers young people up to their 18th birthday. Thereafter, the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care 2018 (*Revised*) and the supporting guidance and tools should be used.

These can be found at: <https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care#history>

3.3 Although a child or a young person may be in receipt of a package of continuing care, they may not be eligible for NHS Continuing Healthcare or NHS-Funded Nursing Care once they turn 18 years of age. A young person who has not been eligible continuing care pre 18 may be eligible for NHS funded nursing care .

4 Definitions

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

4.2 Continuing care for children and young people is needed where a child or young person (18 or under) has

complex health needs which may require additional health support, other than that which is routinely available from health services, and which is commissioned by clinical commissioning groups (CCGs) or NHS England. It has

been defined in recent regulations as:

- 4.3 A package of care which is arranged and funded by a relevant body for a person aged under 18 to meet needs which have arisen as a result of disability, accident or illness (The Framework).
- 4.4 Where a child or young person has needs that require the input of end of life (EOL) services, children will have input from palliative services, but End of Life services are not conditional on EOL assessment. For Lincolnshire local offer for children and young people with palliative care needs see website:- <https://lincolnshire.fsd.org.uk>
- 4.5 Children and young people who require fast-track assessment because of the nature of their needs (such as a palliative care need) should 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 to meet their needs.

5 Roles and Responsibilities

- 5.1 CCGs are responsible for establishing and managing appropriate governance arrangements for the process. The Clinical Lead for Continuing Health Care and Continuing Care has responsibility for continuing care for children and young people, who ensures there is effective liaison with the local authority and other partners, as well as the effective management of the process.
- 5.2 The appropriate care of children with profound multiple disabilities or chronic severe illness generally involves input from all statutory agencies: Health, Social Care and Education. High quality care for this small, but highly complex group of children depends on timely, comprehensive interagency assessment and co-ordination of services.
- 5.3 Parents have the primary responsibility for the care of their child with statutory agencies supporting them to meet the child's identified outcomes. Continuing care assesses and supports parents/main carer with delivery of identified health outcomes for the child. We work closely with the local authority who are responsible for assessing social care and education requirements.
- 5.4 Integrated Education, Health and Care plan (EHC plan) brings together a child or young person's education,

health and social care needs into a single, legal document.

5.5. EHC plans are for children and young people aged up to 25 who have special educational needs and disability

and who need more support than is available through the graduated response from their pre-school, school or college establishment.

5.6 EHC plans must specify the outcomes sought for the child or young person. EHC plans should be focused on education and training, health and care outcomes that will enable children and young people to progress in their learning and, as they get older, to be well prepared for adulthood. EHC plans can also include wider outcomes such as positive social relationships and emotional resilience and stability. Outcomes should always enable children and young people to move towards the long-term aspirations of employment or higher education, independent living and community participation.

5.7 The new arrangements for children with SEND in particular provide a framework for outcomes-focused joint assessments EHC plan involving different partners across Education, Health and Social Care, and many children and young people who need continuing care will have special educational needs or disability. There may be common elements to both the continuing care assessment and the EHC plan and where appropriate there should be joint working to bring together a single set of outcomes for the child or young person.

6 Continuing Care Process (Appendix 1)

6.1 The continuing care assessment gathers information to provide a holistic picture of the needs of the child/young person and the family in order to support partnership working. Continuing care eligibility is determined by the presenting health needs, their level of complexity, and whether existing services can meet the identified outcomes. Diagnosis of a disease or a particular condition is not in itself a determinant of a need for continuing care. Continuing care should be part of a wider package of care agreed and delivered by collaboration between Health, Education and Social Care, to meet identified outcomes.

6.2 The Children's Continuing Care team is responsible for leading the continuing care process, while recognising the individual may require services commissioned by the NHS, local authority and other partners. Each agency is responsible for commissioning and funding their own contributions to the continuing care package, in line with their statutory functions. The co-ordination role of the Children's Continuing Care Service will ensure that all agencies work together to provide seamless care for a child and their family.

6.3 All enquires relating to children with complex needs, or continuing care needs, or referrals for continuing care assessment will be directed to the Children's Continuing Care Service at lccg.continuingcare@nhs.net who will act as the single point of contact.

7 Identification

- 7.1 The continuing care process begins with the recognition that a child or young person may have need of additional health services. Referrals can be made by a variety of professionals, including professionals in primary, secondary and tertiary care, Child and Adolescent Mental Health Services, community nursing teams, local authority-commissioned public health, school nursing and also education and social care
- 7.2 Professionals in these settings should also be able to provide evidence on a child's needs to inform the continuing care assessment. The CCG have a clear local process for submitting both requests for a continuing care assessment, and for submitting professional evidence – Appendix 1 & 2 pathway and referral document.
- 7.3 Clear information is available to the child or young person and their family on the process and timescales, the roles of the nominated children and young people's health assessor and decision-making panel.
- 7.4 The consent of the child or young person, or more usually their parents, must be sought. It should be made explicit to the individual that this consent includes the sharing of personal information between different professionals and organisations involved in their assessment or delivery of care.
- 7.5 A pre-assessment referral and checklist is completed following identification of a child/young person.
- 7.6 A decision on whether or not a child should proceed to a formal assessment will be made within two working days and must be robust, fully documented and agreed in line with the commissioner's continuing care governance arrangements. It is likely that a relatively quick paper-based assessment will give a suitable indication if a child or young person should proceed to a full assessment. In cases where there is doubt, at the pre-assessment stage, then a full assessment may be undertaken depending on sufficient evidence.
- 7.7 The child or young person and their family being considered for continuing care must be fully involved in the process. Their views should be documented and taken into account, and considered alongside the benefits and risks of different types of provision as part of their assessment.

8 Referral (Appendix 2)

- 8.1. Referral to the CCG for continuing care assessment will be made when a need has been identified that cannot be met through universal, targeted or specialist services and where needs are such that they can only be met through a package of continuing care. Consent from a young person or parent must be obtained to refer to continuing care, including consent for referral to social care so that a Social worker can contribute to the Decision Support Tool (DST) and if appropriate undertake a social care assessment if required and appropriate. If the referral has been initiated by social care, this will not be required. Consent from a young person or parent or person with parental responsibility must also be obtained to access professionals caring for the child to provide reports for the assessment. Where the views of the child or young person are different from those of their family, the possibility of advocacy should be discussed.
- 8.2 Referrals should be made on the current referral form (appendix 2) and contain all the additional information to support the referral. This must include as appropriate, a Nursing Assessment, Specialist Nurse Assessment, School Nurse report, medical information, Child and Family Assessment and EHC Plan. Referrals will not be accepted unless all the required information accompanies the referral form.

9 Fast Track

- 9.1 Children who require fast-track assessment because of the nature of their needs, i.e. palliative care needs should be identified as early as possible and the child or young person's needs met as quickly as possible. The Continuing Care process must not restrict access to end of life care for children and young people who require immediate support over a shorter period and must not result in any delay to appropriate treatment or care being put in place. This is in line with the Framework and within which the Lincolnshire CCG operates.
- 9.2 Cases who are being 'fast tracked' for end of life care are not required to have an assessment before referral to the CCG. In these cases the Fast Track Consideration page must be completed on the Children and Young People's Continuing Care referral and pre-assessment checklist form including a brief outline of reasons for the fast-tracking recommendation if the child or young person meets the following criteria:

'have a health need arising from a rapidly deteriorating condition which may be entering a terminal phase, with an increasing level of dependency'

In such cases a decision made within 24 hours by the CCG. At the first review at 6 weeks a decision will be made whether to progress to a full assessment based on the child's presenting needs.

9.3 In Lincolnshire, the Children's Specialist Palliative Care Team (PATCH team), which is an element of the Children's Community Services, currently provides respite home based nursing care to children and young people with deteriorating life-shortening (life-limiting) condition and who are approaching End-of-Life.

For criteria to the 'Children's Palliative Care Team – Short Breaks' service, see appendix 3.

9.4 Continuing Care support is available to support those children and young people with highly complex healthcare needs that cannot be met by respite home based nursing care alone and require referral to specialist Hospice.

9.4 In cases when urgent decisions (non-fast track) are required and where waiting for a recommendation at the Children's continuing Care Panel, the Clinical Lead will make a decision if a child or young person meets eligibility for continuing care services. These decisions will then be presented at the next Children's Continuing Care Panel to ratify the recommendation or at the CCG panel for sign off of the decision.

10 Assessment

10.1 The allocated children and young people's health assessor should be a registered nurse with the relevant skills and competencies to undertake children's health / continuing care assessments.

10.2 The decision to proceed to a full assessment should be documented and it is from this point that timescales will apply – see pathway and timeline appendix 1.

10.3 Consent from a young person or parent should always be gained prior to commencing an assessment.

It should be made explicit to the individual as for what their consent is being sought, including the sharing of personal information between different professionals and organisations involved in their care. If a young person, or those responsible for them, does not consent to an assessment of eligibility for continuing care, the potential effect this will have should be explained to them.

10.4 Once the referral has been accepted, if there is not an allocated social worker, the Continuing Care Team will refer to the appropriate local authority in order to contribute to the assessment. Our local agreement with Lincolnshire County Council is that a social worker will be allocated to attend the DST and at that point social care will agree if a full social care assessment needs to be undertaken. A time and date for a joint visit will be agreed with the family to ensure that the assessment is completed and a decision is made within 6 weeks to

comply with The Framework.

- 10.5 The family will be given a clear timetable with regular updates. If more time is required to undertake this process, the referring party and the family will be informed of this extension, the reasons why and the proposed date of completion.
- 10.6 The child or young person and their family will receive advice and information regarding the continuing care Process via a Lincolnshire CCG Children's Continuing Care Team leaflet at time of booking the full assessment by the Continuing Care Team alongside a blank copy of the DST.
- The new leaflet and information is currently in development*
- 10.7 The assessment will be clear, comprehensive and evidenced based provided from a range of sources that takes into account the child's particular health needs in a holistic and family-centred context and embrace the principles of personalisation.
- 10.8 The assessment must be child centred and include what outcomes the child/young person and their family wish to achieve and how services including health, could support delivery of them. The assessment must identify other elements of support that the child/young person receives. This may include relevant previous assessments. Everyone who contributes to an assessment should be fully aware of its intended use and distribution.
- 10.9 An assessor with the competence to assess the needs of a child or young person with complex physical needs will not necessarily have the competence to assess a child or young person with complex behavioural or emotional needs. The assessor will collate relevant information, and liaise with the appropriate professionals to requests assessments by local authority children and young people's services on behalf of the commissioners.
- 10.10 The nurse assessor is not necessarily required to have the full skills or specific training to provide the specific individual care the child requires, as they are not providing the care. The nurse assessor is required to collate and understand medical evidence and understand the health needs by working as part of a multidisciplinary team.
- 10.11 The following must be considered as part of the assessment:
- Identified health outcomes and preferences of the child/young person and family and how these outcomes can be met.
 - Holistic assessment of the child's/young person's needs, including health reports, social care

assessments including carer assessment, education reports (information from the EHCP).

The local authority will be responsible for assessing and meeting social care and education needs.

- Risk assessments
- Children's DST

- 10.12 Health information must include clinical guidelines or protocols, where the use of technology has been agreed, the rationale for this must be included. Use of technology such as oxygen saturation monitors will only be considered in the assessment when clinically indicated.
- 10.13 The outcome of the continuing care assessment is a recommendation from the multi-disciplinary team (MDT) as to whether or not the child or young person has continuing care needs that cannot be met by existing universal or specialist services. The outcome and recommendation on whether the child or young person meets eligibility for continuing care should include the elements of Risk, Intensity and Complexity and each of these characteristics must, in combination or alone, demonstrate continuing care needs.
- 10.14 The findings from the assessment and supporting evidence, including the social care assessment, should be brought together in a care prescription (appendix 4). The care prescription should clearly identify health outcomes and how the assessed needs will be met, including how universal services meet the needs of the child. Continuing care reviews will measure whether the support is meeting the assessed needs.
- 10.15 The assessment of children and young people for continuing care must take account of safeguarding Policies and legislation, which place a duty on all agencies to safeguard and promote the welfare of children and young people. Exceptionally, information may be withheld from a child or young person or someone with parental responsibility for them if the CCG considers that it would be likely to cause significant harm to the physical or mental health or condition of the child or young person or would otherwise not be in their best interests. Social services should be involved, if they are not already, where it is thought that the child is at risk of significant harm or is suffering significant harm.
- 10.16 The child/young person and their family should be made aware that continuing care support is not indefinite as needs may change. The child/young person who has continuing care funding will be reviewed at 3 months and annually thereafter or when their circumstances are known to have changed. If there has been a significant change a full reassessment is necessary. The Child/Young person and their family can request a review at any time, however the CCG has a right to decline this request if there is no evidence the child or young person's needs have not changed.

11 Decision Making

- 11.1 Following the completion of the assessment, the children and young people's health assessor will produce recommendations for presentation to the Children's Joint Agency Panel (Appendix 5 – *the name to be agreed by the new joint agency panel at first meeting*). The Role of the Joint Agency Panel is to agree eligibility and not to agree the care package itself. They should make a recommendation regarding the care package required. The evidence will be documented and available for the panel to consider. The panel will be independent from those involved in assessment, and include key CCG and local authority professionals, and at least one clinician and social worker or equivalent. The results of the continuing care joint agency panel assessments should be shared with the child or young person and their family.
- 11.2 A decision regarding whether the child or young person is eligible for continuing care will be made by the Joint Agency Panel.
- 11.3 The Joint Agency Panel will have representatives from health and the local authority. The outcome of the panel will be recorded by the JCP Chair and supporting administration.
- 11.4 The recommendation of the panel will be communicated to the child/young person, parents, carers and Professionals involved in the process by the CCG in writing within 5 working days of the decision regarding eligibility being made. This should include a clear rationale for the decision.
- 11.5 Once eligibility has been agreed at the Joint Agency Panel, the CCG director sign off panel have responsibility for agreeing and final sign off of the package of care.
- 11.6 Decisions of the panel will be reported to their respective agencies through their appropriate governance route. The six week timescale will discontinue once health care eligibility is agreed at the joint panel.
- 11.7 Once eligibility has been established and the panel has made a decision, the local authority lead professional (Social worker , ESCO, SEND case worker) will be informed. The lead professionals will follow their own internal processes. If a joint package of care has been approved the lead professional (usually social care) will seek approval for their element of the funding.
- 11.8 Once eligibility has been established and the panel has made a decision, the next step within the CCG is for final sign off of the number of care hours and sign off for funding of the care package; i.e. the recommended care package will be sourced by Continuing care and presented to the CCG's package sign off panel.

- 11.9 A second visit to the family by the nurse assessor will be to complete the care prescription (appendix 4) and care and support plan (appendix 6) to ensure package is meeting goals and outcomes for the child.
- 11.10 The completed care prescription will be provided to the chosen care provider to support the child care plan.
- 11.11 In the event a young person is not eligible for continuing health care the panel can make recommendations and advice and signposting to appropriate agencies who may need to support . This will be documented on the panel log.

12 Resolving Complaints

- 12.1 The CCG will be the first point of contact for all disagreements, complaints or appeals relating to JCP decisions for continuing care.
- 12.2 Where a child or young person is found not to have a need for continuing care, a clear written explanation of the rationale for the decision should be provided to the child or young person and family following verbal notification as above.
- 12.3 A meaningful attempt should be made to resolve complaints through the CCG local resolution and complaints process, usually within a 3 month timescale.
- 12.4 In the first instance it is the Nurse Assessors role to visit the family to review the assessment. If the family wish additional information to be considered the Nurse Assessor will update the assessment and represent at the next Joint Agency Panel for review of the decision.
- 12.5 The child or young person and their family will be informed of their rights and of the complaints procedure in the case of a decision which does not meet their preferences and/or expectations. This forms part of any public documentation on the continuing care process and is included within the published Local Offer of services for children with SEND.
- 12.6 If there remains a complaint in with the review of the decision by panel, the family can request in writing a review of the assessment by a Local Review Panel. This request needs to be made within 2 weeks of the final continuing care panel.
- 12.7 The CCG has arrangements for reviewing assessments or decisions to provide greater confidence in the impartiality in decision-making. Any package of care will remain in place whilst any complaint is ongoing.
- 12.8 The Local Review Panel should generally be convened within 30 working days of the application for a

hearing being received by the case manager. However, appeals for review of eligibility and allocation of care package may require the collection of additional documented evidence, in which case the 30 day limit may be extended after consultation with the parent/carer. The panel will inform the parent/carer of the decision within 10 working days of the panel meeting.

- 12.9 The decision of the Local Review Panel is final.
- 12.10 Complaints relating specifically to service provision should follow the complaints procedure of the relevant organisation.
- 12.11 Complainants who remain dissatisfied may contact the 'Parliamentary and Health Service Ombudsman' (PHSO), to request an independent review of their case. This must be done within a year after the day on which the person aggrieved first had notice of the matters alleged in the complaint, unless the PHSO considers that it is reasonable to review the complaint outside of this timescale.

This request can be made in the following ways: Telephone the PHSO on 0345 015 4033, or submit a complaint via the website:- <http://www.ombudsman.org.uk/make-a-complaint/contact-us>;

13 Review & Reassessment

- 13.1 It is important that the process is transparent, and involvement of the child or young person and their family, is essential to maintain the fairness and consistency of the review.
- 13.2 All continuing care packages will be reviewed on a regular basis. Reviews will identify whether the outcomes in the child's care prescription and care and support plan are being met. The first review should take place at approximately 3 months from the service commencing and yearly thereafter and should also involve the Social Worker if open to social care .
- 13.3 The child/young person and family should be engaged fully in the review process. The child/young person or family can also request a review at any time. Children who have been agreed through the fast track process should be reviewed at six weeks or an appropriate time agreed with the family.
- 13.4 Reviews should respond to changes in a child's or young person's condition. There will be cases where successful management has reduced an ongoing need. Continuing care support is not indefinite as needs may change and this should be made clear to the child/young person and family.
- 13.5 Where the needs have changed and the recommendation is that universal, targeted and specialist services can meet the need, a support plan should be agreed. The family will need to be supported throughout this

- 13.6 The review of the continuing care assessment and recommendation should be discussed with the Social Worker or Lead Practitioner before being presented to the joint agency panel by the Nurse Assessor.
- The panel's decision is confirmed in writing to the family and appropriate others within 5 working days.

14 Transition

- 14.1 As far as possible, the aim of providing a transition period is to support the move from dependence to independence, with children and young people being enabled to manage their condition themselves with a full understanding of the implications of their condition.
- 14.2 Every child or young person with a package of continuing care who is approaching adulthood should have a multi-agency plan for transition. This process may be led by children's social care with the active involvement of the CCG.
- 14.3 The CCG will identify the need for transition of a young person at the age of 16, and Adult Continuing Care services notified.
- 14.4 The CCG will refer the young person for formal screening by Adult Continuing Care services at 17.
- 14.5 At the age of 17 – 17½, adult continuing healthcare should be determined in principle of an individual's eligibility for Adult Continuing healthcare in order that packages of care can be commissioned in time for the individual's 18th birthday.

15 Allocation of Hours

- 15.1 Children who have been agreed as eligible for continuing care services will be able to access personalised health support to meet the outcomes agreed in the child's care prescription. This can be through traditionally commissioned services or through a personal health budget (ref: PHB Policy 03/02/2020)
- 15.2 The health offer includes the total package irrespective of the setting it is delivered in, e.g. a health short breaks services and residential placements for Children Looked After (CLA).
- 15.3 Continuing Care funding may be available for specialist bespoke equipment to meet health needs, that is not available through universal equipment arrangements.
- 15.4 Health support is commissioned from a variety of sources through the CCG Brokerage of private providers (nursing agencies), or through Personal Health Budgets. Health support is delivered by trained carers and only in exceptional and agreed circumstances by qualified staff.

15.5 In the event that a private provider/agency is unable to fulfil the total care package, the staffing hours must be used within any given month and not be banked or be used in future months under any circumstances.

15.6 There may be exceptional circumstances that fall outside of the allocation criteria. Exceptions to the allocation criteria must be agreed by the Lead Commissioner / Clinical Lead for the CCG in the context of the resources available.

16 Personal Health Budgets (Ref: Lincolnshire PHB Policy 03/02/2020)

16.1 Personalisation, the shaping of services around the individual needs and wishes of children/young people and their families, has become central to current health policy. Choice and control through personal health budgets can significantly improve quality of life and lead to improved outcomes for children and young people.

16.2 All children/young person's (or their family) eligible for continuing care will receive information on PHB's from the nurse assessor at the second visit to complete the care prescription and care and support plan. If the family wish to have a personal health budget, options will be explored with parents and nurse practitioner at this visit. *PHB leaflet to be developed for parents, children & young people.*

16.3 There are three ways in which a child/young person can receive a PHB (or a combination of the three):

Notional Budget

Individuals develop their care and support plan with their healthcare professional and are aware of the options and of the financial implications of their choices. The CCG is responsible for managing the budget, retaining all contracting and service coordination functions.

Third Party Budget

An organisation, which is independent of the person, the local authority and CCG, is responsible for ensuring the right care is put in place by working together with the individual and their family. The third party helps the individual to choose services within the budget based on their agreed health and wellbeing outcomes. The third party are required to sign an agreement with the CCG and maintain sufficient records to be able to demonstrate that any monies have been used in accordance with achieving the outcomes agreed in the individual's care and support plan, the costs for this will be incorporated into the PHB budget.

Direct Payment

Individuals develop their care and support plan with their healthcare professional and purchase and manage services themselves as detailed in their care & support plan (See appendix 3 for Lincolnshire's Direct Payment Policy). Where PAs or carers are required, the individual will become the employer and will be fully responsible for ensuring the staff are employed in accordance with employment law. There is a requirement to maintain all records to be able to demonstrate where the budget has been spent. The budget must only be spent in accordance with the budget agreed and signed off by the CCG.

- 16.4 If the family wish to have a personal health budget a PHB request will be sent via the continuing care team administrator to the PHB panel on the CCG proforma. If the plan is agreed the final budget will be confirmed and finance informed.
- 16.5 If a child/young person is no longer eligible for continuing care services their PHB will be removed.

17 Risks

- 17.1 Patient safety Incidents
- 17.2 Funding is made available by the CCG to meet the agreed health outcomes, There may be unforeseen incidences such as inclement weather, pandemic etc, when it may not be possible to fulfil the packages due to the lack of resource from the providers.
- 17.3 Each provider will have a business continuity plan to mitigate risk and continue to meet the clients assessed Needs.

18 Prioritisation of Children

- 18.1 At times, despite best endeavours to deliver packages of care, there will be exceptional circumstances which impact on delivery, e.g. outbreak of flu, COVID 19 or an emergency response such as providing end of life care. In these cases the CCG has endorsed the following approach to prioritisation of existing nursing resources:

- Children whose conditions carry a high degree of clinical risk, such as those children requiring assisted ventilation, or where the clinical situation is unstable or persistently difficult to manage.
- Acute deterioration in condition/terminal stages of illness as identified by medical assessment.
- Potential breakdown of the family unit due to the impact of care responsibilities as identified via a joint

care planning meeting or where several professionals involved in the care are raising serious concerns.

- Marked increase in the need for waking interventions as identified by nursing assessment.

- 18.2 This approach to prioritisation may in exceptional circumstances result in the withdrawal of some existing health support to families currently receiving agreed packages in order that other families may receive some health support, for example to provide emergency support for a child being discharged for end of life care.
- 18.3 In other cases, the families of some newly assessed children who do meet criteria may have their support delayed. This will be kept under constant review by the CCG so that all packages receive a service as soon as it is possible.
- 18.6 The child centred care and support plan should clearly identify outcomes and the support required to deliver the outcomes. Families should have a clear understanding at the outset about the factors which may impact upon delivery of the outcomes.
- 18.7 It is important that parents maintain their competencies for caring for their child during a 24 hour period, as in the event of cancellation of support due to unforeseen circumstances and despite all efforts to provide alternative support, the expectation is that parents will continue to provide the child's care.

19 Quality Assurance

- 19.1 The assessment and provision of children's continuing care is a complex and highly sensitive area which can affect children/young people and their families at a difficult stage of their lives. It is essential that the process is carried out utilising the principles of the 6Cs: care, compassion, competence, communication, courage and commitment and supports individuals, their families and staff to provide the best possible service (NHS England Operating Model for NHS Continuing Healthcare, NHS England, 2015 and The National Framework for Children and Young People's continuing Care 2018 Draft)
- 19.2 **Care.** We need to ensure that the assessment process accurately identifies care needs and that the commissioning of packages of care delivered are of high 15 quality, offer choice and value for money and are focused on outcomes including a positive experience of their care.
- 19.3 **Competent.** Good quality assessments are crucial and should be conducted professionally and with empathy whilst fully informing and involving the individual and their family.
- 19.6 **Communication.** Good communication is central to successful relationships and to effective team working. Involving the child/young person and their family in the process is an essential part of the process.

Good quality accessible information should be available to families.

- 19.7 **Courage.** Most children/young people are dependent on their families to care for their complex health needs and this can lead to families experiencing difficult times. Navigating through processes in order to gain support to do this can significantly add to the difficulties they experience. Courage is needed to explore different ways that packages of care can support children and young people and to work in an open and honest way.
- 19.6 **Commitment.** There is a commitment to a child and family centred approach.

20 Staff Training

- 20.1 Information sessions will be offered to all relevant staff working across NHS Community and Acute providers, and the Local Authority. These will include the clear referral process and pathway linking into the Policy and using the National Framework for Children and Young People's Continuing Care 2016.
- 20.2 It is the CCG expectation that the carers in the packages will be trained and this remains the responsibility of the private provider / agency or if a direct payment is in place, it is the responsibility of the employer.

21 Equality Statement and Monitoring

An Equality Monitoring Form will be used so that equality of opportunity for those found eligible for children and young people's continuing care is monitored. The CCG will report on the number of referrals into the service and those assessed as eligible by protected characteristics annually to identify any issues of accessibility.

Equality Statement

'Lincolnshire CCG aims to design and implement policies that meet the diverse needs of the services, population and workforce, ensuring that none are placed at a disadvantage over others. It takes into account current UK legislative requirements, including the Equality Act 2010 and the Human Rights Act 1998, and promotes equal opportunities for all. This document policy has been designed to ensure that no child or young person receives less favourable treatment due to their personal circumstances i.e. the protected characteristics of their age, disability, gender, gender reassignment, sexual orientation, marriage and civil partnership, race, religion or

belief, pregnancy and maternity. Appropriate consideration has also been given to gender identity, socio-economic status, immigration status & the principles of the Human Rights Act.

In carrying out its functions, Lincolnshire CCG is committed to having due regard to the Public Sector Equality Duty. This applies to all the activities for Lincolnshire CCG including policy development, review and implementation.'

22 References

- Department of Health (DH) (2010) National Framework for children and young people's continuing care. London: Department of Health. Available at:
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GLOSSARY OF TERMS:

Education, Health and Care plan (EHC plan):

An EHC plan details the education, health and social care support that is to be provided to a child or young person who has SEN or a disability. It is drawn up by the local authority after an EHC needs assessment of the child or young person has determined that an EHC plan is necessary, and after consultation with relevant partner agencies.

NHS Continuing Care:

NHS Continuing Care is support provided for children and young people under 18 who need a tailored package of care because of their disability, an accident or illness.

NHS Continuing Healthcare:

NHS Continuing Healthcare is the name given to a package of care that is arranged and funded solely by the NHS for individuals aged 18 and over who are not in hospital but have complex ongoing healthcare needs. It can be provided in any setting, for example in the home or in a residential care home.

NHS England:

NHS England is an independent body, at arm's length to the government and held to account through the NHS Mandate. Its main role is to improve health outcomes for people in England by providing national leadership for improving outcomes and driving up the quality of care; overseeing the 283 operation of clinical commissioning groups; allocating resources to clinical commissioning groups, and commissioning primary care and specialist services.

Parent:

Under section 576 of the Education Act 1996, the term 'parent' includes any person who is not a parent of the child, but has parental responsibility or who cares for him or her.

Parental responsibility:

Parental responsibility is defined under Section 3 (1) of the Children Act 1989 as meaning all the duties, rights, powers, responsibilities and authority which parents have with respect to their children and their children's property. Under Section 2 of the Children Act 1989, parental responsibility falls upon:

- All mothers and fathers who were married to each other at the time of the child's birth (including those who have since separated or divorced)
- Mothers who were not married to the father at the time of the child's birth, and
- fathers who were not married to the mother at the time of the child's birth, but who have obtained parental responsibility either by agreement with the child's mother or through a court order .
- Under Section 12 of the Children Act 1989, where a court makes a residence order in favour of any person who is not the parent or guardian of the child, that person has parental responsibility for the child while the residence order remains in force.
- Under section 33 (3) of the Children Act 1989, while a care order is in force with respect to a child, the social services department designated by the order will have parental responsibility for that child, and will have the power (subject to certain provisions) to determine the extent to which a parent or guardian of the child may meet his or her parental responsibility for the child. The social services department cannot have parental responsibility for a child unless that child is the subject of a care order, except for very limited purposes where an emergency protection order is in force under Section 44 of the Children Act 1989.

Personal Budget:

A Personal Budget is an amount of money identified by the local authority to deliver provision set out in an EHC plan where the parent or young person is involved in securing that provision. The funds can be held directly by the parent or young person, or may be held and managed on their behalf by the local authority, school, college or other organisation or individual and used to commission the support specified in the EHC plan.

(SEND) Special educational needs and disabilities

SEND can affect a child or young person's ability to learn. They can affect their behaviour or ability to socialise, for example they struggle to make friends reading and writing, for example because they have dyslexia ability to understand things concentration levels, for example because they have ADHD physical ability.

APPENDICES

Appendix 1

Childrens Continuing Health Care Pathway & Timeline



CC childrens
pathway timeline (Ap

Appendix 2

Children and Young People's Continuing Care Referral & Pre-assessment Checklist



New referral CYP
(Appendix 2).doc

Appendix 3

United Lincolnshire Hospitals NHS Trust Children's Palliative Care Team - Short Breaks

Criteria for Referral to the Service



Palliative Care
referral criteria (Appe

Appendix 4

Care Prescription - Children and Young People



New Care
Prescription (Appendi

Appendix 5

Joint Agency Panel for Children's and Young People's Continuing Care (DRAFT)



Joint Agency Panel
(Draft) Appendix 5.d

Appendix 6

Care and Support Plan - for Children and Young People



Care and Support
Plan (Appendix 6).do

