



**Barking and Dagenham,  
Havering and Redbridge**  
Clinical Commissioning Groups

# Children and Young People's Continuing Care Policy 2019

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<b>Author:</b>	Paul Archer, Elaine Wynter, Gillian McNeice	
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## CONTENTS

No	Section	Page Number
1	Introduction	3
2	Purpose	3
3	Scope	3
4	Definitions	4
5	Roles and responsibilities	4
6	Continuing Care Process	5
7	Identification	5
8	Referral	6
9	Assessment	7
10	Decision Making	8
11	Resolving Disputes	9
12	Review and Reassessment	10
13	Transition	10
14	Allocation of Hours	11
15	PHB	11
16	Risk	12
17	Prioritisation of Children	12
18	Quality Assurance	13
19	Staff Training	13
20	References	14
21	Equality Impact Assessment Form	15
	Glossary of Terms	16
	Appendix 1: Children's continuing care process	18
	Appendix 2: Referral Form	19
	Appendix 3: End Of Life	24
	Appendix 4: Terms of reference for Continuing Care Panel	25
	Appendix 5: Appeals Process	29
	Appendix 6: Transitions Process	30
	Appendix 7: CCHAT	31
	Appendix 8: Personal Health Budgets process	34

## **1. Introduction**

- 1.1 In March 2010, the Department of Health published the 'National Framework for Children and Young People's Continuing Care'. A revised National Framework was published in 2016, and is currently under revision. (*Supporting Children with complex health needs. The National Framework for children and young people's continuing care*)
- 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 SEND which the Children and Families Act 2014 has introduced, and the changes to adult social care introduced by the Care Act 2014.
- 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 clinical commissioning groups (CCGs) to help them 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 Barking and Dagenham, Havering and Redbridge CCGs policy by which children and young people with complex health needs are assessed using the principles established in revised National Framework 2018. It supports partnership working between the Clinical Commissioning Groups (CCG's) and the corresponding local authorities.

## **2. Purpose**

- 2.1 The purpose of this policy is to establish the BHR CCG's and local authorities responsibilities in meeting the continuing care needs of children and young people, and to clarify the process for assessment and eligibility of children and young people who may have continuing care needs.

## **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 Barking and Dagenham, Havering or Redbridge GP. The policy has been developed in partnership with the three local authorities.  
Children and Young persons who have been fostered out of borough and whose care remain under one of our three local authorities responsibility will continue to be under their respective CCG
- 3.2 This framework covers young people up to their 18<sup>th</sup> birthday. Thereafter, the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care 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 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.

#### **4. Definitions**

- 4.1 There are no clear definitions of continuing care needs but it is generally recognised that they include multiple health needs where care pathways require co-ordination because of the complexity of service provision and input from local authority children's and young people's services.
- 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 18 or under to meet needs which have arisen as a result of disability, accident or illness.' (Revised National Framework, 2018)
- 4.4 Where a child or young person has needs that require the input of end-of life services, children will have input from palliative services, but End of Life services are not conditional on EOL assessment.
- 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. There is a senior member of the CCG organisation with 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 Education, health and care (EHC) plans bring 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 need more support than is available through 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 special educational needs or disability (SEND) in particular provide a framework for outcomes-focused joint assessments (Education, Health and Care Plan, [EHCP]) 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 EHCP, and where appropriate there should be joint working to bring together a single set of outcomes.

## **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, [bhr.childrens@nhs.net](mailto:bhr.childrens@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.

- 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 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 quickly, and must be robust, fully documented and agreed in line with the commissioner's continuing care governance arrangements. This pre-assessment should not take more than a day or two and 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, 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**
- 8.1 Referral to the CCG's 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 joint assessment can be carried out. 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 appropriate referral form (see appendix 2) and contain all the additional information to support the referral. This should include as appropriate, a Nursing Assessment, Specialist Nurse Assessment, School Nurse report, medical information, Initial or Child and Family Assessment, and Education, Health and Care plan (EHCP). Referrals will not be accepted unless all the required information accompanies the referral form.
- 8.3 Cases who are being 'fast tracked' for end of life care are not required to have an assessment before referral to CCG's. (See appendix 3) In these cases a Fast Track Form will be completed and a decision made within 24 hours, at the first review at 6 weeks a decision will be made whether to progress to a full assessment.
- 8.4 In cases when urgent decisions (non-fast track) are required and where waiting for an agreement at the Children's continuing Care Panel. Quality Assurance 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 / Quality Assurance team for ratification.



## **9. Assessment**

- 9.1 The nominated children and young people's health assessor should be a health practitioner with relevant skills and competencies to undertake children's health assessments.
- 9.2 The decision to proceed to a full assessment should be documented and it is from this point that timescales will apply.
- 9.3 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.
- 9.4 Once the referral has been accepted, if there is not an allocated social worker, the Nurse Assessor will refer to the appropriate local authority in order that a joint assessment can take place. A social worker will be allocated within 72 hours. 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 national framework.
- 9.5 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.
- 9.6 The child or young person and their family will receive advice and information regarding the continuing care process.
- 9.7 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.
- 9.8 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
- 9.9 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
- 9.10 The following should 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 Decision Support Tool
- 9.11 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.
- 9.12 The outcome of the continuing care assessment is a recommendation from the assessor as to whether or not the child or young person has continuing care needs that cannot be met by existing universal or specialist services.
- 9.13 Once the continuing care assessment and the social work assessment have been completed, a joint meeting between the Nurse Assessor and the Social Worker will take place to discuss the findings of the assessments and the recommendations.
- 9.14 The findings from both assessments should be brought together in a child centred support plan. The support plan should clearly identify health outcomes and how the assessed needs will be met. Continuing care reviews will measure whether the support is meeting the assessed needs.
- 9.15 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.
- 9.16 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 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.

## **10. Decision Making**

- 10.1 Following the completion of the assessment, the children and young people's health assessor will produce recommendations for presentation to a decision-making Quality Assurance panel. 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. The results of continuing care assessments should be shared with the child or young person and their family. A decision should be made within 6 weeks of the commencement of assessment.
- 10.2 A decision regarding whether a continuing care package is required will be made by the Children's Continuing Care Panel (CCCP) or Quality Assurance team.
- 10.3 The CCCP will have representatives from Health, and the local authority. The outcome of the panel will be recorded by CCCP.

- 10.4 The decision of the panel /Quality Assurance team will be communicated to the child/young person, parents, carers and professionals involved in the process by the CCGs in writing within 5 working days of the decision being made. This should include a clear rationale for the decision.
- 10.5 Decisions of the panel/Quality Assurance team will be reported to their respective agencies through their appropriate governance route.
- 10.6 Once eligibility has been established and the panel/Quality Assurance has made a decision, the social worker will be informed. The Social Worker will follow their own internal processes to seek approval for the social care element of the joint package where appropriate.

## **11. Resolving disputes**

- 11.1 The CCGs will be the first point of contact for all disagreements, disputes or appeals relating to CCCP decisions.
- 11.2 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.
- 11.3 A meaningful attempt should be made to resolve dispute through the CCGs local resolution process, usually within a 3 month timescale.
- 11.4 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 children's continuing care panel/Quality assurance for review of the decision. This will be done within 4 weeks of the CCGs receiving in writing the intention to appeal
- 11.5 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.
- 11.6 If there remains a dispute with the review of the decision by panel/Quality Assurance, the family can request in writing a review of the assessment by an Independent Review Panel. This request needs to be made within 2 weeks of the final continuing care panel or Quality Assurance decision.
- 11.7 The CCGs have arrangements for reviewing assessments or decisions to provide greater patient confidence in the impartiality in decision-making. Any package of care will remain in place whilst any dispute is ongoing.
- 11.8 The Independent 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.
- 11.9 The decision of the independent Review Panel is final.

- 11.10 Complaints relating specifically to service provision should follow the complaints procedure of the relevant organisation.
- 11.11 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>

## **12. Review and Reassessment**

- 12.1 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.
- 12.2 All continuing care packages will be reviewed on a regular basis. Reviews will identify whether the outcomes in the child's support plan are being met. The first review should take place at approximately 3 months from the service commencing and should also involve the Social Worker or Lead Practitioner.
- 12.3 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.
- 12.4 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.
- 12.5 Where the needs have changed and the recommendation is that universal, targeted and specialist services can meet the need, a transition plan should be agreed. The family will need to be supported throughout this transition.
- 12.6 The review of the continuing care assessment and recommendation should be discussed with the Social Worker or Lead Practitioner before being presented to the continuing care panel by the Nurse Assessor. The panel's decision is confirmed in writing to the family and appropriate others within 5 working days.

## **13. Transition (Appendix 6)**

- 13.1 As far as possible, the aim of providing continuing care should be 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.
- 13.2 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 CCGs.
- 13.3 The CCGs will identify the need for transition of a young person at the age of 14, and Adult Continuing Care services notified.
- 13.4 The CCGs will refer the young person for formal screening by Adult Continuing Care services at 16.

13.5 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.

#### **14. Allocation of Hours (Appendix 7)**

14.1 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 support plan. This can be through traditionally commissioned services or through a personal health budget.

14.2 The health offer includes the total package irrespective of the setting it is delivered in, e.g. a health short breaks services.

14.3 Continuing Care funding may be available for specialist bespoke equipment to meet health needs, that is not available through universal equipment arrangements.

14.4 Health support is commissioned from a variety of sources and can be delivered through NELFT, BHRUT, private providers (nursing agencies), or through Personal Health Budgets. Health support can be delivered by qualified staff or trained carers.

14.5 Health support will be based on assessed need and allocated by using the identified allocation of health support tool.

14.6 There may be exceptional circumstances that fall outside of the allocation criteria. Exceptions to the allocation criteria must be agreed by the Lead Commissioner, Children and Maternity Services, for the CCG's, in the context of the resources available.

#### **15. Personal Health Budgets (Appendix 8)**

15.1 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.

15.2 All children/young person's (or their family) eligible for continuing care will receive information on PHB's, including their indicative budget. If the family wish to have a personal health budget, interim support can be arranged until the personal health budget can be set up. At the first review (3 months), personal health budgets will be discussed again to allow the family the opportunity to explore this option for them.

15.3 If the family wish to have a personal health budget a PHB request will be emailed to [phealthbudgets@nhs.net](mailto:phealthbudgets@nhs.net). The type of PHB the family are interested in will also be agreed:

- Direct payment made to the young person or their family.
- The agreement of a notional budget to be spent by the CCG following discussions with the child or young person, and their family (or other representative) as to how best to secure the provision they need.
- A real budget held by a third party agreed as above, to a person or organisation which applies the money in a way agreed between the CCG and the child or young person, and their family (or other representative)
- Combination of the above.

15.4 If the plan is agreed the final budget will be confirmed and finance informed.

- 15.5 If the PHB is a direct payment or budget transfer, the direct payment agreement will need to be signed and the bank account details form completed. Both documents are processed and signed off by finance before the budget can start.
- 15.6 The first review of the PHB is at 3 months from the PHB commencing, this includes a finance review to check that the systems and processes are in place and that financial records satisfactorily meets the requirements of the CCG's. PHB's will be subject to an annual financial audit.
- 15.7 If a child/young person is no longer eligible for continuing care services their PHB will be reassessed, a transition plan should be put into place and should include other options for support.
- 15.8 Under the Children & Families Act 2014, a child/young person with SEND that requires support beyond that available in a typical mainstream school should have an EHCP. The child/young person or parent can request that elements of the EHCP are taken as a personal budget.
- 15.9 Section 11.45 SEN Code of Practice ' the tribunal does not hear appeals about Personal Budgets, but may hear appeals about the special education provision to which a personal budget may apply'

## **16. Risks**

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

## **17. Prioritisation of children**

- 17.1 At times, despite best endeavours to deliver packages of care, there will be exceptional circumstances which impact on delivery, e.g. outbreak of flu, or an emergency response such as providing end of life care. In these cases the CCG's 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.
- 17.2 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.

- 17.3 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 CCGs so that all packages receive a service as soon as it is possible.
- 17.4 The child centred 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.
- 17.5 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.

## **18. Quality Assurance**

- 18.1 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)
- 18.2 **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.
- 18.3 **Competent.** Good quality assessments are crucial and should be conducted professionally and with empathy whilst fully informing and involving the individual and their family.
- 18.4 **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.
- 18.5 **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.
- 18.6 **Commitment.** There is a commitment to a child and family centred approach.
- ## **19. Staff Training**
- 19.1 Information sessions will be offered to all relevant staff working across NHS Community and Acute providers, and Local Authorities.

## 20. References

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Her Majesties Stationary Office (HMSO) (2012) Health and Social Care Act. London: Available at: <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted> (accessed 14/06/2018)

Her Majesties Stationary Office (HMSO) (2018) Working together to safeguard children. London: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/729914/Working\\_Together\\_to\\_Safeguard\\_Children-2018.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/729914/Working_Together_to_Safeguard_Children-2018.pdf) (accessed 24/01/2019)



## Equality Impact Assessment Form - Policy

Equality Impact Assessment Form	
Policy author: Paul Archer/ Elaine Wynter	Date of assessment: 24/01/2019
Title of policy: Children and Young People's Continuing Care Policy 2018	Is this a new or existing policy? New
1. Is there a concern that the policy does or could have a differential impact in any of the following areas?	
	Y/N – delete as appropriate
Age	No
Marriage/civil partnership	No
Disability	No
Religion/beliefs	No
Gender	No
Race	No
Pregnancy/maternity	No
Sexual orientation	No
Gender re-assignment	No
2. If the answer is 'no' for the groups above, please sign and date the form and add this form to the end of the policy.	
3. If the answer is 'yes' for any of the groups above, please explain the reasons and complete box 4 (below). For help please contact the engagement adviser for advice (020 8926 5048).	
4. Are there any additions or actions to be added to the policy which ensure the policy does not have an adverse impact on any of the protected groups? If the answer is "yes", please detail below.	
<b>Signed:</b> Paul Archer (Policy author)	<b>Date:</b> 24/01/2019
Your contact details (department; e-mail; telephone number)	<a href="mailto:paul.archer@nhs.net">paul.archer@nhs.net</a> 020 3182 3144

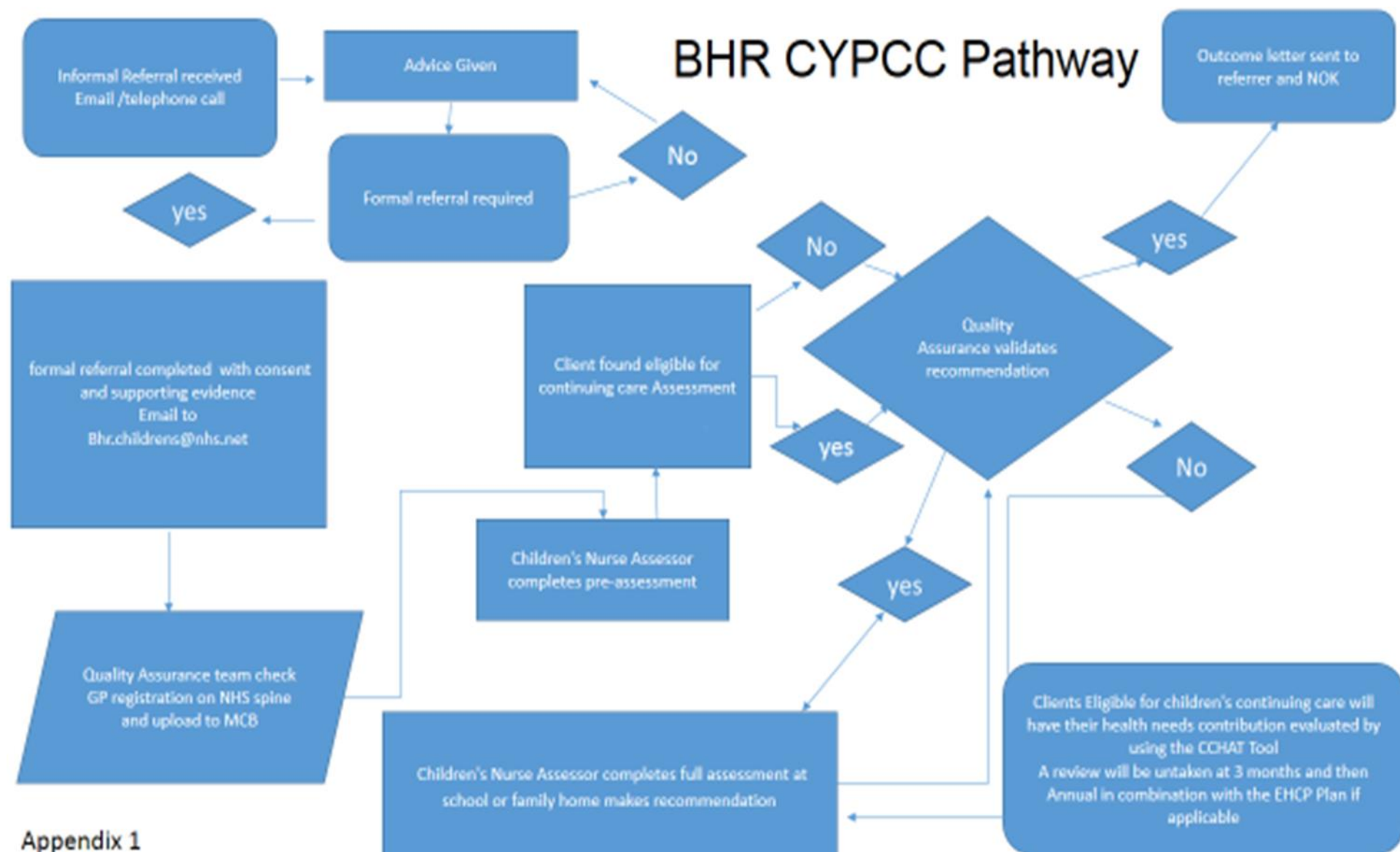
## Glossary of terms:

- **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.
- **CCHAT - Children's Continuing Healthcare Assessment Tool**  
Decisions about the amount and type of support needed by a child and family must be informed by a comprehensive assessment of needs using the Getting It Right for Every Child (GIRFEC) practice model. The GIRFEC model provides tools for a comprehensive integrated assessment (i.e. My World Triangle and Resilience Matrix). At all stages of intervention, practitioners should reflect on the questions that shape how they respond to the holistic needs of the child and family:
- **(SEND) Special educational needs and disabilities 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*



## Appendix 2

# Children and Young People's Continuing Care Referral Form

Child or young person's details			
<b>Name</b>			
<b>Date of birth</b>		<b>NHS Number</b>	
<b>Address</b>			
<b>Post Code</b>			
<b>Gender</b> (delete as appropriate)	<b>MALE</b>	<b>FEMALE</b>	
<b>First language (if not English)</b>			<b>Translator needed</b>
			<b>Other communication support needed</b>
<b>Mother's name</b>		<b>Father's name</b>	
<b>Contact no.</b>		<b>Contact no.</b>	
NB. Details of one parent only are acceptable, but it must be the parent with responsibility.			
<b>Siblings names and ages</b>			
If parental responsibility is not held by parents			
<b>Parental responsibility held by</b>		<b>Contact no.</b>	
		<b>E-mail</b>	
<b>Basis of parental responsibility</b> (e.g. legal guardian, LA section 20 etc.)		<b>Address</b>	
<b>Address of GP practice</b>			
<b>Name of GP</b> (if child or young person has a named doctor)			
<b>Clinical commissioning group</b> (where known):			
<b>Local authority</b> (where known)			

## Medical history

Provide a brief summary below of the child or young person's primary health needs, with details of any diagnoses and provision.

## Social care

Provide a brief summary below of the child or young person's social care needs with details of any arrangements in place.

## Education

<b>Name of nursery, school or college attending</b>	
<b>Year group</b>	
<b>Contact details</b> (where known)	
<b>Summarise any special arrangements made in the school environment to support the child or young person</b>	
<b>Does the child or young person have special educational needs?</b>	
<b>Does the child have an Education, Health and Care Plan or SEND statement?</b> This should be attached	

Details of referral	
<b>Date of referral (completion)</b>	
<b>Name of person completing</b> (Use the box below for details of other contributors.)	
<b>Employer</b>	
<b>Contact no.</b>	
<b>E-mail</b>	
<b>How was the referral for continuing care made?</b>	

Other individuals / organisations who support the child or young person	
Please give details below. Supportive evidence should be attached and relative to the Children's Continuing Care Domains (separate document)	
1.	<b>Name</b>
	<b>Organisation</b>
	<b>Role in relation to the child or young person</b>
	<b>Nature of contribution</b> (e.g. report, advice, MDT meeting etc.)
	<b>Contact no.</b>
	<b>E-mail</b>
2.	<b>Name</b>
	<b>Organisation</b>
	<b>Nature of contribution</b>
	<b>Contact no.</b>
	<b>E-mail</b>
3.	<b>Name</b>
	<b>Organisation</b>
	<b>Nature of contribution</b>
	<b>Contact no.</b>
	<b>E-mail</b>
4.	<b>Name</b>
	<b>Organisation</b>
	<b>Nature of contribution</b>
	<b>Contact no.</b>
	<b>E-mail</b>
5.	<b>Name</b>
	<b>Organisation</b>
	<b>Nature of contribution</b>
	<b>Contact no.</b>
	<b>E-mail</b>

## Existing assessments

Provide details below of any relevant assessments made in the last 2 years (e.g. CAF, Education, Health and Care plan or Statement of SEND, CAMHS assessments, Child in Need plan). Summary plans or other evidence can be attached.



## Further comments

--

<b>Consent</b> ✓ as appropriate		Yes	No
I have gained the consent of the child/young person/family to provide the above information to be used in a pre-assessment using the separate consent form			
<b>Recommendation</b> ✓ as appropriate		Yes	No
I have provided the above information and supporting evidence for this child to undergo a pre-assessment checklist completed by a nurse assessor. This information and supporting evidence is accurate and up to date to the best of my knowledge.			
<b>Signature:</b>		<b>Print name:</b>	
<b>Date:</b>		<b>Relationship / Designation:</b>	
<b>E-mail:</b>		<b>Contact Number:</b>	

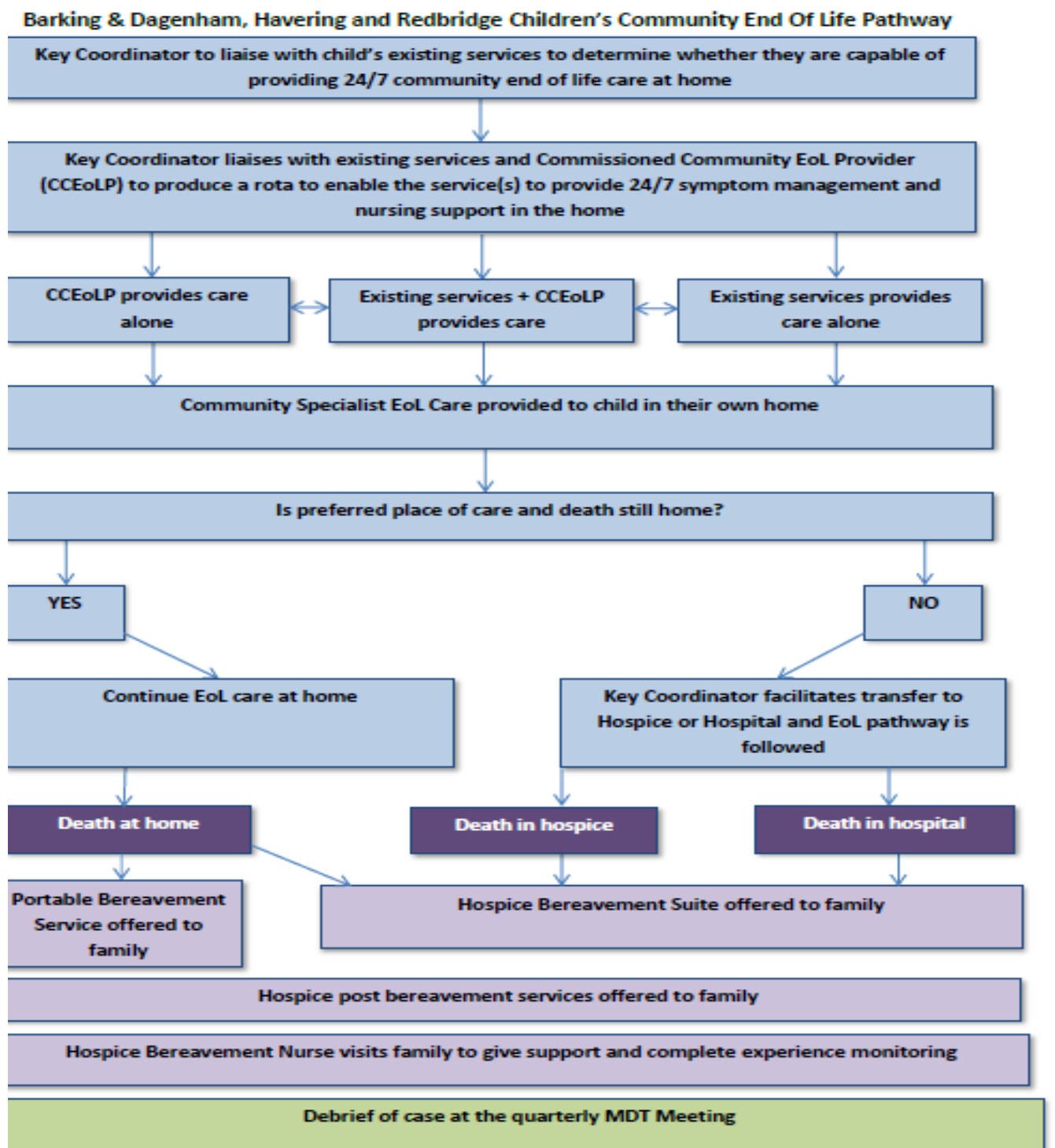
The referral form must be forwarded with the completed copy of the correct consent form to the Continuing Care Team at:

Children and Young People's Continuing Care Team  
Barking and Dagenham, Havering and Redbridge Clinical Commissioning Groups

E: [bhr.childrens@nhs.net](mailto:bhr.childrens@nhs.net)  
T: 020 3416 5905 option 1

## Appendix 3

### EOL Process



If death does not occur, the CYP's care will continue to be discussed with the Key Co-ordinator and MDT

Pathway designed by Barking & Dagenham, Havering and Redbridge Children's Continuing Care Team and Haven House Children's Hospice.  
Pathway ratified in November 2017

## Appendix 4

### **Joint Children's and Young People's Continuing Care Panel** **(DRAFT)**

#### **Scope**

This protocol sets out the principles and arrangements agreed between Health, Education and Children's Social Care Service commissioning agencies for the joint funding of specialist, external placements and provision.

It is expected all children will be Looked After, highly likely to have statements of SEN and/or high levels of SEN and meet health Continuing Care criteria.

#### **Key principles:**

- All children considered for joint funding must have already identified and recorded Severe/exceptional needs by the agencies from which funding is sought.
- Each agency should act to promote best value from public funding rather than purely from a Department budget perspective although agencies will also take account of the specific budget limitations of each agency.
- Joint funded placements should be based on clear joint planning and consultation but it is understood this will not always be possible with some placements needing to be made before full consideration and agreement is possible

The principles in this protocol should still be applied in such cases and all agencies will act in good faith to promote fair funding arrangements taking account of their statutory responsibilities.

#### **Process:**

The placements team will forward the referral form for children that are deemed to have complex and continuing health needs. BHR Children's continuing care assessor will consider the referral and where deemed appropriate complete an assessment, based on the Joint Children's and Young People's Continuing Care Panel. (Quality Assurance process)

#### **Terms of Reference:**

##### **1. Aim**

- 1.1. The Joint Children's Continuing Care Panel will ensure consistent decision-making and process following the guidance in the National Framework for Children and Young People's Continuing Care cases in Barking Havering and Redbridge and ensure appropriate provision is available.
- 1.2. This panel will align with the Education, Health and Care Plan (EHCP) process.

## **2. Objectives:**

- 2.1. To consider recommendations based on health, education and social care needs following multi agency assessments (Decision Support Tool for health), which includes the three CCG and education and social care colleagues.
- 2.2. To ensure there is evidenced rationale for recommendations made by the CCGs regarding eligibility-based on assessments obtained from the multi-disciplinary team.
- 2.3. To negotiate and agree each agency's funding contribution to individual care packages, based on evidenced health, education and social care needs.
- 2.4. To consider proposed packages of care and ensure both appropriateness of the provider and that there is equity of provision to individuals who are deemed eligible.
- 2.5. To consider the details of individual cases where difficulties have been experienced in reaching an agreement, regardless of their financial implications.
- 2.6. To appropriately support on-going health needs and enable the child or young person to achieve improved outcomes across health, education and social care.
- 2.7. To ensure the assessment includes the views of the child/young person and their family.
- 2.8. To ensure that cases are regularly reviewed and a summary of the review is presented at the panel (initial review at 3 months and then at least annually). Cases may be reviewed earlier in exceptional circumstances. Where possible to join up reviews with other areas i.e. LAC reviews
- 2.9. To ensure that we meet the needs of Children and Young People with conditions that may deteriorate in between panels and require a rapid response to emerging need.
- 2.10. To maintain accurate and confidential records of the cases considered and the decisions reached.
- 2.11. To acknowledge children and young people with increasing complex care needs who are identified as potentially requiring continuing care in the future, but do not currently meet the criteria at the time of assessment. Some low level support may be allocated to support and manage any health risk identified.

## **3. Membership**

- 3.1. The members and chair of the Joint Children's Continuing Care Panel as detailed below.

- 3.2. In exceptional circumstances a designated professional appropriate to the decision making process may attend the panels.
- 3.3. Members must have authorisation to agree funding associated with the package of care.
- 3.4. Each member should nominate a deputy to attend in their absence to enable the panel to be quorate.

#### **4. Meetings**

- 4.1. The Children's Continuing Care Panel will meet every two weeks. The meeting will be chaired by the designated clinical review and assessment manager.

For meetings to be deemed quorate, attendees present should represent the following:

- Designated Clinical Nurse Continuing care Assessor (Chair) on behalf of CCGs
- Appropriate senior quality representative from the local authority
- Children's Continuing Care Service Complex Case Manager or Children's Nurse
- Children's Continuing Care Service Administrator
- Team Manager (ICDS) Integrated Children's Disability Service (to represent Education)
- Service Manager LAC (Children's Social Care)
- Service Manager Placements (Social Care) or Service Manager – Children's Disability Service (Social Care)

#### **5. Process**

- 5.1. Cases will be referred to the Joint Children's Continuing Care Panel with full information which must include a fully completed Decision Support Tool and supporting assessments (E.g. health needs, social care needs, education needs, Occupational Therapist, Physiotherapist) and details of the care package/placement and costs. Additional Supporting documentation will be available for consideration if necessary.
- 5.2. The relevant budget holders will action the agreement immediately or as soon as possible after the meeting (within 3 working days).
- 5.3. The minutes of the meeting will be taken by CCG and a draft version will be sent to the chair for approval before circulation to the panel members.
- 5.4. The agenda for the meeting will be sent out one week prior to the panel so that respective panel members can collate an update from their service area.
- 5.5. The CCGS will communicate funding decisions in writing to the referrer who share with the child or young person and their family within 5 working days.

- 5.6. Cases must be re-authorised at the Joint Children's Continuing Care Panel should the care package change significantly i.e. where costs have changed by 10% or more.
- 5.7. Where costs have changed by less than 10% the CCCS will notify the commissioners via telephone or email and provide written confirmation of the agreed changes to the package.
- 5.8. After the initial 3 month review, cases authorised by the Joint Children's Continuing Care Panel will be reviewed on at least an annual basis using the Decision Support Tool and appropriate assessments.
- 5.9. In extraordinary circumstances decisions can be taken outside the panel and reported to the panel at the earliest opportunity with relevant commissioner.

## **6. Accountability, consent and sharing information**

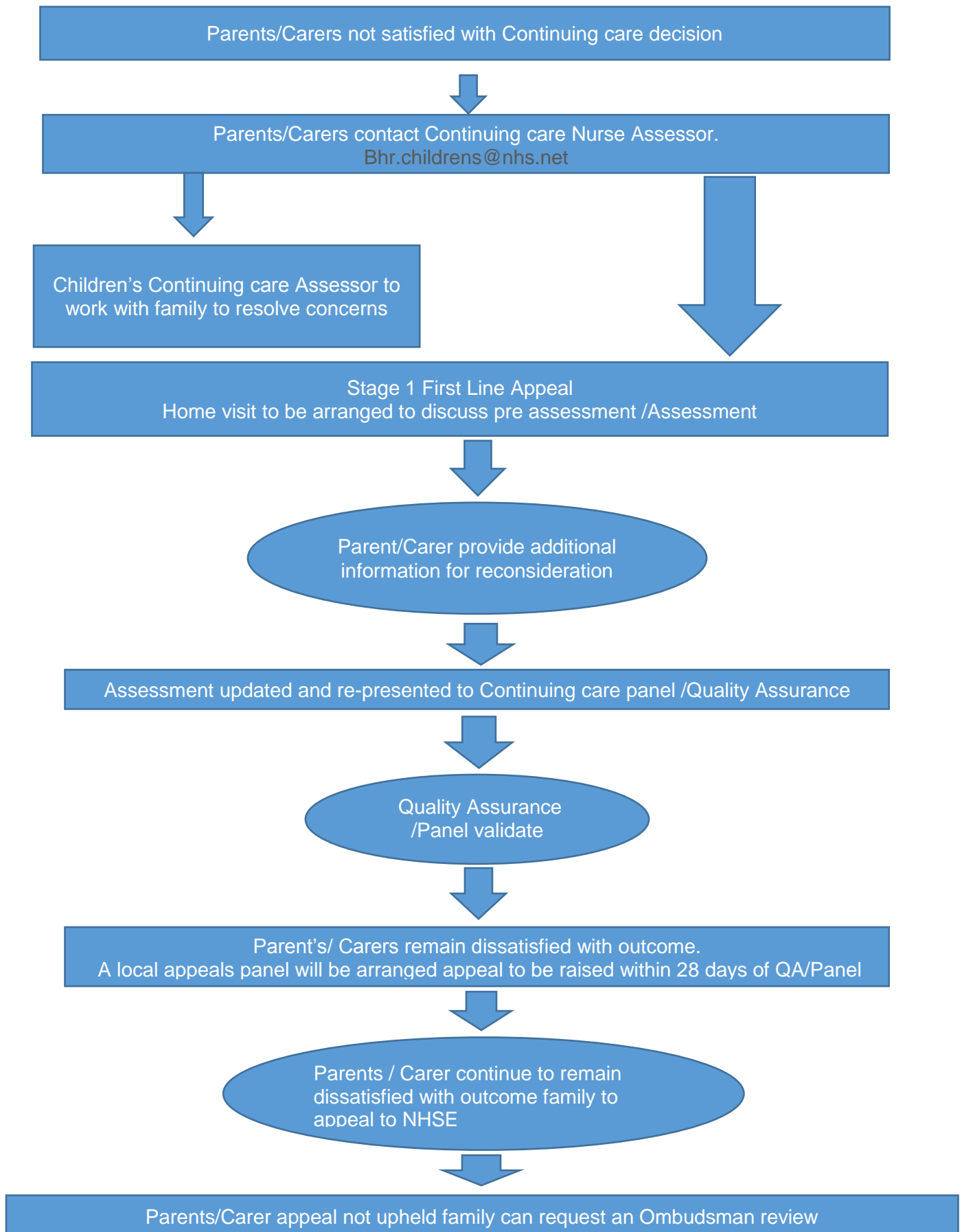
- 6.1. The members of the Joint Children's Continuing Care Panel are accountable to their respective organisations.
- 6.2. Consent for obtaining and sharing of information will be acquired by the referring professional involved from the relevant party i.e. carer/family member/professional, following organisational protocols for obtaining consent and the sharing of data. This will reflect the need to collect the information required so that the panel can understand what help and support the child and family may need.
- 6.3. Information collected will be treated as confidential and will not be shared with any other organisation unless required by law to do, which includes the need to safeguard children or vulnerable adults.
- 6.4. We will only ever share the relevant information required. The professionals or agencies that may be involved in sharing information include health (community and acute trusts), CAMHs, education providers, social care, voluntary sector and police. (This is not an exhaustive list).

## **7. Review**

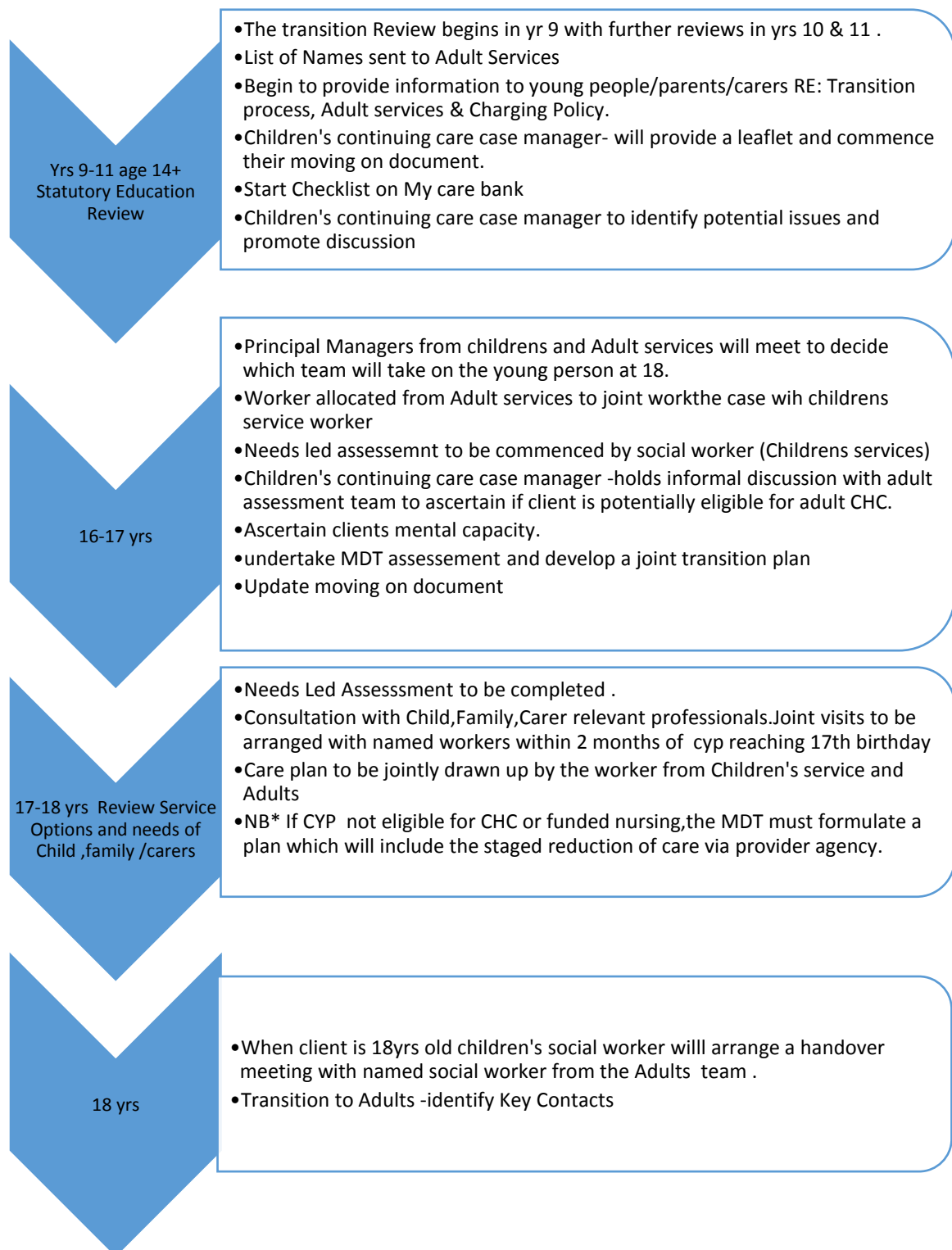
- 7.1. The terms of reference are to be read in conjunction with the Children and Young People's Continuing Care Framework

**Appendix 5**

**NHS BHR CCG APPEALS PROCESS**



## Appendix 6 Transitions Process





## **Appendix 7**

### **CCHAT - Children's Continuing Healthcare Assessment Tool**

Developments in clinical care have improved the outlook for many children with life threatening conditions. However, for a small number of children, life at home is neither safe nor sustainable without intensive support from a team of carers to help families provide continuous one-to-one care. These children need 'continuing care'.

**Children's Continuing Care** is where specialist assessment and a multi-agency package of care is needed to support the family caring for a child or young person with multiple, complex and enduring health care needs due to disability, accident or illness. The child requires:

- An intensity, complexity and continuity of care that cannot be met by local universal services, and cannot be sustained by the family without a bespoke package of support.
- One-to-one or two-to-one care for all or part of the day, to ensure the safety of the child, or that of other people, and allow educational and social inclusion.
- Collaborative support from two or more agencies to assess, fund, provide and monitor the care package.

Adapted from DOH 2005 & 2008 p.22

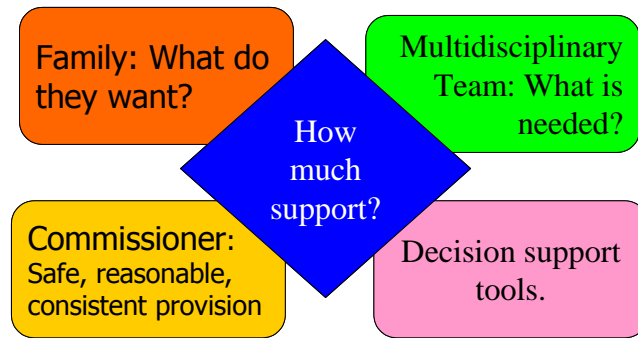
Children's continuing care packages are small in number but resource intensive. Commonly staff are specifically recruited and trained to provide care for the child in home, school and community. In some cases a package will be put to tender from commercial agencies.

#### **Using CCHAT to support decision making.**

Decisions about the amount and type of support needed by a child and family must be informed by a comprehensive assessment of needs using the Getting It Right for Every Child (GIRFEC) practice model. The GIRFEC model provides tools for a comprehensive integrated assessment (i.e. My World Triangle and Resilience Matrix). At all stages of intervention, practitioners should reflect on the questions that shape how they respond to the holistic needs of the child and family:

- What is getting in the way of this child or young person's well-being?
- Do I have all the information I need to help this child or young person?
- What can I do now to help this child or young person?
- What can my agency do to help this child or young person?
- What additional help, if any, may be needed from others?

CCHAT is used to support decision making by helping to answer the question "How much care support is needed by this child?" It focusses purely on the health needs of the child and the risks associated with any health conditions and interventions. The tool uses 'tick box' answers to a generic set of descriptors to estimate of the number of hours of care support needed. It does not assess the ability of the family to meet the child's needs or the needs of others in the household. These factors must be addressed through the comprehensive assessment and collaboration with Social Work, Education and other agencies. Professional judgement, rationally considered and recorded, will always ta



The starting point for CCHAT was other assessment tools used across the UK, including examples from Leeds, Bradford, Swansea and Rotherham. The English 'Framework for Children's Continuing Care' (Department of Health 2010) was also considered. Most tools were found to give consistent

Assessments for children on long-term ventilation but underestimated the support needs associated with complex neuro-disability. A team of nurses in Lothian developed the set of descriptors for the risks and support needs of children with complex needs and allocated a score for each descriptor. The tool was tested in five health board areas and adjusted to reflect professional judgements. Once the tool was found to give consistent results it was built into a spreadsheet to automate the calculation.

CCHAT is designed for collaborative decision making. Assessment works best when undertaken jointly by professionals who know the child and family well, understand the local continuing care commissioning process and are familiar with the Tool.

### Using the tool

CCHAT has two components:

- **CCHAT Assessment** used to collect information from professionals who know the health needs of a child.
- **CCHAT Scoring** which uses the assessment to generate an estimate of the support needed.

Both components are very easy to use and, if assessment information is to hand, can be completed within 15-20 minutes. The documents are 'locked' so that information can only be entered on a computer, in text or tick-boxes. The Tab key, keyboard arrows or mouse are used to navigate between the boxes and a left mouse click will check a tick-box. The documents are Templates. When you alter a template you will be asked to save it as a separate Word or Excel document. The original template will remain unaltered for future use.

**The CCHAT Assessment** is a Microsoft Word form that is completed jointly by two independent Assessors with knowledge of the child's healthcare needs, and of the assessment process. These might be a lead member of the child's care team and a professional involved with the planning or delivery of the continuing care service. The form can be completed electronically or printed and completed manually. The information is confidential and must be stored and transmitted in accordance with NHS eHealth Security Policies.

The Assessment has nine sets of descriptors and the Assessors agree on the one from each set that applies to the child, as in the example below.

<b>8. Medication: Tick one</b>		Tick <small>Office use</small>
<b>Low Risk</b>	Support appropriate to age & development level. May require prescribed medication regimes and occasional emergency medication.	<input type="checkbox"/>
<b>Moderate Risk</b>	Prescribed medication regimes, which may include regular use of emergency medication. Administration by a parent or carer specifically trained for the task, working to agreed protocols.	<input checked="" type="checkbox"/>
<b>High Risk</b>	Complex medication regimes and protocols to ensure effective symptom control with a fluctuating, unstable or deteriorating condition, requiring frequent nursing reassessment. <b>Chiefly associated with end-of-life care.</b>	<input type="checkbox"/>
<b>Notes:</b>		

The Assessment also records information on the current and proposed continuing care and respite provision. Information is collected in a format that will allow for variation in the frequency of provision. For example: Overnight care, 10 hours every night of the year will be shown as in line 1 below. Support during the school day for 6 hours in term time may appear as line 2. This detailed information can identify gaps in the continuity of care for the family and helps in calculating the cost of a care package.

<b>3.1 Current care package:</b>		<b>No current package</b> <input type="checkbox"/>		
<b>Type of care</b> (note if day or night e.g. overnight care in home, school support, respite care)	<b>Provider</b> (e.g. health, social work)	<b>Hours per 24hr period</b>	<b>Days per week</b>	<b>Weeks per year</b>
1. Overnight care from trained carer in home	Health	10	7	52
2. Support in school day	Education	6	5	40
3. Play scheme holiday support	Social work	6	5	4

### **CCHAT Scoring.**

The completed Assessment Form is forwarded to a Continuing Care Manager for scoring. Scoring uses a Microsoft Excel spreadsheet to automatically generate an estimate of 'hours of health support'. It must be completed on the computer to allow the automation to work. On receipt of an Assessment the Scorer simply checks the corresponding boxes on the Excel Score Sheet. The 'hours of health support' is calculated automatically and shown in the blue highlighted section at the bottom of the assessment (see illustration below). The two pages of the score sheet can then be printed.

Users need to be familiar with the basics of Excel, including navigation between and around spreadsheet pages, simple data entry and renaming sheets. It is protected so that data can only be entered in PINK text boxes or tick boxes. The spreadsheet has five identical assessment pages. Ideally a child should have his/her own spreadsheet to allow repeat assessments over time. Remember to save any changes and store the spreadsheet securely in accordance with NHS eHealth Security Policy.

## Appendix 8

### PHB - Standard Operating Procedures

1	PHB interest received/CHC notified	Letter/email sent with PHB booklet/information to acknowledge receipt.	Patient notes updated on CHC care plan.
2	PHB formal request for received	Letter/email sent to acknowledge request and request confirmation of PHB option.	Patient notes updated on CHC care plan and attachments.
3	Panel meet	Patient case discussed at Panel to check for Safeguarding and Management	Patient notes updated on CHC care plan.
4	Panel decision	Letter/email sent with Panel meet outcome and if appropriate informed of Direct Payment Agreement being sent once indicative budget calculated.	Patient notes updated on CHC care plan and attachments.
5	Care plan assessed needs	Check with assessing Nurse that the care plan needs are up-to-date, if not request to be done.	Patient notes updated on CHC care plan.
6	PHB calculated based on assessed needs (with/without respite)	Request Panel to approve total costs	Patient notes updated on CHC care plan.
7	Costs approved	Send 2x (CCG Copy & Patient Copy) completed Direct Payment Agreement with enclosed SAE for signature CCG copy return.	Patient notes updated on CHC care plan and attachments.
8	Signed DPA returned	Set up PHB ILA provision with weekly cost dated from previous month to provide 1 month contingency.	Provision updated with correct budget codes
9	Inform PHB - Independent Living Agency	Letter/email sent to advise of utilisation process contacts and links for employment/training responsibilities	Patient notes updated on CHC care plan.
10	PHB list monthly Provision date audit	Extend Provision dates when required and add missing invoices.	Patient notes updated on CHC care plan.
11	End of Year PHB list audit - ILA	Process remuneration on surplus funds	Inform finance and add credit invoice to system