

# **CHILDREN'S & YOUNG PEOPLE'S CONTINUING CARE POLICY**

**UNIQUE REFERENCE NUMBER:** CD/XX/079/V1.1  
**DOCUMENT STATUS:** Approved at CDC 22 March 2017  
**DATE ISSUED:** January 2017  
**DATE TO BE REVIEWED:** January 2020

## AMENDMENT HISTORY

VERSION	DATE	AMENDMENT HISTORY
D7.0	October 2016	First Draft created
CD/XX/079/V1	December 2016	Formatted in to CCG Format and issues identifier
CD/XX/079/V1.1	April 2017	Addition of 13.2 and new RAT Tool incorporated
CD/XX/079/V1.2	June 2017	Additional information added in section 9.20

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## APPROVALS

This document has been approved by:

VERSION	NAME	DATE
V1.0	Commissioning Development Committee	16 November 2016
V1.1	Commissioning Development Committee	22 March 2017

N.B: the version of this policy posted on the intranet must be a PDF copy of the approved version.

## DOCUMENT STATUS

This is a controlled document. Whilst this document may be printed, the electronic version posted on the intranet is the controlled copy. Any printed copies of the document are not controlled.

## RELATED DOCUMENTS

These documents will provide additional information.

NAME OF DOCUMENT	VERSION
Safeguarding Children and Young People Policy	
Safeguarding Adults Policy	
Mental Capacity Act 2005, The Children Act 1989 & 2004	
National Framework for Children and Young People's Continuing Care 2016	
Children and Families Act 2014	
Working Together to Safeguard Children 2013	

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## **1.0 POLICY OVERVIEW**

- 1.1 This policy replaces the former Dudley CCG Continuing/Complex Healthcare: Policy and Proforma (2011).
- 1.2 The purpose of this policy is to ensure that there is a consistent approach to ensure quality, equality and transparency in the assessment and agreement of eligibility for Continuing Care.
- 1.3 This policy must be read in conjunction with the National Framework for Children and Young People's Continuing Care (2016) and other policies mentioned forthwith when assessing the needs of children and young people whose complex needs cannot be met through existing universal or specialist services.

## **2.0 INTRODUCTION**

- 2.1 This policy describes the way in which Dudley Clinical Commissioning Group (CCG) makes provision for the care of children and young people who have been assessed as eligible for NHS Continuing Care as outlined in the National Framework (2016) to ensure that the CCG meets its statutory responsibilities and adheres to good practice guidelines.
- 2.2 This policy reflects the changes in the National Framework, its new principles and takes into account the new commissioning structures in the National Health Service resulting from the Health and Social Care Act (2012) and the new integrated approaches to commissioning children and young people's services with special educational needs or disability (SEND) specified in the Children and Families Act (2014).
- 2.3 The National Framework for Children and Young People's Continuing Care (2016) outlines the process for assessment and subsequent eligibility for continuing care. It describes the process for assessing, deciding and agreeing packages of continuing care for children and young people, whose needs cannot be met by universal or specialised services. Continuing care is not available to children or young people whose care needs can be met appropriately through existing universal or specialist health services. In this instance their needs should be addressed using a case management approach from existing service providers.
- 2.4 When providing support for a child or young person with a SEND, the CCG and Local Authority should endeavour to work together to assess and coordinate a jointly-agreed package of continuing care and, in doing so, inform the health needs of the child's and young person's Education, Health and Care Plan (EHCP).
- 2.5 It is essential that all professionals understand how children and young people's continuing care is assessed and that it is commissioned differently to adult's NHS Continuing Healthcare and NHS-funded Nursing Care and the how transitional arrangements from children's to adult's continuing care are addressed.

## **3.0 PURPOSE**

- 3.1 This policy offers guidance to professionals involved in assessing individuals who may be eligible for continuing care and clarifies the processes for future management of that care, where eligible. It highlights the responsibilities of Dudley CCG and Dudley MBC in meeting the continuing care needs of the children and young people within the Dudley Borough.

## **4.0 POLICY STATEMENT**

- 4.1 Dudley CCG has a legal responsibility for assessing and commissioning, the reasonable healthcare requirements of an individual. The guidance describes the process which should be followed for the equitable discharge of that responsibility for children and young people with complex needs.
- 4.2 The CCG is responsible for leading the process of identifying if a child or young person for whom it has a commissioning responsibility under section 3 of the NHS Act 2006, has a continuing care need. However, both Dudley CCG and Dudley MBC have a statutory responsibility to meet the health care, social care and educational needs of children and young people with continuing care needs which may require services commissioned by multiple organisations. It is therefore imperative that Dudley CCG and Dudley MBC work together to provide a holistic care package adhering to the principle of securing the best outcomes for both the child/young person and their family, however, each organisation remains responsible for its' own statutory duties.
- 4.3 The Commissioning Manager- Children, Young People and Families is responsible for commissioning continuing care for children and young people, for overseeing effective liaison with Dudley MBC and other partners, and the management of the process.
- 4.4 The Paediatric Continuing Care Coordinator (PCCC) is the single point of contact, with whom professionals can liaise when wishing to discuss a child and young person with possible continuing care needs. The PCCC acts as the CCG's nominated children and young people's health assessor and coordinates the process ensuring effective management and liaison with local authorities and partners in accordance with the National Framework (2016) and this policy. The PCCC liaises closely with the CCG's Designated Medical Officer (DMO) for SEND and works closely with professionals in Dudley MBC, to ensure the child or young person has a comprehensive package of care across health, education and social care.
- 4.5 Continuing care provision is designed to support children and young people with complex needs, to lead an ordinary life where possible, both in the home environment and at school. Health funding to support children and young people in schools, regardless of their eligibility for continuing care support, will be subject to individual consideration and awarded on an individual basis, or as agreed within the child or young person's EHCP.

## **5.0 SCOPE**

- 5.1 This policy applies to all children and young people from 0-17 years (up to their 18<sup>th</sup> birthday) with complex health needs that are registered with a Dudley GP and who may have continuing care needs.
- 5.2 'Continuing care' is a term for a tailor made package of care which is defined in the National Frameworks (2016) as a "package of care which is arranged and funded by a relevant body for a person aged 17 or under to meet needs which have arisen as a result of disability, accident or illness."
- 5.3 Some children and young people may have very complex needs. These may be the result of congenital conditions, long-term, life-limiting or life-threatening conditions, disability, or the effects of serious illness or injury. These needs may be so complex, that they cannot be met by services which are routinely available from GP practices,

hospitals or in the community, specifically commissioned by the CCG or NHS England. These children or young people may need additional health support. This additional support is known as 'continuing care'.

- 5.4 Any package of care agreed by the CCG, or jointly with Dudley MBC, must be sustainable and integrated with other relevant services, such as primary care.
- 5.5 All health professionals that work directly with children/young people have a duty to ensure that safeguarding and working to promote the welfare of the child or young person forms an integral part of all elements of the care they offer (Working Together to Safeguard Children, 2010).
- 5.6 All staff working with children and young people will have the necessary training in line with safeguarding policy. Any safeguarding issues are to be reported to the CCG's Designated Senior Nurse for Safeguarding Children.

## **6.0 ROLES AND RESPONSIBILITIES**

- 6.1 The National Framework stresses the importance of the child/young person and their family being considered for continuing care, understanding the continuing care process and receiving advice and information in a timely and clear manner.
- 6.2 Parents and carers, as the experts in their child/young person's care, have the primary responsibility for the care of their child/young person with statutory agencies supporting them to meet the child/young person's identified needs.
- 6.3 The CCG is responsible for assessing and commissioning continuing care packages to meet the reasonable health care needs of children and young people aged 0-18 years of age who are eligible for continuing care. The needs are identified following a full continuing care assessment using the Decision Support Tool (DST) as stipulated in the National Framework (2016). The PCCC will present the outcome to a multi-agency panel for agreement of eligibility. The panel will consider the evidence and reach a decision as to whether the child or young person has a continuing care need. Following this agreement, the Commissioning Manager-Children, Young People and Families will use the CCG's resource allocation tool to assist with assessing the proportion and level of resource required to meet the assessed need. This will be commissioned and the arrangement of provision coordinated through consultation with the child/young person and their family; promoting personalisation.

## **7.0 EDUCATION, HEALTH AND CARE PLANS**

- 7.1 Children and young people with complex needs may not only need support from health services. They may also have special educational needs. Appropriate care of children or young people with profound multiple disabilities or chronic severe illness involves input from all statutory agencies: Health, Social Care and Education.
- 7.2 Since September 2014, under section 26 of the Children and Families Act 2014, children and young people (up to 25 years old) with a SEND are entitled to a single plan which consists of a multi-professional assessment to agree an Education, Health and Care Plan (EHCP). The EHCP process has, at its heart, a coordinated assessment of a child or young person's needs, based on multi-professional input and focussed on the outcomes which make the most difference to the child or young person and their family. CCGs and Local authorities must work together to make EHCPs work through joint assessment and arrangement and include an agreement

as to how continuing care fits within the EHCP process. The joint assessment will ensure outcomes are established across education, health and social care that the views, interests and aspirations of the child or young person and their family are documented and that collaborative joint working leads to good practice. Dudley MBC remains responsible for conducting an assessment of education, health and social care needs when arranging for specialist educational provision.

7.3 The Code of Practice “Special educational needs and disability code of practice: 0 to 25 years. Statutory guidance for organisations who work with and support children and young people with special educational needs and disabilities” (2014) outlines the statutory guidance for the EHCP process and covers all legal requirements. <http://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

7.4 Each agency is responsible for their own contributions to the continuing care package or EHCP, in line with their statutory functions. The CCG must work with all agencies to ensure seamless care for a child/young person and their family/carers as far as are practically possible.

## **8.0 RISK**

8.1 The CCG must endeavour to commission appropriate tailor-made care packages however, despite best efforts, there may be a delay, where due to lack of resources from providers, for example training.

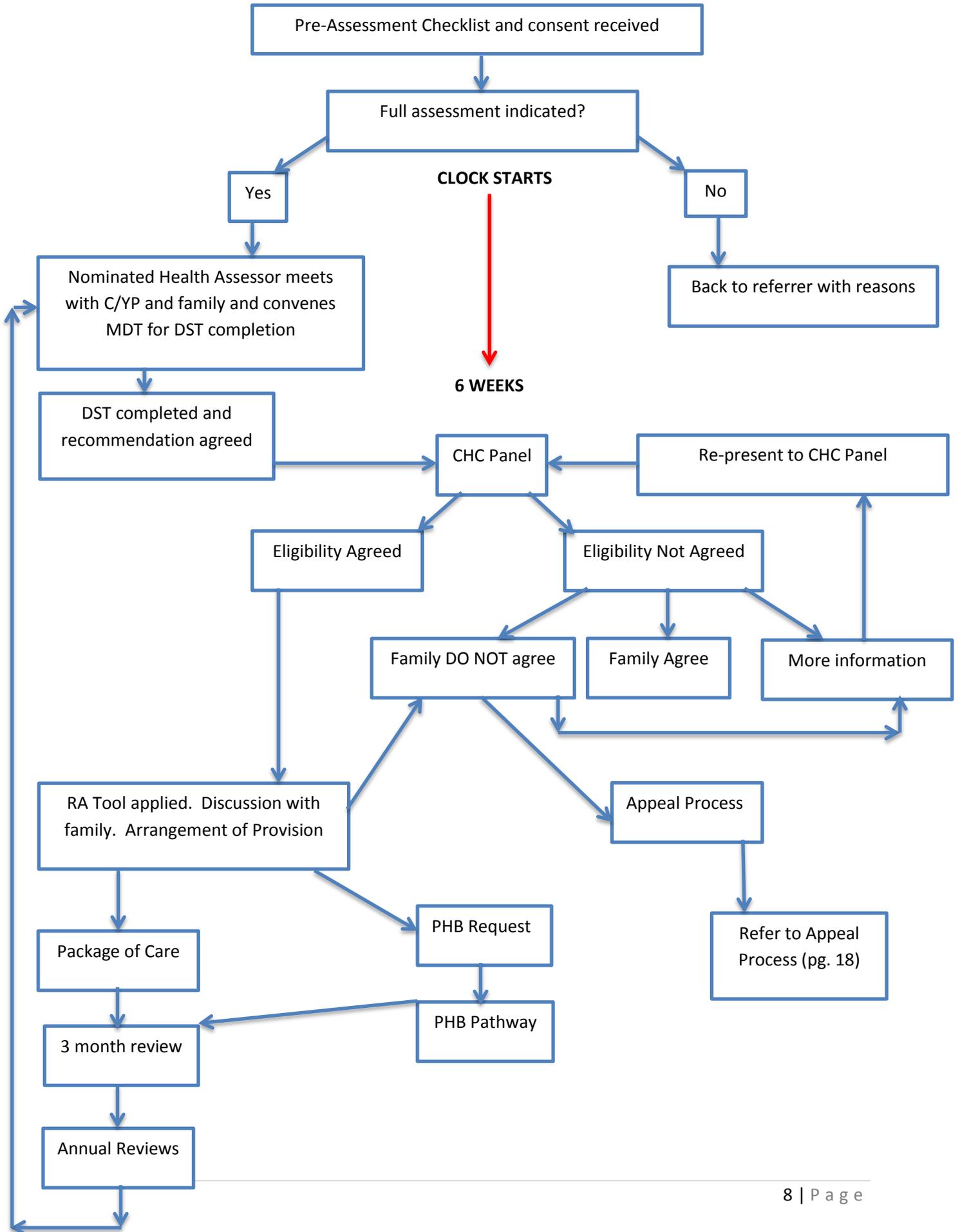
8.2 As outlined in 6 above, parents and carers have the primary responsibility for the care of their child/young person’s needs. Therefore, it is important that parents/carers maintain their own competencies to care for their child/young person 24 hours per day. In the event of unforeseen circumstances, when the Continuing Care provider cancels a shift, the expectation is that parents/carers have the responsibility to ensure that the needs of their child/young person are met.

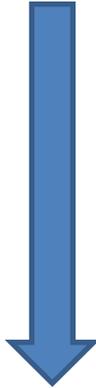
8.3 There may be individual circumstances whereby a child or young person may require support but their health needs may fall outside of the eligibility for continuing care. Under these circumstances it is anticipated that services will be provided under existing contractual arrangements.

## **9.0 CONTINUING CARE PROCESS AND PATHWAY**

9.1 The continuing care process determines if a child’s needs could be met by universal or specialist services and if not, what additional care would be needed. A decision about a child/young person’s continuing care need is based on an individual assessment of their health needs. The diagnosis of a particular condition or symptom in itself is not a determinant of a need for continuing care or indicator of the level of need.

# Continuing Care Process



<u>Phase</u>	<u>Step</u>	<u>Summary of Key Actions</u>	<u>Timescale</u>
<b>Assessment</b>	<b>Identify</b>	A child or young person with a possible continuing care need is referred to the CCG. [Pre-assessment] A child or young person's health assessor is nominated, and the process of assessment begins.	<b>Clock starts</b> 
	<b>Assess</b>	The health assessor undertakes the assessment, comprising: - preferences of child or young person and their family; - holistic assessment of need; - reports from multi-disciplinary team; - Decision Support Tool for children and young people.	
	<b>Recommend</b>	The health assessor completes the process of assessment, and makes a recommendation.	
<b>Decision-Making</b>	<b>Decide</b>	The multi-agency forum considers the recommendation and decides if the child or young person has a continuing care need.	
<b>Arrangement of Provision</b>	<b>Inform</b>	The child or young person and their family are informed of the decision. Development of costed package of care. Any relevant organisations, such as the local authority, and key health professionals involved in the child or young person's care (e.g. GP, paediatrician) should also be notified.	<b>6 Weeks</b>
	<b>Deliver</b>	Commissioning of the package of care and its provision to the child or young person. Ongoing monitoring / contract management for the commissioned service.	
<b>Ongoing</b>	<b>Review</b>	Reassessment of the child or young person's continuing care needs.	

## Identify

- 9.2 The continuing care process begins when there is recognition that a child or young person **may** have a continuing care need. A child or young person may be referred for a pre-assessment through a variety of routes. All enquiries relating to children or young people with possible continuing care needs, or referrals will be directed to the PCCC using the '**National Frameworks (2016) Children and Young People's Continuing Care Pre-Assessment Checklist**' (appendix 1).
- 9.3 Parents/Carers will have been given the **Continuing Care Information Leaflet** (appendix 2) and **Appeals Process leaflet** (appendix 3) by the referrer, prior to checklist completion.

- 9.4 Informed consent must be sought prior to completing the pre-assessment checklist. The '**Children and Young People's Continuing Care Consent Form**' (appendix 4) must be sent with the completed pre-assessment checklist to the PCCC.
- 9.5 The referral should include documentation such as nursing assessments, School Nurse reports, EHCPs, Early Help plans etc. and clearly identify the child or young person's outstanding health needs not able to be met by universal or specialist services.
- 9.6 The pre-assessment will indicate whether or not the child or young person should proceed to a full formal assessment.
- 9.7 If the referral does not indicate that a full formal assessment is required, then a letter will be sent to the family and the referrer notified and signposted to other services.
- 9.8 Children or Young People who are entering an End of Life Care phase are not required to undergo pre-assessment and the Fast Track (**Section 12**) pathway should be followed.

### **Assessment**

- 9.9 Should the pre-assessment checklist indicate that a full assessment (assessment phase) is required, then the PCCC will complete all areas of the '**National Framework (2016) Decision Support Tool**' document (appendix 5) and present this to the Continuing HealthCare Panel (Decision- making phase) for a decision regarding eligibility for continuing care support within 6 weeks from the beginning of the assessment phase.
- 9.10 The clock starts at the point of recognition that a child or young person should have a full continuing care assessment (i.e. following any pre-assessment). The family will be given a clear timescale and should expect a decision within 6 weeks.
- 9.11 Any extensions of time required will be discussed with the family and clear explanations given.
- 9.12 If the child/young person does not have an allocated Social Worker then the PCCC will make a referral to Dudley MBC in order to undertake a joint assessment. A joint visit date/time will be agreed with the family within 48 hours of the social care referral.
- 9.13 It is important that the child/young person and/or their family understand that continuing care packages are not indefinite and as the health needs change so may the package of care.

### **Decision Making**

- 9.14 Following consideration by the Continuing Health Care Panel (CHCP), the decision will be communicated to the family and key professionals verbally and in writing within 5 working days, giving a clear explanation of the rationale for decision.
- 9.15 The CHCP will have appropriate representation from Dudley CCG and Dudley MBC.
- 9.16 The Commissioning Manager-Children, Young People and Families will use the **CCG's Resource Allocation Tool** (appendix 6) to establish the amount of health support required based upon the assessed need of the child or young person. Support will be personalised to meet the medical and nursing needs. Continuing care

is generally used to provide bespoke care packages in the home but at times may include care in a hospice or residential setting as part of the package. Alternatively, access is available to a Personal Health Budget (**Section 11**) if requested.

- 9.17 The PCCC and Social Worker will work with the family to arrange appropriate provision and to deliver the package as soon as possible.

## Review

- 9.18 All packages of care will be subject to review using the '**National Framework (2016) Decision Support Tool**' to ensure the developing needs of the child or young person continue to be supported. Reviews are at 3 months following the start of a package and then annually, or in line with transition to appropriate services. They are also responsive to changes in a child or young person's fundamental need. The responsibility to commission care is not indefinite, as needs change eligibility may change as well, resulting in a change to the nature of the care required. This will be made clear to the child or young person and their family. In instances where transition back to universal or specialist health services is appropriate, the child or young person and their family will be supported throughout by their existing care team.
- 9.19 The child or young person and/or their family/carer reserve the right to have the needs assessed earlier should it be felt the health needs have changed prior to review.
- 9.20 Should a child/young person be admitted to an acute hospital, the package of care can continue within the hospital setting for a 4 week period, providing both the Commissioning Manager for Children, Young People and Families, and the Acute Hospital agree. If the child or young person is not likely to return home within the 4 week period, then further negotiation with the Commissioning Manager for Children, Young People and Families is required.

## 10.0 TRANSITION

- 10.1 Once a young person reaches the age of 18 years, they are no longer eligible for continuing care for children but may be eligible for Adult NHS Continuing Healthcare, which is subject to its own legislation and specific guidance. It is important that young people and their families are helped to understand that eligibility to Children's Continuing Care does not automatically imply eligibility to Adult NHS Continuing Health Care and the implications of this will be made clear right from the start of transition planning.
- At 14 years of age, the young person will be brought to the attention of the CCG's Adult NHS Continuing Healthcare Team using the **Continuing Care Transition Notification Form** (appendix 7).
  - At 16 years of age, screening for Adult NHS Continuing Healthcare will be undertaken using the adult screening tool.
  - At 17 years of age, an agreement in principle for Adult NHS Continuing Healthcare will have been made.
  - At 18 years of age, full transition to Adult NHS Continuing Healthcare or to universal and specialist services will have been made, except in instances where this is not appropriate.

10.2 Where the young person has an allocated Children's Disability Team Social Worker, they will lead the transition process, working alongside the identified Transition Team Social Worker.

#### **11.0 PERSONAL HEALTH BUDGETS** (to be read in conjunction with PHB Policy)

11.1 Under the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) (Amendment) Regulations (2013), the families of a child/young person eligible for continuing care have a right to a personal health budget (PHB), covering the part of their care package which would be provided by the NHS.

11.2 Where a child or young person is found eligible for continuing care and requests a personal health budget, this must be requested via the '**Children and Young People's Continuing Care Personal Health Budget: Expression of Interest Form**' (appendix 8).

11.3 Interim support will be offered while a personalised package through PHB is set up.

11.4 The family have the right to request a PHB at any time during the time their child or young person has a package of care and will be discussed at reviews.

11.5 Once the PHB Expression of Interest Form has been submitted to the CCG the PCCC will then arrange a home visit to discuss the indicative budget and support plan, and agree outcomes developed with the child/young person and/or their family. The meeting will also discuss which type of PHB the family are interested in. A PHB can be made available in a number of ways.

- A **direct payment** made to the young person or their family;
- The agreement of a **notional budget** to be spent by the CCG following discussions with the child or young person, and their family (or other representative) as to how best to secure the provision needed;
- The transfer of a **real budget** agreed as above, to the 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).

11.6 The completed support plan will then be submitted to the PHB Panel for decision. Once the support plan is agreed at PHB Panel then the final budget will be confirmed and finance informed. Direct payment agreements must be signed off (direct payment or real budget) by the Chief Finance and Operating Officer, or his representative, before the budget can start. A PHB is subject to the same review process as continuing care packages of care and therefore if a child/young person is no longer eligible for continuing care, the PHB will cease and a transition plan for support from existing universal or specialist services will be implemented.

11.7 The CCG is only obliged to provide services that meet the assessed needs. A parent/carer has the right to decline NHS funded services and make their own private arrangements.

11.8 For more guidance on personal health budgets, see guidance on the "right to have" a Personal Health Budget in Adult NHS Continuing Healthcare and Children and Young People's Continuing Care (September 2014).

## **12.0 FAST TRACK**

- 12.1 End of Life care refers to a rapidly deteriorating condition characterised by an increasing level of dependency, whereby the lifespan is thought to be days or weeks rather than months or years.
- 12.2 Any child or young person deemed to be requiring End of Life Care will require a Fast Track assessment for immediate provision of continuing care. In these cases the **'Children and Young People's Continuing Care Fast Track'** documentation (appendix 9) will be completed by the appropriate professional and sent to the PCCC. The PCCC will discuss immediately with the Commissioning Manager-Children, Young People and Families and determine appropriate provision. In emergency cases, the PCCC or any other person acting with the authority of the Director of Commissioning, or any other executive director, can agree continuing care provision outside of the usual process with notification and discussion afterwards.

## **13.0 DISPUTES, APPEALS AND COMPLAINTS PROCESS**

- 13.1 In the event of a decision which did not meet their preferences and/or expectations, the child/young person and their family will have been informed of their rights and of the complaints procedure.

### **Complaints/Disputes**

- 13.2 Should a child/young person and/or their family wish to complain about a package of care or a service already being provided or commissioned, they should make this known to the PCCC. The PCCC will work with the family to resolve the dispute.

### **Appeals**

- 13.3 Following the decision from the Continuing Health Care Panel, a letter will be sent to the child/young person or their family/carer stating whether or not the child/young person has met continuing care eligibility or not.
- 13.4 Following CHCP agreed eligibility; the PCCC will make contact with the child/young person and family and discuss the level of support offered.
- 13.5 If the panel decision and/or provision offered is not agreed with, the parent/carer has the right to appeal and request a review of the decision.

### **Stage 1: First Line Appeal**

- 13.6 The parents/carer should contact the PCCC to discuss their concerns/issues. The decision-support tool (and resource allocation tool, where appropriate) will be discussed in detail at a mutually agreed time and place with the PCCC and Commissioner for Children, Young People and Families and will aim to seek agreement where possible. If the family wish for additional information to be considered then the PCCC will update the assessment (where appropriate) and represent this to the next Continuing Healthcare Panel for a review of the decision. Parents/Carers must appeal within 6 months of the date of the panel outcome letter.

## **Stage 2: Local Resolution Panel**

- 13.7 If the parent/carer remains dissatisfied with the decision of the panel and/or provision offered or there is no agreement then they must write to:

**Director of Commissioning  
Dudley Clinical Commissioning Group  
2<sup>nd</sup> Floor Brierley Hill Health and Social Care Centre  
Venture Way  
Brierley Hill  
West Midlands  
DY5 1RU**

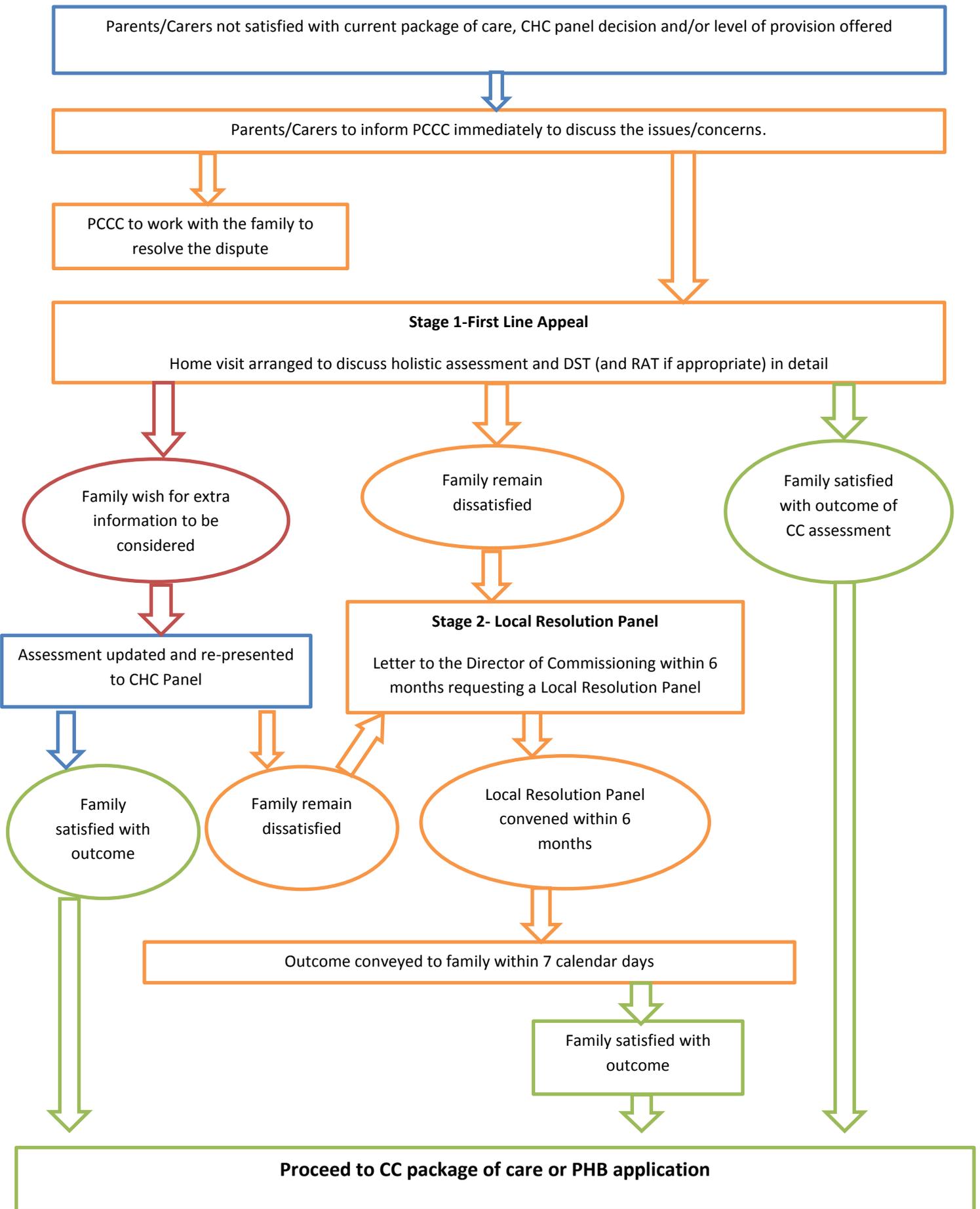
within 6 months of receiving the assessment decision, declaring why they disagree and that they wish to appeal.

- 13.8 Upon the receipt of this letter, and following approval by the Director of Commissioning, a Local Resolution Panel will be convened and the appellant/s will be invited to attend within 6 months dependant on receipt of information from the various Health and Social Care bodies involved in the care of the child/young person.
- 13.9 The CCG and the child/young person and/or their family/carer will be asked to present their respective cases to the panel.
- 13.10 The panel membership will consist of an Independent Chair (appointed by the CCG), a Non-Executive Director of the CCG and a representative from Dudley MBC. The decision from the Local Resolution Panel will be conveyed to the family verbally and in writing within 7 calendar days. The decision from the Local Resolution Panel is final.
- 13.11 The terms of reference for the panel are as follows:-
- “To consider and determine any appeal against a decision regarding the package of care awarded for Children’s Continuing Care.”
- 13.12 The existing package of care will remain unchanged until the appeal process is concluded.

## **Organisational Disputes**

- 13.12 Continuing care arrangements have the potential to generate disputes regarding responsibilities for health, social care and education funding.
- 13.13 All organisational disputes will be managed in accordance with the Dispute Resolution Policy (appendix 10).

## NHS Dudley CCG Appeals Process



## Appendices

APPENDIX	TITLE	PAGE
1	<b>National Frameworks (2016) Children and Young People's Continuing Care Pre-Assessment Checklist</b>	 Continuing_care_pre-assessment_checklis
2	<b>Children and Young People's Continuing Care Information Leaflet</b>	 Continuing Care Leaflet.rtf
3	<b>Children and Young People's Appeals Process leaflet</b>	 Appeals Leaflet.docx
4	<b>Children and Young People's Continuing Care Consent Form</b>	 Consent Form.docx
5	<b>National Frameworks (2016) Decision Support Tool</b>	 Decision_support_to ol_Feb_16 (2).rtf
6	<b>Dudley CCG's Resource Allocation Tool</b>	 Resource Allocation Tool NEW.docx
7	<b>Continuing Care Transition Notification Form</b>	 Continuing Care Transition Notification
8	<b>Children and Young People's Continuing Care Personal Health Budget: Expression of Interest Form</b>	 PHB Expression of Interest Form.docx
9	<b>Children and Young People's Continuing Care Fast Track</b>	 Continuing Care Fast Track Document.rtf
10	<b>Dispute Resolution Policy</b>	 CHC dispute policy.docx