

**CONSULTATION  
ON A  
NATIONAL FRAMEWORK FOR ASSESSING  
CHILDREN AND YOUNG PEOPLE'S  
CONTINUING CARE**



department for  
**children, schools and families**



*Department  
of Health*

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<b>For Recipient's Use</b>	

## CHILDREN AND YOUNG PEOPLE'S CONTINUING CARE

### INTRODUCTION

1. You are invited to comment on our proposals for a National Framework for assessing children and young people's<sup>1</sup> continuing care. The Framework is intended to assist Primary Care Trusts (PCTs) to apply a consistent and transparent approach to assessing the healthcare needs of children and young people and to work jointly with local authorities (LAs) to provide services in the light of those needs. This Framework will apply in respect of children and young people under the age of 18 years.
2. Currently there is no single tool for assessing children and young people's continuing care needs so PCTs have adopted their own procedures and some have adapted the adult continuing care framework. The decision about whether a child or young person is eligible for a continuing care package is therefore based on local procedures and may vary from area to area. The Government thinks this is not acceptable and wants to see a transparent and consistent national assessment process.

### What is Children's Continuing Care?

3. *Continuing Care* is a general term that describes a tailor made package of care needed over an extended period of time for children with complex health needs which arise because of disability, accident or illness (including life limiting or life threatening conditions). This is for children and young people whose health needs cannot be met by existing local health services. The aim of the package is to support the child/young person's parents or carers to manage their child/young person's care at home and/or in other settings. It may require services from the NHS and/or social care to enable the person to function in the community.
4. Children's continuing care is different from NHS Continuing Healthcare for adults. It is care provided in a child and family centred way either in the family home, at school or college, or in residential care settings, including residential special schools. The needs of children and young people are different to those of adults. This is because of their growing and developmental needs, the right to education for children of compulsory school age (5-16 years old), and the dependency of children on their parents as carers. This means families will require support from education and social services provided through joint working between the agencies but with each agency responsible for meeting the cost of their respective contribution to the care package.

5. Continuing care of children & young people with complex needs, who are at home, is provided mainly by their parents and families. For some of these children health input may be required either to support their families or to provide care under skilled supervision. However, across England, there is no single systematic framework for assessing children and young people's needs for continuing care, where there are health needs.
6. Social services for children are provided under the Children Act 1989, following an assessment under the *Framework for the Assessment of Children in Need and their Families*. Each local authority providing children services sets its own eligibility criteria for social care and therefore, children and families experience different thresholds too. Both the Children's National Service Framework 2004( NSF) , the Framework for the Assessment of Children in Need and more recently, guidance for children under 3 years old who are disabled or have complex health needs advocates multi-agency comprehensive needs assessment and joint planning of care with integrated provision to help maximise children and young people's development and achievement in life. Likewise, the Disability Discrimination Act 1995 makes it unlawful to discriminate against disabled children with a physical or mental impairment where that has a substantial long-term adverse effect on their ability to carry out normal day-to-day activities.
7. Nonetheless, current continuing care arrangements, in relation to health or social care have a capacity to generate disagreements about agency responsibilities and funding, which maybe complicated further by the right to education for children aged 5-16 years old and the duty of local authorities to make it available for all children of these ages. The growth of children and young people is one of rapidly changing physical, intellectual and emotional maturation in the context of social and educational development. Their continuing care needs are therefore best addressed holistically, and on a joint basis where agencies are involved in the providing them with public services or care'

### **Adult continuing care**

8. NHS Continuing Healthcare however, is a term exclusively for use in adult services ie over age 18. It refers to a complete package of ongoing care and funding arranged and solely funded by the NHS, where a person's health need has been assessed as a primary health need. It means that because of a condition (physical, mental, psychological or emotional) all their resulting care needs are such that it is the responsibility of the NHS to provide, whether at home or in a care home.

## Context

9. The Children's NSF sets out the vision for disabled children's services.

Standard 8:

*Children and young people who are disabled or who have complex health needs receive co-ordinated, high quality child and family centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives*

10. In September 2006, DH completed consultation on the *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care in England*. The consultation did not cover people under 18 years old. It promised a separate paper on children and young people's continuing healthcare and acknowledged that "whilst similar principles and values should apply, there are different legislative drivers for younger people's services, including their need for social care and education."
11. The Health White Paper *Our health, our care, our say*, published in January 2007, pledged to "clarify how the NHS Continuing Care strategy should work for children." The White Paper also required that "for disabled children, children with complex health needs and those in need of palliative care, PCTs should ensure that the right model of service is developed by undertaking a review to audit capacity (including children's community nursing) and delivery of integrated care pathways against National Service Framework standards, agreeing service models, funding and commissioning arrangements with their SHAs."
12. The development of the National Framework for Children & Young People's Continuing Care was informed by the following questions which were discussed at a stakeholders's event in March 2006:
- What do you think the scope of a children and young people continuing care framework should be?
  - If the scope should be limited very clearly to those children and young people whose need is primarily for healthcare, do the parallel care planning processes within social care and/or education join up to meet their needs? Where are the gaps?
  - For those children and young people with complex needs that are not mainly for healthcare, is there sufficient clarity to determine and meet social care and/or education needs?

- d. Can the Adult National Framework for NHS Continuing Healthcare be made sufficiently comprehensive to meet the agreed healthcare needs of children and young people?

13. The response from stakeholders suggested that a key difference between adult and children and young people's continuing care, is the growing or developmental needs of children and the involvement of education. It was quite feasible and essential, particularly for the transition to adult services, to build on the *National Framework for NHS Continuing Healthcare*. It was thought that:

- a. A whole system approach is needed that reflects an integrated care pathway for children with complex health needs.
- b. All children and young people with complex health needs and/or disability should be included from birth through transition to adult services, but the framework should enable an early screening out.
- c. A minimum outcome should be an adequate assessment that enables decision-making about what healthcare should be put into place ;
- d. The process should enable identification of the need to refer to education or social services, underpinned by PCTs working strategically with local authorities, schools and colleges and early years' settings;
- e. The assessment for continuing care should enable identification of tiers 1 and 2 CAMHS needs and referral for more specialist assessment;
- f. The Framework should enable early identification of needs that may require services from the NHS.
- g. Defining an assessment framework that could work for children and young people would have been difficult from scratch, as children with such complex health needs rarely need healthcare only. The [then] proposed adult Framework provides a way forward with some modifications in terms of the domains of need. Overall, the defining difference with adults is the right to education for children of compulsory school age (5-16 years old), and the dependency of children on their parents as carers.
- h. Recognition that the policy and legislative drivers for adult continuing healthcare do not apply to children but there is an issue in common of postcode lottery in access. In particular that the issue of "primary health need" is therefore not a key driver in children and young people's continuing care and the consequential issue of "eligibility" for "fully funded" NHS continuing healthcare is not a major consideration for children and young people.

- i. Opinion was split on the extent to which a children and young people's continuing care framework for healthcare needs, should nonetheless, extend beyond assessment of need to include entitlements to care packages or further eligibility for specified levels of care. It was thought that at the very minimum, a children and young people's continuing care framework should give an indication of the sorts of packages of care that may be put into place to meet different levels of assessed need.
  - j. The continuing care framework that emerges should allow immediate action to be taken or for access to be fast-tracked to end of life care for the children and young people who may need it.
14. In May 2007 a joint HMT/DfES report was published on services for disabled children (including those with complex health or palliative care needs), *Aiming high for disabled children: better support for families*. The Report identified three priority areas to improve outcomes for disabled children:
- Access and empowerment
  - Responsive services and timely support; and
  - Improving quality and capacity

To empower disabled children, young people and their parents, the Government has published a clear standard - a national core offer that encompasses minimum standards on information, transparency, participation, assessment and feedback to make it clear what entitlements and services families can expect. Both LA and NHS services now need to draw up their local core offer.

15. Application of the National Framework will contribute to how PCTs with their LA partners meet this commitment locally. It will also enable children and young people, parents and carers to understand the basis on which decisions are made and to challenge decisions.
16. Disabled children and their families will also be more fully involved in local service development and in designing their packages of care.

### **The National Framework for Assessing Children's Continuing Care**

17. The National Framework for children is based on the provisions and responsibilities of the current legal framework. When the National Framework is operational, PCTs will be expected to determine a child or young person's need for continuing care by reference to the assessment process set out in the Decision Support Tool in the National Framework.

18. The National Framework consists of the following:

- A Decision Support Tool (DST) to aid identification of continuing care needs in children and young people and eligibility for continuing care in order to inform local decision-making about the care that is needed ;
- A Continuing Care Pathway to help plan, design and deliver services. This Care Pathway is based on the Association for Children's Palliative Care Integrated Multi-agency Care Pathway for Children with Life Threatening and Life-limiting Conditions
- Brief summary of the Haringey case which determined that the *Coughlan* criteria, used to determine whether a local authority or a Primary Care Trust should provide required services to an adult in need of NHS continuing care, applied equally to children.

Good practice material will be published to help PCTs when the final National Framework is published.

19. Application of a National Framework will ensure that all PCTs are applying the same assessment criteria in reaching their decisions. Furthermore families will know the basis on which the decision is made and will be able to bench mark their PCT provision with other PCTs across the country. They will also be able to challenge their PCT on provision of children's continuing care locally.

20. The draft National Framework has been developed in consultation with representatives from health and social care and voluntary organisations. An earlier draft was piloted in 12 PCT areas and an evaluation of their experiences was undertaken. The draft has been refined as a result of the experiences of the pilot sites.

21. Directions could require PCTs and LAs to apply the DST when assessing a child or young person's continuing care needs. We are considering the status of the Decision Support Tool and whether the Secretary of State should exercise the powers conferred on him by S8, 272(7) and 273(1) of the NHS Act 2006 and S7A of the Local Authority Social Services Act 1970. Annex A refers.

### **Eligibility for continuing care**

22. It is a principle of the National Framework (paragraph 13) that the assessment should be based on the health needs of the child or young person without consideration of the costs. However, PCTs are responsible for determining local service provision and priorities to meet the needs of their local population. This means that after an assessment of the child or young person's continuing care needs the PCT will have to decide what care to put in place (paragraph 24).



## **Developing services to meet identified need**

23. Services for disabled children (including those with complex health and palliative care needs) will be the subject of a new indicator from 2009-10. This indicator will be based on a survey of parents of disabled children measuring their families general experience and their experience of the elements of the core offer. This indicator will underpin PSA 12 nationally and will be one of the vital signs, as an option identified for consideration as a local priority for PCTs by the National Operating Framework for the NHS in 2008/09. It will also form part of the National Indicator Set for local government and LAs and PCTs will need to be mindful of this when developing services.

## **Consultation Questions**

24. We would welcome your views on the draft National Children's Continuing Care Framework. A list of questions is attached at Annex B.

Please send your comments by 31 December 2008 to  
[cccconsultation@dh.gsi.gov.uk](mailto:cccconsultation@dh.gsi.gov.uk)

If you are unable to respond electronically, please send your response to-

Pat Nicholls  
Department of Health  
Area 211  
Wellington House  
133-155 Waterloo Road  
London  
SE1 8UG

## **The Consultation Process**

### **Criteria for consultation**

This consultation follows the 'Cabinet Office Code of Practice', in particular we aim to:

- consult widely throughout the process, allowing a minimum of 12 weeks for written consultation at least once during the development of the policy;
- be clear about what our proposals are, who may be affected, what questions we want to ask and the timescale for responses;
- ensure that our consultation is clear, concise and widely accessible;
- ensure that we provide feedback regarding the responses received and how the consultation process influenced the development of the policy;
- monitor our effectiveness at consultation including through the use of a designated consultation co-ordinator; and
- ensure our consultation follows better regulation best practice, including carrying out a Regulatory Impact Assessment if appropriate.

The full text of the code of practice is on the Better Regulation website at:

[Link to consultation Code of Practice](#)

## Comments on the consultation process itself

If you have concerns or comments which you would like to make relating specifically to the consultation process itself please

contact      Consultations Coordinator  
Department of Health  
3E58, Quarry House  
Leeds  
LS2 7UE

e-mail      [consultations.co-ordinator@dh.gsi.gov.uk](mailto:consultations.co-ordinator@dh.gsi.gov.uk)

**Please do not send consultation responses to this address.**

## Confidentiality of information

Information provided in response to this consultation, including personal information, may be published or disclosed in accordance with the access to information regimes (these are primarily the Freedom of Information Act 2000 (FOIA), the Data Protection Act 1998 (DPA) and the Environmental Information Regulations 2004).

If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice with which public authorities must comply and which deals, amongst other things, with obligations of confidence. In view of this it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department.

The Department will process your personal data in accordance with the DPA and in most circumstances this will mean that your personal data will not be disclosed to third parties.

## Summary of the consultation

A summary of the response to this consultation will be made available within three months of the end of the live consultation period and will be placed on the Consultations website at

<http://www.dh.gov.uk/en/Consultations/Responsestoconsultations/index.htm>

## **Annex A**

### **THE DUTIES OF THE PCT AND SOCIAL SERVICE AUTHORITY WHICH MIGHT BE INCLUDED IN ANY MANDATORY DIRECTIONS TO PCTs and LAs**

1. A PCT should take reasonable steps to ensure that an assessment for children's continuing care is undertaken where it appears to the Trust that there may be a need for such care or a review of care already provided.
2. Any assessment is undertaken by a multi-disciplinary team.
3. The Decision Support Tool should be completed and it, together with other relevant information, is used to decide whether the child or young person needs continuing care.
4. Once a decision is taken the child and/or the person with parental responsibility should be notified in writing of the decision, the reasons for the decision and how the decision can be reviewed.
5. The PCT should take reasonable steps to consult with the social services authority before making a decision
6. The social service authority should provide appropriate advice and assistance to the PCT making the decision
7. If it is decided that a child or young person needs continuing care both the PCT and social service authority should state what services they will provide.

**Q. Would these be the correct ones? Do you have any additions?**

## CONSULTATION QUESTIONS

We would welcome your views on the draft National Children's Continuing Care Framework. In particular, we would like you to let us know-

### National Framework

- a) Do you agree that a national assessment process, which includes the Decision Support Tool, is necessary to ensure transparency, consistency?
- b) Are the core values and principles of the National Framework the right ones? **(page 25)**
- c) Is there anything missing from the National Framework? **(page 32)**
- d) Does the draft continuing care pathway accurately capture the child/young person and family's journey? If not why not?**(page 35)**
- e) Are the 3 stages described in the pathway useful? **(page 45)**
- f) Will the flow chart assist you in implementing the pathway? **(page 45)**
- g) Are the four areas of the assessment process the correct ones? **( Annex B page 46)**
- h) Does the diagram on **page 56** help demonstrate the shared approach to continuing care?

### The Decision Support Tool

- i) We are considering the status of the Decision Support Tool and how the duties of Primary Care Trusts and Local Social Services Authorities should be set out. A list of matters which could be covered if Directions to the NHS and LA Children's services were made is at Annex A of the Introduction. Would these be the correct ones? **( Page 12)**
- j) In assessing the care domains is the rating of 3 highs or 1 priority or 1 severe the correct level to indicate a continuing care need? If not what would be? **(page 56)**
- k) Are the domains the correct ones (professional judgement is still important and assessors can add to/override these on a case- by-case basis where they can justify doing so). **(page76)**
- l) Are there any necessary domains missing? **(page 76)**
- m) Do they assist PCTs to understand their responsibilities? **(page**

76)

- n) If you think the use of the Decision Support Tool will lead to an increase in demand for children's continuing care what will be the effect on what can be provided locally?

### **Impact Assessment**

- o) Do you have any comments to make on the Impact assessments and the costings? In particular, the lack of data on the number of children and young people who might need continuing care has meant we have made certain assumptions. If you disagree with those assumptions please provide supporting data from your area wherever possible, including whether the DST will lead to an increase or decrease in the number of children a) assessed, b) need to be considered for funding for continuing care and c) be funded.
- p) Will adoption of the National Framework impact on particular groups of children or their families differently? We believe the proposed Framework could impact positively on families from Black and Minority Ethnic groups but If you disagree please state why.
- q) Are there any specific equality issues we have not considered in the impact assessment?
- r) A more transparent system of assessment should help families understand what care packages can be provided. What effect will this have on the delivery of care (including designing individual care packages, dealing with or resolving disputes and complaints procedures)?
- s) Because PCTs and LAs will still decide which package of assessed need can be funded, we have, for the purposes of the Impact Assessment, assumed that the only overall increase in costs to PCTs and LAs will be relating to training and familiarisation in the new procedures. Is this a reasonable assumption?
- t) Do you have any additional comments?

**NATIONAL FRAMEWORK  
FOR ASSESSING  
CHILDREN'S CONTINUING CARE NEEDS**

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## Glossary

Children's Continuing Care is intended for children, young people, families, NHS organisations, local authorities and all other providers of services for children and young people. It provides a systematic approach to assessing the ongoing health needs of children, 0-18 years of age, who require support over and above those that can be met by existing universal services (eg GPs and HVs) and specialist (eg Community Children's Nurses, CAMHS). This will be done as part of a holistic multi-agency plan.

### **1. The National Framework**

This document sets out the policy on a national framework for Children and Young Peoples Continuing Care to assist PCTs to apply a consistent and transparent approach to assessing the healthcare of children and young people and to work jointly with local authorities to provide services in light of those needs.

### **2. Legal Framework**

We set out the main responsibilities for the NHS and Local Authorities that are in primary legislation. We point out the links to other policies and guidance that may be relevant to this Framework.

### **3. Key Principles and Core Values**

We set out the main things to remember when assessing children and young people's continuing care. The child, young person and their family should be kept at the heart of the process. We set out best practice which should underpin the national framework.

### **4. An Assessment Process**

Following recognition that the child or young person's health needs require additional support the lead professional will refer to the local PCT lead for Children's Continuing Care. A nominated health assessor will gather evidence from the child and family, and the multi-agency team supporting them, using existing reports whenever possible following the guidance set out in Annex B.

The completed evidence will be presented to the decision making forum for a judgement about eligibility and subsequent package of care. The health contribution will consist of between 1-99% of the funding of the care package based on the child or young person's health, social care, education and family needs. This decision will then be communicated to the child and family. The lead professional will provide ongoing support, coordination and review of the package.

### **5. A Care Pathway**

A continuing care pathway has been designed to be used with all children and young people with complex health needs who may require continuing care. There are five sentinel standards across three stages, supported by goals to help users of the pathway identify the steps needed to achieve the standards.

## **6. Dispute Resolution**

PCTs should deal promptly with any requests to review disagreements about the children and young peoples continuing care assessment or decision. PCTs will usually have a local resolution process, usually in the form of a PCT panel. Ultimately, children, young people and their families can use the NHS complaints procedure to resolve concerns or disputes.

## **7. Governance**

Both PCTs and SHAs have roles in ensuring that governance arrangements are in place and for overseeing the process.

We hope that this framework provides practical guidance to enable all agencies to work together to ensure that children and young people with ongoing health needs receive equitable care that results in them achieving the best possible outcomes.

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## The Policy Framework

### Introduction

25. This document sets out a National Framework for assessing children and young people's<sup>1</sup> continuing care. The National Framework builds on the Children's National Service Framework and aims to ensure that all PCTs apply a consistent and transparent approach to assessing the continuing care needs of children and young people and to work jointly with local authorities to provide services in the light of those needs. Application of the National Framework will enable children, young people, parents and carers to understand the basis on which decisions are made about their care and to benchmark their own PCT against others in the country and if necessary to challenge the assessment process or decisions. Application of the National Framework will also contribute to the local delivery of the Aiming high for disabled children (AHDC)Core Offer<sup>2</sup> principles of information and transparency, participation, assessment and feedback.
26. This Framework is primarily for PCTs but LAs need to be aware of it as each organisation has a duty to cooperate<sup>3</sup> with the other to promote the health and wellbeing of children.
27. The Framework only applies in respect of children and young people under the age of 18 years.
28. In addition to setting out PCT and SHA responsibilities, the National Framework consists of the following:
- **Annex A** - a Continuing Care Pathway;
  - **Annex B** - a Decision Support Tool (DST);
  - **Annex C** - a summary of the judgement in the case of T,D,B and London Borough of Haringey and D and Haringey PCT<sup>4</sup>

### Adult continuing care

29. NHS Continuing Healthcare<sup>5</sup> is a term exclusively for use in adult services. It refers to a complete package of ongoing care and funding arranged and funded solely by the NHS, where a person's health need has been assessed as a primary health need. It means that because of a condition (physical, mental, psychological or emotional) all their resulting care needs whether at home or in a care home, are such that it is the

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<sup>1</sup> For the purposes of children's continuing care, the term "child" means a person under the age of 18 years but children's services authorities also have some social services (and education) responsibilities for persons who are over 18 and the powers and duties under section 10 of the Children Act 2004 extend to these persons.

<sup>2</sup> Aiming high for disabled children: <http://www.everychildmatters.gov.uk/socialcare/ahdc/coreoffer>

<sup>3</sup> Children Act 2004 S 10(5)

<sup>4</sup> T,D,B and London Borough of Haringey and D and Haringey Primary Care Trust. High Court Judgment, 21 October 2005R (on the application of D and another) v Haringey London Borough Council [2005] All ER (d) 256.

<sup>5</sup> National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care in England. Consultation Document. Department of Health 2006.

responsibility of the NHS to provide.

### What is Children's Continuing Care?

- 30.** Children's continuing care is different from NHS Continuing Healthcare for adults. Children's continuing care means a package of care needed over an extended period of time for children with complex healthcare needs which arise because of disability, accident or illness<sup>6</sup>. It may require services from the NHS and/or social care to enable the person to function. The needs of children and young people are generally more diverse as inevitably there will be elements of their overall care which will require support and funding from education and/or social services which will necessitate joint working between the agencies. Each agency remains responsible for funding their own contribution to the care package.
- 31.** Continuing care of children & young people with complex healthcare needs who are at home is provided mainly by their parents and families. For some of these children health input may be required either to support their families or to provide care under skilled supervision.
- 32.** Social services for children are mostly provided under the Children Act 1989, following an assessment under the *Framework for the Assessment of Children in Need and their Families*.<sup>7</sup> Although children's services are not 'means tested' each local authority sets its own eligibility criteria and therefore, children and families experience different thresholds. The guidance for children under 3 years old who are disabled<sup>8</sup> or have complex health needs<sup>9, 10</sup>, the Children's National Service Framework (NSF), and the Framework for the Assessment of Children in Need expect a comprehensive multi-agency needs assessment and joint planning of care with integrated provision to help maximise children and young people's development and achievement in life. The Disability Discrimination Act 1995,<sup>11</sup> proscribes service discrimination against disabled children with a physical or mental impairment where that has a substantial long-term adverse effect on their ability to carry out normal day-to-day activities.
- 33.** The growth of children and young people is one of rapidly changing physical, intellectual and emotional maturation in the context of social and educational development. This means their continuing care needs

<sup>6</sup> The NHS Act 2006: "Illness" includes mental disorder within the meaning of the Mental Health Act 1983 (c. 20) and any injury or disability requiring medical or dental treatment or nursing.

<sup>7</sup> Department of Health, Department for Education and Employment and the Home Office. Framework for the Assessment of Children in Need and their Families. The Stationery Office 2000

<sup>8</sup> Together from the Start. Practical guidance for professionals working with disabled children (from birth to third birthday) and their families. DfES May 2003

<sup>9</sup> There are no clear definitions of complex health needs but it is generally recognised that it includes children with multiple health needs whose care pathways require co-ordination because of the complexity of service provision. This would include children with complex or multiple disabilities who need medical care, as well as children with multiple health conditions, or complex symptoms or those requiring palliative care. It may also include children with a statement of special education needs statement where health contributes to meeting their needs.

<sup>10</sup> Including me. Managing complex health needs in schools and early years settings. Council for Disabled Children, DfES2005

<sup>11</sup> The Disability Discrimination Act 1995. The Stationery Office

are best addressed holistically, and on a joint basis with all the agencies which are involved in providing them with public services or care<sup>12</sup>.

### **Children & Young People Covered by this National Framework**

34. The Framework covers children and young people with complex healthcare needs which arise because of accident, illness or disability. It may include children and young people with life limiting or life threatening conditions. It is not designed for use where children and young people have less complex or preventive care needs which may be managed more appropriately through access to universal or specialist health services.
35. Feedback from children and parents during the development of this Framework emphasised the complexity of healthcare needs for these children and young people, particularly the critical role played by families in providing the majority of their care and supporting their children to live at home, and the importance of providing support that is high quality, responsive and well coordinated across the relevant agencies.

#### **An example of cases requiring a continuing care assessment**

“Both A and B (brother and sister) have significant, complex and unstable health needs associated with their disabilities. Their impairments are caused by a genetic condition that is life limiting, meaning that the older they get the more complex their impairments are becoming and, as a consequence, the greater the dependency on medical and technological support and the competency of support staff around them becomes.

Following a recent deterioration, A has recently had a tracheotomy, needing regular intra-tracheal suction which is further complicated by respiratory infections. A also needs 24 hour constant support with seizure management, gastrostomy feeds, complex medication regime, resuscitation when required, continence and all personal care. B also needs 24 hour constant support and has similar needs to his sister but has not yet had a tracheotomy. Both A and B are at risk of mental health depression because of their disabilities and inability to communicate. The level of mental impairment has not been adequately assessed but it appears that both A and B have complex communication issues exacerbated by complexity of disability rather than significant learning disabilities.”

Source: Families working with the Valuing People Support Team, CSIP

<sup>12</sup> Every Child Matters (Cm 5860). The Stationery Office, September 2003.

## The National Framework on Children's & Young People's Continuing Care

### Key Principles and Core Values

36. This section of the Framework document sets out the core values, principles and best practice for considering continuing care needs which underpin an integrated National Framework for Children & Young People's Continuing Care. These values and underpinning principles were developed in consultation with representatives from health, local authority children's services, schools, voluntary organisations, children and young people and their carers.

- i. The National Framework for assessing children and young people's continuing care applies only to those with complex "healthcare" needs. However to meet their needs for continuing care more generally, implementation at local level requires clear arrangements to ensure multi-agency input for primary and secondary care, local authority children's social care and education and, during transition to adult care, adult health and social care and further education establishments.
- ii. Unlike the *National Framework for NHS Continuing Healthcare* i.e. the adult Framework, the scope of children and young people's continuing care is not limited to 100% primary health need and enables identification of a spectrum of health, social care and education needs .
- iii. A proper assessment of continuing care needs will involve a clear, reasoned evidence base from a range of sources which takes account of the child's particular needs in a holistic and family-centred context<sup>13</sup>. Children with complex needs will often have had a range of other individual assessments, for example from the common assessment framework<sup>14,15</sup>, or specialist assessments. The results of these should inform the continuing care assessment.
- iv. A whole system approach that reflects an integrated care pathway should be taken for children with continuing care needs. This will ensure primary, secondary or tertiary care is co-ordinated, referrals to or input from specialist assessment such as in CAMHS are made, and the need to refer to education or social care is identified, if not being met already. It is essential that PCTs and local authorities

<sup>13</sup> The term "family" refers to mothers, fathers, carers and other adults with responsibility for caring for a child; and includes the child's siblings, even if they may be looked after

<sup>14</sup> Common Assessment Framework: Practitioners' and Managers' Guides. DfES, April 2006

<sup>15</sup> The Common Assessment Framework for Children and Young People: Supporting Tools. DfES, 2006



work together at a strategic level often through children's trust arrangements, to take the lead and agree the vision for commissioning continuing care for children and young people<sup>16,17</sup>.

- v. The assessment and delivery of children and young people's continuing care should be organised so that the child/young person, their parents and their carer(s) understand the process and receive advice and information to enable them to participate in informed decisions about the child's future care. The assessment and decision-making process and funding arrangements should be transparent to children, young people and their families, and staff from the outset. The arrangements should meet the standards in the AHDC Core Offer<sup>18</sup>
- vi. Consideration of provision to children and young people needing continuing care is based on the person's assessed health needs and is not disease-specific, nor determined by either the setting where the care is provided nor who delivers the care. Access to assessment should be transparent and the basis of subsequent local decision-making must be fair, with no discrimination based on age, disability, condition or type of health need (e.g. physical, psychological, emotional or mental).
- vii. When the PCT and LA are deciding how the child or young person's needs are to be met their choices and wishes and those of their family, regarding how and where the care will be delivered, need to be taken into account, along with the risks of different types of provision and fairness in access to resources. Where a child or young person and family's needs or choices are not met clear reasons should be given to them.
- viii. A decision on the continuing care that may be provided should not be budget or finance led; the primary consideration should be the child's assessed health needs being supported within the available resources.
- ix. Parents and families provide the majority of care to the child or young person and need to be supported to manage the risks and be skilled and confident in their caring, whilst ensuring that quality of life is maintained for the family as a whole.

<sup>16</sup> Commissioning framework for health and well-being. Department of Health, March 2007.

<sup>17</sup> Joint Planning & Commissioning Framework for Children, Young People & Maternity Services. HM Government, March 2006

<sup>18</sup> Aiming high for disabled children: <http://www.everychildmatters.gov.uk/socialcare/ahdc/coreoffer>

- x. Maintenance of consistent relationships is a particularly important aspect of continuing care of children and young people with complex healthcare needs and more so where they communicate non verbally. This requires a consistent approach to care.
- xi. The Children and Young People's Continuing Care Framework should not restrict access to end of life care for children and young people, as that requires immediate action over shorter periods.

In summary, the core values and principles of the policy on assessment are set out below:

- Children and young people's continuing care assessment and subsequent decisions about care are needs led, not based on diagnosis alone, and acknowledge layers of complexity.
- A comprehensive, multi professional assessment and subsequent decision about provision of care are made in context of the child's or young person's social care, education and family needs and are as joined up as possible.
- The assessment and provision of children and young people's continuing care and assessments are available in a variety of settings.
- The continuing care assessment draws on earlier assessments that the child or young person may have already undergone.
- Assessment of children and young people for continuing care considers the safety of the care to be provided and takes account of safeguarding policies and legislation. .
- Decisions about the provision of continuing care supports and enhances the care that parents/family are giving already to the child or young person, enables them to develop meaningful relationships with the whole family through provision of consistent and skilled support and takes account of the family circumstances and the child's and family's preferences.
- Assessment of children and young people's needs for continuing care considers whether there is further potential for rehabilitation and how the outcome of any treatments or medication may affect ongoing needs.
- The risks and benefits to the child or young person of a change of location or support (including funding implications) are considered carefully before any move or change is confirmed.



- Decisions about continuing care are fair, culturally sensitive, client-centred and do not marginalise a need because it is being managed well by the family or carers.
- The assessment and decision making process meets the standards set out in the National AHDC Core Offer<sup>19</sup>.
- Regular reviews are built into the process.

### Q. Are the principles and core values of the National Framework the right ones?

## PCT Responsibilities for Continuing Care

### Commissioning

37. Although they can delegate commissioning itself to practice-based commissioners, PCTs are the responsible commissioners<sup>20</sup> for children and young people's continuing care where there are health requirements. It is essential they work in collaboration with local authority children services (as well as early years' settings and schools) from the earliest opportunity. The *Joint planning and commissioning framework for children, young people and maternity services*<sup>15</sup> introduces a framework to help local commissioners (both PCTs and LA Children's services) to design a unified system in each local area for a joined-up picture of children and young people's needs and collaboration to achieve best use of joint resources for better outcomes.
38. The judgement in the Haringey case<sup>21</sup> helped to clarify the scope of continuing care nursing and medical provision that falls outside the scope of the Children Act 1989 (**summary at Annex C**)
39. Under section 10 of the Children Act 2004, PCTs are under a duty to co-operate with local authority children's services and other key partners in making arrangements to improve the well-being of children in their population and must have regard to guidance given by the Secretary of State in exercising their functions in that regard. "Well-being" is defined by reference to the five key Every Child Matters outcomes. *Statutory Guidance on Inter-agency Co-operation to Improve the Wellbeing of Children: Children Trusts*<sup>22</sup> sets out examples of the arrangements that authorities could make to give effect to this duty, in terms of joint working at strategic levels as well as in front-line teams. Joint working embraces

<sup>19</sup> Aiming high for disabled children: <http://www.everychildmatters.gov.uk/socialcare/ahdc/coreoffer/>

<sup>20</sup> National Health Service (Consequential Provisions) Act 2006. .

<sup>21</sup> R (on the application of D and another) v Haringey London Borough Council [2005] All ER (D) 256

<sup>22</sup> Statutory Guidance on Interagency Co-operation to Improve the Wellbeing of Children: Children Trusts, HM Government, Department for Education and Skills, 2005

joint assessment of population need, joint planning and joint commissioning with pooled budgets, setting priorities and providing the necessary resources. The Children and Young People's Plan (CYPP) is an important tool in driving forward better local integration of children's services and the development of local partnership arrangements.  
23,24,25,26

40. The voices of children, young people and their families are expected to inform local design and delivery arrangements of services. This is reinforced in *Aiming high for disabled children* and in the Local Government and Public Involvement in Health Act 2007. The *Joint Planning and Commissioning Framework for Children, Young People & Maternity Services*<sup>16</sup> sets out the processes for commissioning integrated and well-designed services for children and young people. *Commissioning for Health and Wellbeing*<sup>16</sup> reaffirms the need for momentum in joint commissioning in children services.
41. PCTs have a duty under section 244 et seq of the National Health Service Act 2006 to consult with local authority Overview and Scrutiny Committees at a formative stage on any proposed changes to the provision of local health services (not just changes to hospitals). This consultation with local authorities is required where PCTs have under consideration any proposal for a substantial development of the health service in the local authority's area; or a substantial variation in the provision of such service. Overview and Scrutiny Committees can refer proposals they are unhappy with to the Secretary of State for decision.
42. In addition, regarding health services for which they are responsible, PCTs have a duty under the Local Government and Public Involvement Act 2007 to make arrangements to secure that the public are, directly or through representatives, involved in and consulted on:
- a. planning of the provision of health services;
  - b. the development and consideration of proposals for changes in the way those services are provided; and
  - c. decisions to be made by the NHS body affecting the operation of those services.

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(a) <sup>23</sup> The [Children and Young People's Plan \(England\) Regulations 2005](#). (SI 2005/2149)

(b) <sup>24</sup> The [Children and Young People's Plan \(England\) \(Amendment\) Regulations 2007](#) (SI 2007/0057)

<sup>25</sup> [Guidance on the Children and Young People's Plan](#). HM Government, 2005

<sup>26</sup> [Annual Review of the Children and Young People's Plan \(Supplementary Guidance\)](#), DfES 2007

### *Local Co-ordination of the National Framework*

43. The responsible health commissioner can initiate implementation of the National Framework policy, wherever the child or young person resides. It is important that the assessment and decisions about care do not delay treatment or appropriate care being put in place.
44. Use of the National Framework for Children and Young People's Continuing Care will ensure that:
  - a. Those staff whose responsibility it is to make the relevant decisions about children and young people's continuing care have the benefit of access to information on the overall policy and relevant guidance to support decision-making.
  - b. There is full and active involvement of children & young people and their families in the process.
  - c. The Framework is promoted so that the public, health and social care practitioners, and the independent and voluntary sector understand the basis of identifying continuing care needs in children and young people and how to access it.
  - d. Professionals work within the Framework to assess a child or young person's type and level of care needs in order to aid decision-making about care.
  - e. The process of assessment and decision-making are co-ordinated.
  - f. Children and young people who require fast tracking because of the nature of their needs (e.g. if a prognosis indicates end of life care need) are identified early and fast-tracked to make sure their needs are met as quickly as possible.
  - g. The continuing care information includes the results of any relevant assessments that the child or young person may have undergone already e.g. such as the Common Assessment Framework or specialist assessments.
  - h. The use of the National Framework is built into local assessment processes so that full assessments are carried out appropriately.
  - i. Children and young people's needs for continuing care are assessed consistently and fairly, irrespective of the reason for their needs or the nature of those needs.
  - j. Decisions about care are made with reference to a multi-disciplinary team assessment, and where ever necessary are made jointly with education and social care.

- k. The process is underpinned by effective governance arrangements, including local audits of decision-making.
45. In order to ensure fair and consistent access to continuing care for children and young people, the PCT is responsible for ensuring that the process around use of the National Framework and subsequent decision-making are co-ordinated effectively. Whatever local model is employed, practitioners who have experience and expertise in assessment, a thorough working knowledge of the policy on the National Framework and well developed leadership qualities are necessary to ensure the assessment framework guides practice. The co-ordination functions for which the PCT should ensure arrangements are in place include the following:
- a. Timetables agreed locally, with processes in place to establish reasonable targets for each stage.
  - b. Local authority children services as well as schools and early years' settings are involved appropriately in the process and, whether involved or not are, informed of the outcome of the assessment.
  - c. Case management of the decision support process to ensure all relevant input from the NHS multidisciplinary team assessment and any interagency contributions are completed in a timely manner.
  - d. Liaison with the child or young person and their carer/family, if appropriate, to ensure they are kept fully informed and involved throughout the process and informed of the outcome and reasons for the decision.
  - e. Communication with children, young people and their families to inform them that decisions regarding continuing care depends on needs and that regular reviews are necessary to assess and meet changing needs.
  - f. Identification of children and young people who should be fast-tracked for immediate care.
  - g. Co-ordination and evaluation of NHS multi-disciplinary team input using the Decision Support Tool.
  - h. Ensuring that results of assessments are collated, evidenced and presented to the commissioning body with associated risks and benefits for decisions about what care to put into place.
  - i. Discussion with the child, young person and their family on the next steps and timeframes to implement the care plan and/or inform the child and family of their rights.

- j. Ongoing case management for those children in receipt of children and young people's continuing care.

### *Timetables*

46. As well as robust information timetables are important for the following reasons and should be agreed locally and followed from referral to completion of assessment and decision, with appropriate flexibilities to fast-track children and young people with life-threatening illnesses:
- a. it is in the best interest of the child or young person for the outcome to be known as soon as possible;
  - b. it highlights the importance of assessment;
  - c. if the child or young person is being discharged from acute care or tertiary care, it increases the likelihood of the child or young person being discharged in a timely manner, and reduces potential for a delayed discharge.

### *Communications*

47. The relationship between assessors and commissioners of children and young people's continuing care is a critical one. It is recommended that a decision on the care package which should be provided is reported back to the referrer within 5 working days of being made, but if the identified needs require fast tracking, report back should be done in shorter period. As far as possible, a decision on which service will be provided should be within 28 working days from the assessment itself, and should be communicated to all concerned both verbally and in writing, giving reasons, where applicable.
48. The decision should be communicated to the NHS multi-disciplinary team and the local authority children's service and school, where appropriate.
49. The PCT should communicate decisions in writing and in an appropriate form to the child or young person and if appropriate, their family or their representative, providing clear reasons for that decision. Exceptionally, information may be withheld from a child or young person or someone with parental responsibility for him/her if the PCT 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 not already, where it is thought that the child is at risk of significant harm or is suffering significant harm.

## *Governance Arrangements*

50. PCTs are responsible for establishing and managing governance arrangements for children and young people's continuing care. Amongst their primary responsibilities are the following:
- a. Ensuring consistency in the application of the National Framework for Children and Young People's Continuing Care.
  - b. Promoting awareness of the National Framework for Children and Young people's Continuing Care.
  - c. Implementing and maintaining good practice.
  - d. Ensuring quality standards are met and sustained.
  - e. Providing training and development opportunities for practitioners.
  - f. Identifying and acting on issues arising in the provision of children and young people's continuing care.
  - g. Strategic commissioning arrangements and influencing and shaping the design of services to deliver effectively to individual children and young people.

## *Review*

51. All children and young people's continuing care packages should be reviewed on an agreed regular basis. A recommended minimum standard is three months from the initial assessment, and then annually or more frequently according to needs.
52. If the nature or level of needs change significantly, a review of the child or young person's needs should be made as it may no longer be appropriate for their needs to be met through children and young people's continuing care.
53. Any such review should be transparent, involve the child/young person and, if appropriate, their family or carer and supported by a rationale/explanation of the decision. Both verbal and written reports should be given to the child/family as appropriate.

## *Dispute Resolution*

54. PCTs should have a system in place to respond promptly to any request to review disagreements voiced by the child/young person or their parent/carer about the continuing care assessment or decision. Most PCTs have a system for review of assessment/decisions either by a senior panel and/or by referral to an out of area continuing care team to provide greater patient confidence in the impartiality in decision-making.



55. In the first instance, the PCT should refer the case as quickly as possible to its local resolution process. This will usually take the form of a PCT review panel, though local procedures may be adapted to include reference to the review panel of a neighbouring PCT to provide greater patient confidence in the impartiality of decision-making.
56. Children, young people and their families can use the NHS Complaints procedures to resolve concerns or disputes. Where local resolution is not achieved under NHS Complaints procedures, complainants may request an independent review from the Health Care Commission in accordance with regulations and guidance. The Healthcare Commission and CSCI will be replaced by a single health and adult social care regulator from 2009. The Health Care Commission has powers to refer complaints to the Health Service Ombudsman. The Ombudsman can consider complaints directly from complainants, where the issue is about unsatisfactory care or treatment, failure to provide a service that ought to have been provided or maladministration, including poor handling of complaints, misleading advice, not providing information to which an individual is entitled or clerical error. In most cases anyone wishing to complain to the Ombudsman will be expected to have put their complaint first to the PCT or practitioner concerned but the Ombudsman has powers to consider complaints where the NHS Complaints procedures have not been exhausted. Children, young people and their families should be informed of these rights.
57. The following key principles for good practice in local resolution of disagreements about children and young people's continuing care have been adapted from best practice material produced by the Ombudsman's office:
- a. Gather and scrutinise all available and appropriate evidence, including that from the GP, hospital (nursing, medical, mental health, therapies etc), community nursing services, care home provider, social care records etc, as well as any evidence submitted by the claimant.
  - b. Compile a robust and accurate identification of the care needs.
  - c. Audit attempts to gather any records said to be not available.
  - d. Involve claimant/carer as far as possible, including the opportunity for claimants to input information at all stages.
  - e. Keep a full record of a review panel's deliberations.
  - f. Make clear and evidenced written decisions to the child and their family, setting out rationale for the decision on children and young people's continuing care on the basis of their needs only, including

clear reasons where a child or family's express preferences are not met.

- g. Recommendation or decision and reasons for it should not be determined on the basis of:
- the inputs required to manage the care needs
  - the setting of care
  - the ability of the care provider to manage care
  - the use (or not) of NHS employed staff to provide care
  - the need for/presence of 'specialist staff' in care delivery
  - any other input-related (rather than needs-related) rationale; nonetheless, the scale or nature of a child or young person's health needs may be such that he/she cannot be properly cared for by the NHS at home, even though it may be what he/she or the family wants.
- h. There is congruency and consistency between the panel deliberations and the recommendation/decision letter.

#### **Q. Is there anything missing from the National Framework?**

#### **Strategic Health Authorities**

58. SHAs are responsible for managing performance of PCTs and should assure themselves that satisfactory arrangements are in place for children's and young people's continuing care, including dispute resolution.

#### **The Continuing Care Pathway**

59. The Continuing Care Pathway at **Annex A** has been developed in conjunction with the Decision Support Tool at **Annex B** to underpin the assessment of Children and Young People's Continuing Care. The Continuing Care pathway is designed to enable a holistic approach to be taken of the child's needs and care and avoid unco-ordinated and fragmented care. It provides:

- a. A map of the journey in/out of integrated care of a child or young person with complex healthcare needs who may also require continuing care;
- b. 5 standards for recognition and delivery of services across 3 areas of the child's journey, from entry through to living with a complex health condition and moving into adult services;
- c. A number of goals to assess that the standards of care are being attained and that children and families are receiving integrated



assessment and timely child-centred services which take families' needs into account.

## The Decision Support Tool

60. The national Decision Support Tool (DST) at **Annex B** has been developed for practitioners in the application of the National Framework to identify children and young people with complex healthcare needs who are eligible for continuing care, in order to inform local decision-making about what care to provide.
61. The DST will help describe and record an overall picture of the type and levels of the child' or young person's care needs in an objective manner taking into account the results of the extensive assessments but the task of deciding on whether a care package is provided and its extent falls to local determination. Professional judgment is paramount and the tool does not seek to replace this.
62. The DST is only one part of the National Framework. It is designed to assist practitioners to gain a full picture of a child or young person's on-going healthcare needs by ensuring that the full range of factors are assessed, so they can be taken into account in the subsequent decision-making process. It is a way of ensuring that a comprehensive assessment of a child's care needs takes place, and is brought together with other pre-existing assessments and recorded in an understandable format, to facilitate logical and consistent decision-making.
63. The DST provides practitioners with needs-led approach by assessing need on the basis of ten 'care domains'. These domains represent generic areas of need into which the various needs of a child and their family can be placed. The domains are sub-divided into statements of need representing low, moderate, high, severe, or priority levels of need and depending on the particular domain not all the levels are represented. The care domains are:
- Challenging Behaviour
  - Communication
  - Mobility
  - Nutrition, Food and Drink
  - Continence & Elimination
  - Skin & Tissue Viability
  - Breathing
  - Drug Therapies & Medicines
  - Psychological/Emotional Needs
  - Seizures
64. The 'levels of need' described in the tool relate to an assessment of complexity, unpredictability and risk as key indicators of a significant health need. These levels are relative to each other and to the other domains; some domains include needs that are so great that they could reach the 'priority' level, others do not.

65. An individual should be identified by the PCT as responsible for coordinating the assessment and to liaise with the multi-disciplinary team to complete the DST and match, as far as possible, the child or young person's level of need with the description that most closely relates to their specific needs. This approach should build up a detailed analysis of a child or young person's needs and provide the evidence to inform the decision about care.

DRAFT

## Annex A

### Continuing Care Pathway for Children & Young People

#### Background

Currently there are a number of differing pathways being used for children and young people; often these relate to access to existing provision and are not based on the needs of children, young people and their families. However, more recently, some local areas are coming together to streamline the process. It is essential that the process includes multi-agency working and jointly-owned reports to have legitimacy for children/young people.

The trigger for entry to this pathway is an emerging recognition that the child/young person has complex healthcare needs. Children and young people can enter this continuing care pathway via a number of different routes, settings and pathways.

#### Introduction

1. The Continuing Care Pathway is designed to be used with all children and young people with complex health care needs who may require continuing care.
2. There are five sentinel standards across three key stages, supported by goals to help users of the pathway identify the steps needed to achieve the standards.
3. Ultimately, the goal is to identify the child or young person's need for continuing care and provide it in a variety of settings by a variety of people. For example, a child or young person's assessment may begin at home, or in discharge pathway from an acute setting or on presentation in general practice and the care could be provided at home, school or in a variety of community settings or even residential settings.
4. Adaptation to local processes may be appropriate. We recognise that sometimes adjustments might be necessary to align it with local procedures (these should not, however, alter the content or the purpose of the pathway).
5. Early multi-agency discussions and identification for entering the continuing care pathway are important.
6. If a continuing care pathway is not thought to be appropriate for a child/young person, then other care pathways may be more applicable
7. There is potential for a child's needs to move in and out of continuing care - and the review process should build in regular review to enable care needs to be assessed and to support the movement of children moving in and out of the continuing care process, while the child's and family's needs continue to be met.

8. The pathway should be supported by a local review process. Parents/service users should be aware of the review process and they should be aware that the process includes a fast-track process to give timely access to other services.
9. The process should enable the child's needs to be considered holistically and there must be engagement and information from all agencies/ those involved with the child.

### Using a care pathway approach

Care pathways have developed in response to the need for services to be more patient-focused. They often concentrate on the treatment and care of people with specific diagnoses. This Pathway builds on the ACT Integrated Care Pathway for children and young people with life-threatening/life-limiting conditions and their families (2004) and aims to facilitate the development of integrated care pathways for children and young people with complex healthcare needs who require continuing care, irrespective of the setting of care. The pathway aims to link children & young people and their families with community services, hospital based services, social services, education and the voluntary sector in one joined up process. This Pathway should help to strengthen and develop strategic partnerships and planning.

#### ***Principles for the development of Integrated Care Pathways***

- They must be developed and "owned" locally by a multi-disciplinary team
- They can cross organisational and inter-agency boundaries
- They include a plan of anticipated care for an identified group
- They make the patient the focus and allow for variation when appropriate
- They incorporate evidence or research-based standards or guidelines
- They include systems for rigorous record-keeping
- They include measurement of outcomes and promote continuous quality improvement

### Core values and principles

The principles underpinning the development and use of this Care Pathway are set out in paragraph 11 of the [draft] National Framework document.

## STAGE 1: ENTRY - INFORMATION GATHERING & ASSESSMENT

A child and family's preferences and wishes, as to how and where the care will be delivered, should be taken into account, along with the risks of different types of provision and fairness of access to resources, when deciding how their needs will be met.

### **Standard 1: Assessment of Care Needs**

***Every child/young person should receive an assessment of their holistic care needs as soon as possible after it is recognised that they may have complex healthcare needs and should have their needs reviewed at appropriate intervals.***

#### **Goals**

- 1. There is full and active involvement of children & young people and their families in the process.***
- 2. The common assessment process should be used and there should be a mandatory carers assessment to assess carers needs.***
- 3. Information is available to enable all those involved to understand what is likely to happen. This should be accessible to child, young person and parent as well as professionals.***
- 4. The results of any relevant assessments that the child or young person may have undergone already, e.g. the Common Assessment Framework or specialist assessments should be included in this process.***
- 5. Children and young people's continuing care is assessed consistently and fairly for all children, irrespective of the reason for their needs or the type of those needs.***
- 6. There is identification of children and young people who should be fast-tracked to immediate care.***
- 7. Children/young people and if appropriate, their carers/family are kept informed and throughout the process know the outcome and reasons for the decision.***
- 8. The child, young person and their family is kept informed about the next steps and timeframes to implement the care plan and/or inform the child and family of their rights.***
- 9. Clear timeframes from referral to completion of assessment to decision are agreed locally and targets met.***
- 10. Decisions on which services to be provided are reported back to referrers within 5 working days of being made, unless the identified needs require fast-tracking.***

## STAGE 2: MULTI-AGENCY ASSESSMENT, CARE PLANNING & COMMISSIONING

Following a referral, a multi-agency assessment may be indicated to establish whether a child or young person who is thought to have complex healthcare needs requires continuing care. An individual should be identified to co-ordinate the assessment and liaise with the multi-disciplinary team to complete the Decision Support Tool and match, as far as possible, the child's level of need with the description that most closely relates to their specific needs. The tool provides practitioners with needs-led approach by assessing need on the basis of ten 'care domains'. The levels of need described in the DST may not always adequately describe every child's circumstances. Professional judgment and clinical reasoning are paramount in ensuring a child's needs are accurately assessed, taken into account and given due weight when making a decision.

The DST is not relevant where a child or young person's needs are such that access to Children's or Young Person's Continuing Care is fast-tracked, for example as result of rapid deterioration or need for end of life care. Appropriate fast track processes should be identified for children and young people who are not appropriately placed within the continuing care framework. A good referral and robust integrated assessment process is key to the success of the whole process.

The assessment should be followed by a multi-agency planning meeting and decision making process, including commissioning of services.

### **Standard 2: Referral**

***Children and young people with complex healthcare needs who need an assessment for continuing care are identified through an effective referral process and fast-tracked to immediate care for those who need it. The Common Assessment Framework (CAF) offers a standardised approach to conducting an assessment of a child's additional needs and deciding how those needs should be met and particularly in the universal services, can be an early pointer to recognising that there are additional needs that may require a continuing care assessment.***

### **Goals:**

- 1. Children who require fast-tracking because of the nature of their needs (e.g. if a prognosis indicates end of life care need) are identified and referred early, to make sure their needs are met as quickly as possible, without having to undergo a full continuing care assessment in the first instance.***
- 2. For children and young people being discharged from acute settings, consideration should be given to whether there is a continuing care need for referral.***
- 3. The process should allow for fast-tracking out to other more appropriate pathways e.g. disease specific pathways.***
- 4. Referral can be made from a variety of settings by a variety of people.***

5. *There is full and active involvement of children & young people and their families in the process.*
6. *Information should be available for families and age-appropriate information should be available for children/young people to clarify the process of referral.*

### **Standard 3: Multi-agency Assessment & Care Plan**

*Every child/ young person has a timely multi-agency, child & family centred assessment and care plan agreed with them for the delivery of co-ordinates care and support to meet their identified needs. A lead professional or keyworker to assist with this should be identified and agreed with the family.\**

#### **Goals**

1. *There is full and active involvement of children & young people and their families in the process.*
2. *Each family has a keyworker who is the main contact through whom they can communicate and who ensures that the care plan is being delivered effectively.*
3. *Decisions about care are made with reference to a multi-disciplinary team assessment, and where possible are joint with education and social care.*
4. *The multi-agency panel meeting should consider the care options which meet the assessed needs of the child & family and take into account the expressed wishes of the child & family.*
5. *Local Authority children services including schools and early years' settings are involved appropriately in the process and are informed of the outcome of the assessment.*
6. *When the nature or level of needs change significantly, a review of the child or young person's needs is made.*
7. *Reviews are transparent and supported by a rationale/explanation of the decision.*
8. *Verbal and written reports are given to the child/family in user friendly, non-technical language.*
9. *All continuing care packages are reviewed on an agreed regular basis. [A minimum standard is 3 months from the initial assessment, and then at least annually.].*
10. *There should be a holistic approach to the Care Plan.*
11. *The care plan should focus on the child's quality of life including symptom control and personal care, the child's right to education and their emotional and psychological care.*
12. *The Care Plan should include support to access benefits.*

\* The lead professional is a key element of integrated support. They take the lead to coordinate provision and act as a single point of contact for a child and their family when a range of services are involved and an integrated response is required. Appointing a lead professional is central to the effective frontline delivery of services for children with a range of additional needs. When the role is delivered in the context of multi-agency assessment and planning, underpinned by the Common Assessment Framework or relevant specialist assessments, it ensures that professional involvement is rationalised, coordinated and achieves the intended outcomes. Sometimes the lead professional is also the keyworker for a child. A key worker is a named person who helps families to find their way through what may be a complex network of services, acting as a single point of reference for parents who need to ask questions about many different things and oiling the care package provided for a family as a whole. They can be someone who is already working with the family but also takes additional responsibility for co-ordinating the service provision package as a whole or they can be employed specifically and exclusively to work as key workers (or link workers) with a larger number of families. Sometimes a key worker may be a named professional.

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**Standard 4: Involvement in decision making**

***Children, young people and their families should be facilitated to take part in decision making, this includes information giving, listening, discussion & negotiation and the outcome of the process should be communicated clearly to the family, by the lead professional and follow-up in writing.***

**Goals:**

- 1. Advocates should be readily available to support young people to take part in decision-making.***
- 2. Parents/long term carers and the child/young person should be enabled to contribute their knowledge and experience to the assessment process.***
- 3. Where a child or family express preferences are not met, clear reasons should be given to them.***
- 4. There is full and active involvement of children & young people and their families in the process.***
- 5. PCTs communicate any decisions made formally in writing to the child, young person and their family or their representative, providing a clear rationale for that decision.***
- 6. The child/young person and their family/carers are supported to understand the information they receive and to sift and prioritise it.***
- 7. The child/young person and their family/carers have access to interpreters, if needed.***
- 8. The child/young person and their siblings have access to information appropriate to their age and understanding.***
- 9. The roles of assessors and decision makers in the multi-agency decision making process should be clear.***

The Assessment will be used in a variety of settings, it draws on the experience, skills and knowledge of the referrer, it is not dependent upon the location of the child, or who is currently providing care. The need to do a continuing care assessment, unless obvious requires a clear, reasoned evidence base from a range of sources which takes account of the child's particular needs in a holistic and family context.

### STAGE 3: REVIEW & MOVING ON FROM CONTINUING CARE

Children and young people may move on from the continuing care process - either into more appropriate (possibly disease specific) pathways - or into other services such as universal services, adult services or other specialised services.

Regular review is essential to the process - ensuring that the support provided continues to meet need and that care packages are amended to meet the needs of the child/young person. Reassessment should be carried out within 3 months of the initial assessment and the maximum of annual review processes. As care packages change to meet new needs, the care team should work with the child and family to recognise and celebrate improvements and progress.

Young people want to take control of their lives as they enter their teenage years and adulthood. This calls for an early collaboration of children and adult services across health, education, social care, housing and employment. For some young people, a deterioration and death may be expected and the palliative care pathway would be more appropriate. A key worker designate role within adult services to gradually take over the child's key worker role so to ensure smooth transition is recommended (see ACT Transitional Care Pathway). The Department of Health has also published a good practice guide: *Transition: Getting it right for young people*. There are a number of important principles that should be central in the planning and provision of care during the transition to adult services. These are:

- Involvement of young people in decision-making.
- Flexibility and choice.
- Continuity of support.
- Anticipation of needs.
- Individually tailored care plans.

During the transition, the child/young person's key worker will link with adult or other services (such as universal services or disease specific services) and ensure continuation of care until the child/young person is established in the new service.

The key worker designate in the adult/other service will link closely with the child/ young person's key worker, to enable effective access to adult/other services, and to gradually take the baton from them.

The transition to adult continuing care should recognise the process changing to one that is specifically 100% healthcare.

It is important to provide information on the transition process to children/young people that is appropriate to their age and developmental level and takes into account their communication needs and information for their family. As far as is possible and appropriate, they should be enabled to manage their condition themselves with a full understanding of the implications of their condition, how it can be treated and how this will impact on other areas of their life.

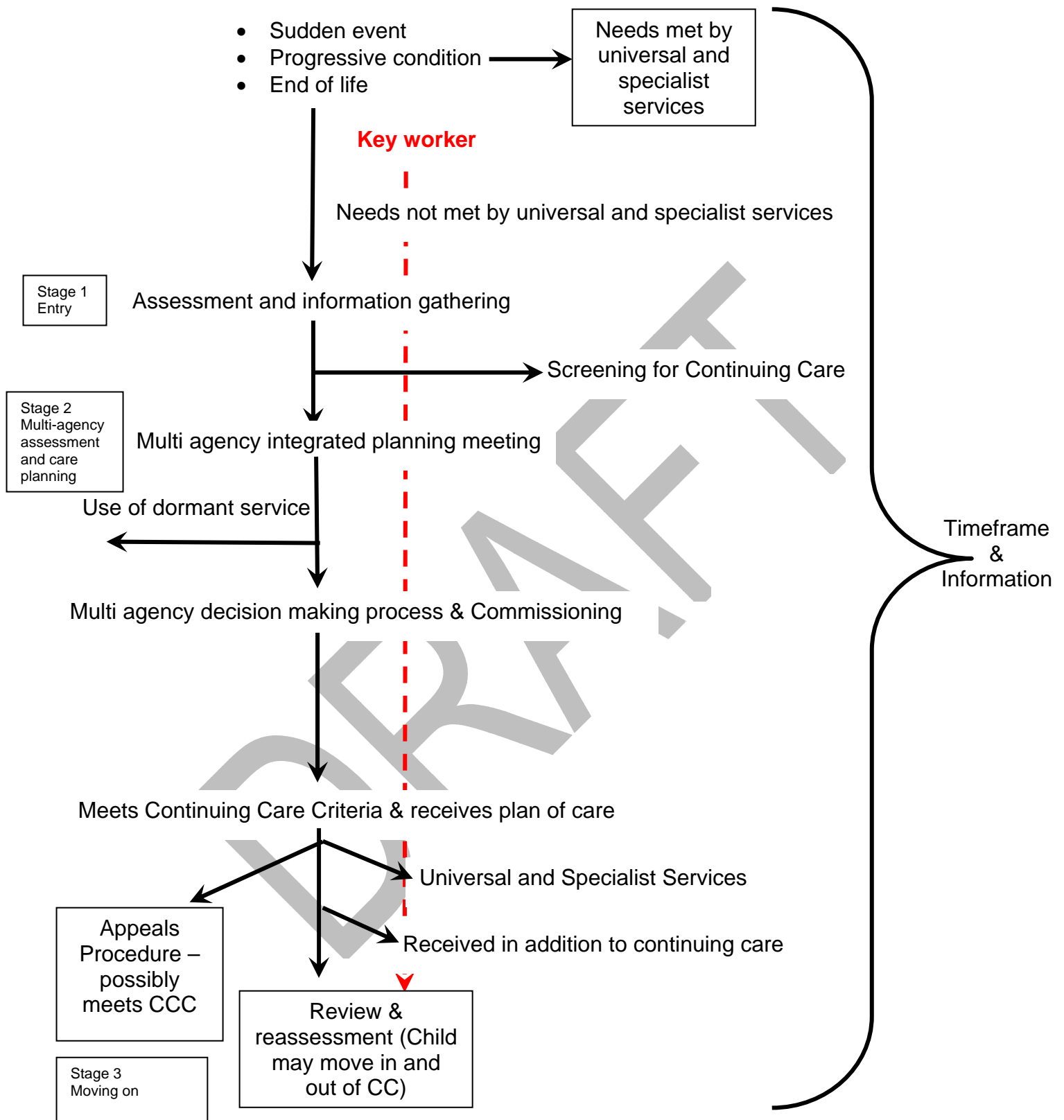
**Standard 5: Active transition**

***Every child or young person will be reviewed and will have a co-ordinated multi-agency plan for an active transition process to adult or universal services or to a more appropriate care pathway (this may include a universal or disease specific pathway, a transition pathway or a palliative care pathway) to take place within an agreed time frame. A co-ordinated care plan is developed to meet the young person's individual needs. A key worker and key worker designate are identified to work alongside the young person/family to facilitate this process.***

**Goals**

- 1. Transition is an actively managed process.***
- 2. A multi-disciplinary approach is essential.***
- 3. A key worker/care manager should be appointed.***
- 4. Where a child or young person has needs that require the input of palliative care services they should be referred to the specialist services for an assessment.***
- 5. Children/young people are listened to, involved and encouraged to ask questions, express opinions and make decisions.***
- 6. There is a keyworker for each child/young person to help them manage their transition to adult/other services.***
- 7. Early engagement with adult/other services is essential for proactive planning.***
- 8. Service planning and commissioning should consider the needs of young adults.***
- 9. There is good inter-agency and interdisciplinary co-ordination across statutory and voluntary sectors and adult/paediatric services.***

### Proposed pathway



**Q. Does the draft Continuing Care pathway accurately capture the child/young person' and family's journey? If not why not?**

**Q. Are the 3 stages described in the pathway useful?**

**Q. Will the flow chart assist you in implementing the pathway?**

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## Annex B

### Assessment of Children, Young People and their Families

The following guidance covers the four key areas and tools of assessment/information required for a continuing care assessment. Assessment for continuing care must meet the Children's National Service Framework standards in particular:

<sup>1</sup>Standard 3 "Children young people and their families receive high quality services which are co-ordinated around their individual needs and take account of their views".

The four areas of assessment are: -

1. Child/YP Preferences/or views  
Family/Carer views.

2. Holistic child/YP & family centred  
assessment including: -carers assessment.

3. Reports and risk assessments from  
Multi –Disciplinary Team.

4. Decision Support Tool.

**Q. Are the 4 areas of the assessment process the correct ones?**

#### Interplay of Four Areas of Assessment.

Each of the four areas of assessment is important to the determination of a need for continuing care. Professionals undertaking the assessment and deciding on eligibility must use professional judgement evidenced by the four areas of assessment to support their recommendation or decision.

#### 1. Child /Young Person and Family Preferences and views.

Full involvement in the assessment process is the first stage focusing care delivery on the child/young person and family's views and preferences. Each family member has a contribution to the understanding of a whole family's needs. <sup>10</sup>Aiming High For Disabled Children' prioritises involvement of children and family's in designing their packages of care.

There are key factors in assessment that may add or detract from gaining the views and preferences of the whole family:

- Timing of assessment - If conducted exclusively in working hours it is likely to exclude fathers and siblings.
- Location of assessment - assessments carried out in hospital or clinic environments will often exclude parts of the family.

- Communication skills - practitioners skilled in children's care and assessment are more likely to effectively involve children, young people and siblings in the identification of needs and in developing packages of care to best meet these needs.
- Skilled interpreters are essential to gain views from families where some or all of the family have no or poor English speaking skills.
- Parents with learning disabilities or communication difficulties require appropriate support from adult services.
- Communication aids - involvement of speech and language therapists/special needs teachers can support children with highly complex needs; make their own needs known.
- Advanced planning techniques – when a family has been engaged by professionals in proactively planning for their future perceived needs and preferences in relation to a child/young person's care and lifestyle, this information can usefully inform the continuing care assessment, ensuring concordance with existing advanced care planning processes.

What do families see as good practice in assessment and service planning?

- Demonstrates flexibility and responsiveness to families' individual needs<sup>13</sup>
- Actively safeguards their 'ordinary' lives and needs<sup>13</sup>
- Works in partnership with families, valuing their knowledge and expertise<sup>13</sup>
- Works with wider networks, including family, friends, other services and settings.<sup>13</sup>

Options can be devised around the preferences of the child/young person and their family. For example, choice of mainstream or special school is a difficult but important choice, which will effect options for care. Local Authorities can arrange school visits to enable children, young people and their families to make informed choices. Both options can be very successful with the right package of care.

The origins of a continuing care need influence the knowledge and support the child/young person and family will have and need to make informed choices.

**Sudden unexpected need-** accidents or after-effects of acute illness can result in a family/child/young person inexperienced in complex disability requiring continuing care to enable them to return home. The evaluation of the children's continuing care pilot identified the important role of PCTs and specialist children's hospitals working in partnership to help parents/children and young people consider options for care. Where these partnerships are not present, unrealistic and inequitable or undeliverable options may be advocated by the acute care team but refused by PCTs; causing unnecessary conflict with care teams and/or families .

Tertiary feeder units and local district general hospitals should work with the placing PCT to develop protocols for continuing care assessments and option planning with children, young people and their families to ensure consistency of approach to assessing and option planning

**Long term deteriorating conditions-** continuing care referrals that arise for children or young people with highly complex, deteriorating conditions will usually be initiated from multi-agency planning groups. PCTs should ensure that there are agreements in place with local authority children's services teams, around when and how to include continuing care into the process.

Local continuing care assessment paperwork must include the views and preferences of parents, children/young people.

PCTs need to develop family friendly information about all stages of the continuing care process. There must be a member of staff clearly identified for families to contact if they have any questions during the continuing care process.

## **2. A child/young person and family centred assessment.**

Assessments for children's continuing care must capture and consider the needs of the whole family. The child and family centred assessment process must be at the very heart of a children's continuing care assessment process. All other aspects of the assessment process must be seen in the context of this assessment.

Children's continuing care assessments will have a very different focus to adult continuing care due to the principles of children's practice which are wide and varied. Two key principles are paramount in children's continuing care: -

- Parents are the experts and primary carers
- Home is the centre of caring <sup>2</sup>

Assessment of a child /young person varies in relation to how they develop a need for continuing care. A new diagnosis of a highly complex, congenital problem or a significant event to a child who was expected to or is developing within normal limits will normally involve acute and community staff undertaking a combined assessment and working with the family to review options. There needs to be a lead professional to co-ordinate this process reducing overlap and centring the process on the child/young persons needs. For children/young people where there is a deterioration, which necessitates continuing care, there has often been an extensive multi-agency/multi-disciplinary assessment, which provides the bedrock of a holistic child, and family assessment. The Lead Professional will be instrumental in co-ordinating this pooling of information and in organizing planning meetings to consider options for care with the child/young person and family. In urgent cases, a simplified form of initial assessment needs to be agreed locally; however the child and family must remain central to the process.

### **Principles of assessment.**

1. Those undertaking continuing care assessments should have relevant qualifications and competencies in child development, working with



children, assessing children and in children's continuing care to ensure appropriate, fair and consistent assessment.

2. It is important that there is clarity with children, young people and families about why a continuing care assessment is being undertaken, what it will involve, where it will take place and what the child, young person, and families input will be. This should be undertaken in a systematic and consistent way to ensure equity and transparency<sup>3, 10</sup>.
3. Individuality, ethnicity and personal beliefs should be respected<sup>6</sup>.
4. Continuing care reports should be worded in such a way to make them understandable to children, young people and families and the different agencies who will be involved in the decision making process.
5. Holistic multi-agency and multi-disciplinary approaches, which also address the child or young person's emotional needs, are key to establishing the whole needs of the child, young person and their family. Families should be made to feel partners in the assessment process. 'Children and young people should be supported to be fully involved in the assessment process'<sup>4,5</sup>. Fathers and siblings should also be fully involved: complex care is often highly invasive of the family home and the preferences of all family members should be sought.<sup>1</sup>
6. The assessment should be seen as an integral part of the care process, therefore "questioning by a professional can give valuable insight into a child's needs but also reinforce feelings of self worth in the parents"<sup>3</sup>. This process should identify parenting capacity, family circumstances, other family members health needs and to fully consider the proposed environment of care.
7. Continuing care assessments should draw on other assessments but not to the exclusion of direct assessment and contact with children/young people and families.
8. Assessment should be a process, not a one off event; as such continuing care assessment must build on the previous assessments. Most children with complex needs will have had multiple assessments, children's needs change quickly so review is an essential part of the process.
9. Continuing care assessments should be shared with families. All who contribute to an assessment should be fully aware of its intended use and distribution.
10. Consent to share information with partner agencies must be obtained for all continuing care assessments. Methods for information sharing must fully comply with local information sharing protocols. Involvement of Caldicott Guardians in the planning of an assessment process ensures these issues are fully addressed.

### Child /Young Person Centred Assessment Tools.

The Common Assessment Framework offers a way to reduce replication in assessment and to gather basic information on a child and family. Combined with a core assessment coordinated by social care, this can produce the key elements of a child and family centred assessment. Where processes are suitably developed this model could underpin the children's continuing care process. The key component of a good continuing care process is a good all round child and family centred assessment. The following table identifies the key areas of information collection

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synthesized with assessment guidance <sup>6</sup>. This is offered as an example of good practice.

<p><b><u>Child's Details</u></b></p> <ul style="list-style-type: none"> <li>• Name, date of birth, address, telephone, religion, ethnicity, first language and gender.</li> <li>• Child's next of kin.</li> <li>• Primary diagnosis, secondary diagnosis, allergies.</li> <li>• Name &amp; address of nursery, school or college attending.</li> <li>• Name &amp; address of short break care using, frequency.</li> <li>• Date referred to service, who referred.</li> <li>• Date of initial eligibility assessment.</li> <li>• Names of nurse &amp; other professional undertaking assessment.</li> </ul>	<p><b><u>Family Details</u></b></p> <ul style="list-style-type: none"> <li>• Mother's name, father's name, work telephone numbers.</li> <li>• First language, interpreter if required</li> <li>• Sibling's names, dates of birth, health status.</li> <li>• Names of significant others, relationship, address, telephone numbers.</li> <li>• Family structure.</li> <li>• Parental responsibility.</li> <li>• Parental disabilities.</li> </ul>
<p><b><u>Professionals &amp; Services Involved – Contact Sheet</u></b></p> <p>Name, telephone and location of:</p> <ul style="list-style-type: none"> <li>• Registered GP (determines responsible PCT).</li> <li>• All Consultants.</li> <li>• Community Paediatrician.</li> <li>• Community children's nurse.</li> <li>• Named ward nurse.</li> <li>• Health Visitor.</li> <li>• School nurse.</li> <li>• District Nurse.</li> <li>• Social Worker.</li> <li>• Occupational therapist.</li> <li>• Speech &amp; Language Therapists.</li> <li>• Physiotherapist.</li> <li>• Other therapists.</li> <li>• Teacher.</li> <li>• Short Break services.</li> <li>• Lead Professional.</li> <li>• Interpreter.</li> <li>•</li> </ul>	<p><b><u>Medical Details</u></b></p> <ul style="list-style-type: none"> <li>• Health biography- dates of significant health events / current issues/medications.</li> <li>• Disposable equipment – type, manufacturer, who responsible, collection.</li> <li>• Hard equipment – type, manufacturer, issue date, supplier, service date, owned by.</li> </ul> <p><b><u>Nursing And Care Needs</u></b></p> <ul style="list-style-type: none"> <li>• Treatment and care needs and who meets these needs.</li> <li>• Equipment needs.</li> <li>• Symptom management and pain control.</li> <li>• How are child, siblings and carers supported?</li> <li>• Does the family have adequate information on child's condition / future?</li> <li>• What is the 24hr daily care routine?</li> <li>• Competencies required to care for child.</li> </ul> <p><b>Identify met and unmet needs.</b></p>
<p><b><u>Activities of Living<sup>7</sup></u></b></p> <ul style="list-style-type: none"> <li>• Maintaining a safe environment.</li> <li>• Communicating.</li> <li>• Breathing.</li> <li>• Eating and drinking.</li> <li>• Eliminating.</li> <li>• Personal cleansing and dressing.</li> <li>• Controlling body temperature.</li> <li>• Mobilising.</li> <li>• Playing.</li> <li>• Learning.</li> <li>• Expressing individuality.</li> <li>• Sleeping.</li> <li>• End of life.</li> </ul>	<p><b><u>Young People (14+)</u></b></p> <p>Has Transition commenced? Lead Professional. Lead Professional designate. Future plans: -</p> <ul style="list-style-type: none"> <li>• Education/employment.</li> <li>• Accommodation care package.</li> <li>• Can they be assisted to achieve independent living?</li> <li>• Are their views different to parents?</li> <li>• Will their parents or main carers need extra emotional and practical support?</li> <li>• Consent to share information with other agencies?</li> </ul>

Emotional Support Needs.	Current Service Provision.
<ul style="list-style-type: none"> <li>• What is the effect of child's condition on each member of the family?</li> <li>• What times are stressful?</li> <li>• How do they cope?</li> <li>• Who do they call on for support at these times?</li> <li>• Are there times when they need particular support?</li> <li>• How do they communicate as a family?</li> <li>• What is the child or young person's understanding of his/her condition?</li> <li>• What understanding do siblings have of the child's condition?</li> <li>• Is an assessment by the child mental health service required.</li> </ul>	<ul style="list-style-type: none"> <li>• Child/young persons issues, concerns, anxieties.</li> <li>• Child/young person's preferences in care delivery.</li> <li>• Family's preferences in care delivery.</li> <li>• Services involved (statutory, voluntary sector, private).</li> <li>• Carers and child's perception of these.</li> <li>• Any problems with education of child or siblings?</li> <li>• Coordination and communication between professionals?</li> <li>• Is there a Lead Professional and is this working well?</li> <li>• Advice or training needs.</li> <li>• What information do professionals need?</li> <li>• How can professionals improve family's quality of life?</li> <li>• Does any other member of the family have health or service needs?</li> <li>• Are siblings involved in care?</li> </ul> <p><b>Identify met and unmet needs.</b></p>

#### Family's Home Circumstances.

##### Family's wider community:

What kind of help is available in the family's circle of friends and relations?

**Are there any other organisations or groups, which support the family?**

##### Housing:

Owned, rented.

Adequacy for child's / family's needs.

Adaptations required.

##### Transport:

Mode of transport, is the family reliant on public transport?

Accessing hospital, appointments etc.

Transport to school.

##### Education and Learning:

Is the child or young person able to access an appropriate educational setting, full or part-time?

What effect does the condition have on their ability to access the curriculum?

What additional support or reasonable adjustments are required in that setting?

If too ill to access a setting, what other provision is in place to ensure continuity of learning?

##### Employment:

Summary of parental occupation, employment/shift patterns.

Effect of child's condition on ability to work. Finance:

Difficulty meeting bills / financial commitments.

Has child's condition affected family's finances?

Is family in receipt of all benefit entitlements?

Do they need extra support from Family Fund or other?

##### Recreation & Leisure:

Is the child or young person able to choose leisure activities?

What is required to enable the child/young person to access leisure activities?

What are their interests or hobbies?

Are the recreational needs of siblings and other family members being met?

**Identify areas of need for action.**

### 3. Reports and Risk Assessments.

Reports from services and agencies provide an important part of the evidence base for making an assessment of eligibility for continuing care and the care package to support assessed need.

#### **Multi-Disciplinary Reports may be obtained from:-**

- Hospital consultants/specialists.
- Specialist nurses.
- Therapists.
- General Practitioners.
- Community children's nurses.
- Learning disability teams.
- Psychologists.
- CAMHS reports.

- Child Development Centre Review Reports.

### **Multi-agency reports that should be accessed-**

- Common Assessment Framework.
- Core or initial assessment report.
- Carer's assessment.
- Family assessment plan.
- Educational statement of SEN and Annual Reviews.
- Team around the child review.

### **Records.**

- Care intervention/evaluation records.
- Overnight assessments from short break centres.
- Family diaries of care interventions.

### **Reports.**

Independent reports may be available from: -

- Consultants/specialists.
- Outside nursing teams.
- Outside children's continuing care experts.

Children with long standing complex needs may have extensive reports and notes. For the purposes of continuing care, reports that demonstrate the frequency, intensity, unpredictability, deterioration, instability or wider family social or educational needs are particularly pertinent.

### **Risk Assessment.**

Risk assessment is a valuable tool in supporting the assessment of eligibility for children's continuing care and for appraising options for care delivery. Risk management can be used to assess clinical or environmental risk. Children with continuing care needs will receive care, support and education in a variety of settings. Risk management has the potential to enable inclusion or to be used as a justification for exclusion. The Dignity of Risk' (2004)<sup>8</sup> and 'Including Me' (2005)<sup>9</sup> are key texts in using risk management to enable, rather than exclude, in social care and educational environments. In continuing care risk assessment can be used to make informed decisions about staff levels and numbers, equipment and back up services.

Organisations have a duty under the Disability Discrimination Act to overcome physical barriers and to take reasonable steps to change practices, policies or procedures, which make it impossible or unreasonably difficult for them to use a service. They must also be provided with auxiliary aids or services, which make it easier for them to use a service<sup>11</sup>.

<sup>9</sup>**The elements in risk management: -**

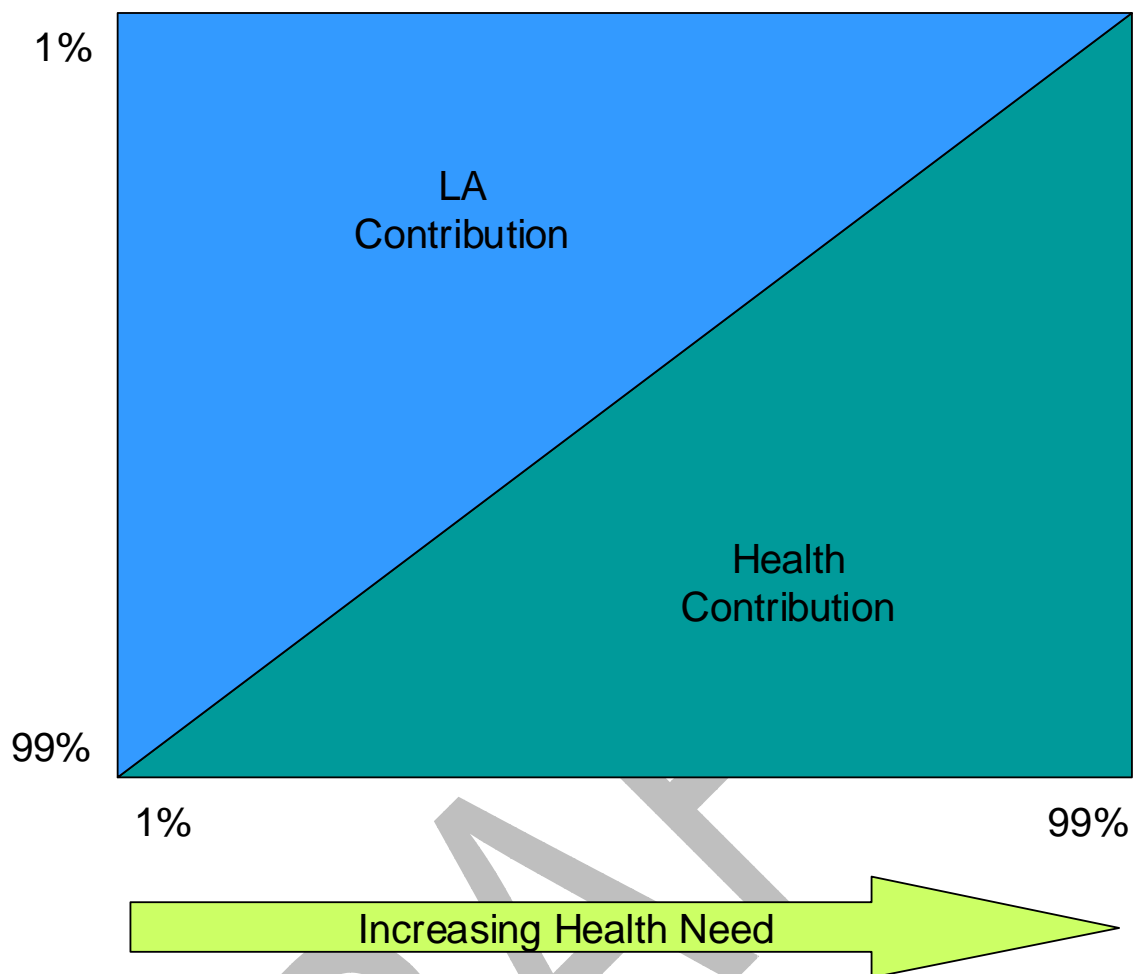
- **Risk** refers to the possibility of a situation occurring which would involve exposure to danger or a hazard, that is, the possibility of something harmful happening.
- Risk is a combination of the **likelihood** of something harmful happening and the **seriousness** of the potential injury.
- A hazard is less likely to cause harm if certain **controls** are in place.
- Controls are the steps taken to either eliminate the hazard or reduce the associated risk to an acceptably low level.
- Risk is managed by **assessing it**, avoiding it if it is unnecessary or reducing it to a level which is 'reasonably practicable'.
- When considering what is '**reasonably practicable**' the needs of both the child and staff should be taken into account.
- **Reasonably practicable**, as defined by the Health and Safety Executive (HSE), means 'an employee has satisfied his/her duty if he/she can show that any further preventative steps would be grossly disproportionate to the further benefit which would accrue from their introduction' (HSE 1992, p 8).
- A key element in any risk management strategy is child protection. Risk assessments should cover issues relating to child protection, for example, intimate care that may be required when carrying out a procedure for a particular child. The assessment should balance both the child's right to be kept safe with the right to be treated with dignity

Risk assessments that may influence eligibility or care package design into the following areas: -

- Clinical risk.
- Staffing levels.
- Moving and handling.
- Environment of care.

Risk assessment should be used to demonstrate whether there is any significance of need in terms of frequency, intensity, unpredictability, deterioration, and instability in cases where the Decision Support Tool does not fully cover an individual's particular need.

PCTs should train children's continuing care assessors in their agreed method of risk assessment. Risk management leads from PCTs have a duty to work with children's continuing care assessors to develop and integrate the use of risk management into local risk assessment strategies.



*Continuing Care Criteria is reached with scores of 3 highs or 1 priority or 1 severe. Professional judgement based on the wider assessment, risk assessment and reports may be considered for continuing care by the decision making panel.*

**Q. Does the diagram above help demonstrate the shared approach to continuing care?**

**Q. In assessing the care domains, is the rating of 3 highs or 1 priority or 1 severe the correct level to indicate a continuing care need? If not what should be?**

#### 4. Decision Support Tool for Children's Continuing Care.

1. The Decision Support Tool (or DST) below has been developed to bring assessment information together to determine whether a child or young person with complex healthcare requirements needs continuing care and the level of that need.
2. An individual skilled in the assessment of children should be identified by the PCT to co-ordinate the assessment and liaise with the multi-disciplinary team (M.D.T) and their multi-agency partners to compile the information



required, including a child and family centred assessment, the child, family and young person's views and relevant professional and risk assessments. The assessor/panel should use the Decision Support Tool to match, as far as possible, the child or young person's level of need with the description that most closely relates to their specific needs. This approach should build up a detailed analysis of individual needs in a family context and provide the evidence to inform the decision on care provision. The tool is not prescriptive, and professional judgment should be exercised in all cases to ensure that the child's or young person's overall level of need is correctly assessed and that appropriate decisions are made.

3. The tool brings together needs from across 10 care domains as follows:
  - Challenging Behaviour
  - Communication
  - Mobility
  - Nutrition, Food & Drink
  - Continence & Elimination
  - Skin & Tissue Viability
  - Breathing
  - Drug Therapies & Medicines
  - Psychological & Emotional
  - Seizures
4. Each care domain can have up to five levels of need based on a mixture of complexity, intensity, unpredictability of need and risk to the child as reflected at the following levels:
  - Priority
  - Severe
  - High
  - Medium
  - Low
5. The structure of the tool is set out in the diagram below:

P				P		P	P		P
S		S	S		S	S	S		S
H	H	H	H	H	H	H	H	H	H
M	M	M	M		M	M	M	M	M
L	L	L	L	L	L		L	L	L
N	N	N	N	N	N	N	N	N	N
Behaviour	Communication	Mobility	Nutrition	Continence or Elimination	Skin	Breathing	Drug Therapies & Medicines	Psychological	Seizures/ASC

## Establishing a Continuing Care Need

- # Assessors skilled in child development will use their skill and judgement to consider for each domain what is over and above what would be expected for a child of that age e.g. continence would only

**become recognised as an issue when a child reached the recognised referral age for that PCT**

6. The assessment process should not get in the way, where a child or young person's needs are such that access to care needs to be fast-tracked, for example as result of rapid deterioration or need for end of life care. These needs should be met first and then according to individual circumstances, followed up with a continuing care assessment.
7. The DST is not a stand-alone tool and should be used in conjunction with the other 3 key areas of assessment - child and family views, holistic child and family centred assessment, reports and risk assessments. The Decision Support Tool does not make a decision about what continuing care should be provided to children and young people. It is designed to help ensure that all relevant needs are assessed and captured to describe and record an overall picture to inform local decisions about the care needed.
8. The needs described collectively in the care domains and levels of need in the Decision Support Tool may not always adequately describe every individual's circumstances. Professional judgment and clinical reasoning are paramount in ensuring an individual's needs are accurately assessed, taken into account and given due weight when making a decision about continuing care. All four parts of the assessment process interact as part of the individual's overall need for care.
9. There may be circumstances, on a case-by-case basis, where a child or young person may have particular needs, which do not appear to match the care domains described in the Decision Support Tool. In this situation, it is the responsibility of the assessors to determine the nature and extent of any other needs and, in conjunction with the needs covered using the tool, present a unified analysis including the following:

***Mental Health Needs or Acquired Brain Injury***

- Children and young people with mental health needs or acquired brain injury being considered for continuing care are likely to have a range of needs requiring assistance or intervention from others. Some needs are consistent and predictable, e.g. the need to be assisted with washing and dressing for a child with four limb cerebral palsy. Other needs are less predictable, e.g. unexpected distress, intermittent restlessness or variable resistance to care.
- These needs will generally be most pronounced in the psychological/emotional and communication domains. However, it is essential that where there are ongoing or recurrent behavioural problems associated with meeting basic care needs or in communication with a child, that the behavioural needs are taken into account and given due weight in the assessment.

### ***Learning Disabilities***

- A learning disability may mean that the child or young person has a significantly reduced ability to understand new or complex information or to learn new skills, with a reduced ability to cope independently (impaired social functioning), which has a lasting effect on development.
- Some of the domains within the assessment framework will not be relevant to children and young people with learning disabilities whilst others may not fully reflect their needs. It is important that assessors consider the totality of the four areas of assessment for the child or young person's needs and how they inter-relate to complicate their care. In particular, communication and behaviour are complex issues for this care group.

### ***Palliative and End-of-Life Care***

- Palliative care for children and young people with life limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of short break and care through death and bereavement. (Commissioning Children's and Young People's Palliative care, DH DfES November 2005). Palliative care may be required for many years, but end-of-life care, which often includes specialist palliative care, is generally required for a relatively short period.
- Where a child or young person has needs that require the input of palliative care services they should be referred to the specialist services for an assessment. The children's and young people's palliative care service will assess both immediate needs and continuing care needs, in the light of the child's prognosis. Where the child or young person's health needs are increasing rapidly and a delay in assessment is anticipated; the children's and young people's palliative care service, in consultation with the care manager, should consider referring for continuing care through a fast track process, to avoid delays in discharge from hospital or hospice to home.
- Children with a rapidly deteriorating condition and expected short-term life expectancy should immediately be able to receive continuing care. 'Short-term' should not to be defined prescriptively or restrictively, but should be based on an assessment of the child's care needs and considered as a period of time, which can be expressed in days and weeks. Strict time limits are not relevant for end of life cases and should not be imposed – it is the responsibility of the skilled assessor to make a decision based on the relevant facts of the case.

10. Care has been taken to avoid duplication and ensure that a specific need is not repeated in two separate care domains. However, assessors should consider how different but interrelated needs, across more than one domain can complicate the individual's overall care needs and demonstrate sufficient complexity, intensity or risk to demonstrate a health need. Examples of this might include be the relationship between skin integrity and continence, or cognitive impairment and behaviour and/or communication.
11. The level of need in a single domain may not, on its own indicate that a child or young person has a continuing care need, but will contribute to the picture of overall care needs from all domains to help inform a decision on the care needed. Levels of need are relative to each other as well as to those in other care domains. It is not possible to equate a number of incidences of one level with a number of incidences of another level for example, that 'two moderates equals one high.' Assessors should consider the level of need identified in all care domains for the overall picture presented in local decisions about the care that may be required.
12. Three high, one severe or one priority rating indicates a need for continuing care. For these children and young people, it is important that PCTs and Local Authority children services plan the co-ordination of their care and support, in liaison with the school, education requirements.
13. These guidelines should not be used in a restrictive way. Assessors should be mindful that children and young people assessed as having a low healthcare need may require other healthcare input from universal services or community children's nursing or other specialist services.
14. A summary sheet is provided to evidence the assessed needs of the individual and level of need determined by the assessor, in the context of an MDT assessment. It is important that these needs are described in measurable terms using paediatric clinical expertise, and are supported by Child and family focused assessment, child, family and young persons views, and appropriate reports and risk assessments.

## CARE DOMAINS.

### 1. Challenging behaviour.

Culturally abnormal behaviors of such intensity, frequency, or duration that the physical safety of the person or others is likely to be placed in jeopardy or behavior which is likely to seriously limit use of or result in the person being denied access to ordinary community facilities<sup>12</sup>.

A specialist assessment of an individual with serious behavioural issues will usually be required which includes an overall assessment of the risk(s) which are likely to impair a child's personal growth, development and family life.

Description	Level of Need
Functioning within current environment with or without the demonstration of behaviours that can be managed without further specific specialist training of carers / professionals.	No additional needs
Some incidents of behaviour that are manageable and do not pose a significant risk or barrier to intervention, but that require some additional direct / indirect input from identified resources / professionals within frontline services.	Low
<p>Challenging behaviour that follows a predictable pattern and can be managed by a skilled carer or care worker who is able to maintain a level of behaviour that does not pose a risk to self or others.</p> <p>Behaviors that do not jeopardize the young person's place within their existing infrastructure (home, school etc) and do not pose a significant risk or barrier to intervention but that require some additional direct/indirect input from specialist workers in addition to those of frontline service:</p> <p style="text-align: center;">OR</p> <p>Behaviors that indicate a marked difficulty in self-regulating his or her own behaviors. This may include impulsive behaviors and or self-neglect (self-neglect differs from parental neglect and is more applicable to adolescents). It is [what is?] also separate from peer or cultural trends/ uniform or identity.</p>	Moderate
Behaviors that jeopardize the young person's placement within their existing infrastructure and continue to manifest despite specialist health intervention. Likely to require intense multi-agency involvement to maintain existing infrastructure and additional high-level support from several agencies.	High
Behaviors that challenge the young person's existing infrastructure and/or posing a significant risk of exclusion from all of the young person's existing environments and continue to manifest despite specialist health intervention. Likely to require ongoing intense multi-agency involvement to maintain any infrastructure and additional high-level support from several agencies. Usually requiring direct specialist clinical assessment, treatment and review from specialist health care professionals in addition	Severe

to those of frontline service.	
<p>Behavior of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy:</p> <p style="text-align: center;">&amp;</p> <p>Behaviors that exceed the young persons existing infrastructure and create a barrier to intervention resulting in exclusion from all of the young person's existing environments. Requiring direct urgent intensive specialist clinical assessment**, treatment and review from specialist health care professionals in addition to those of frontline service:</p> <p style="text-align: center;">&amp;</p> <p>Sustained behaviors that demonstrate the impairment of a child's personal growth and development through an inability to access necessary resources.</p>	Priority

\* A skilled carer or care worker is one that has had appropriate training or experience in supporting an individual with challenging behaviour. Under the severe and priority levels, this is likely to be under the supervision of a health professional.

## 2. Communication.

This section relates to difficulties with receptive and expressive language, both verbal and non-verbal, or technology assisted that is not commensurate with age and developmental milestones. It does not include those children that do not speak English as their first language but are able to communicate in other languages.

Description	Level of Need
<p>Communicates clearly, verbally or non-verbally, appropriate to developmental needs. Has a good understanding of their primary language. May require translation if English is not their first language. Able to understand or communicate clearly, verbally or non-verbally within their primary language appropriate to their developmental level.</p> <ul style="list-style-type: none"> <li>The child or young person's ability to understand or communicate is appropriate for their age and developmental level within their first language</li> </ul> <p>May require translation if English is not their first language</p>	No additional needs
<p>Needs prompting to communicate their needs. The child or young person's ability to understand and communicate is appropriate for age and recognised developmental milestones. Special effort may be needed to ensure accurate interpretation of needs or may need additional support visually, either through touch or with hearing. Carers may be able to anticipate needs through non-verbal signs due to familiarity with the individual. Expressive or receptive language.</p> <ul style="list-style-type: none"> <li>The child or young person's ability to understand or communicate is appropriate for their age and developmental level</li> </ul> <p><b>However</b></p> <ul style="list-style-type: none"> <li>Special effort may be needed to ensure accurate interpretation of their needs, for example <ul style="list-style-type: none"> <li>Person may need prompting to communicate their needs</li> <li>Person may need additional support - visual support such as symbols, signing or support with hearing e.g. use of hearing aids</li> </ul> </li> <li>Carers may be able to anticipate and interpret the young person or child's needs due to familiarity</li> </ul>	Low
<p>Communication about basic needs is difficult to understand or interpret, even when prompted, unless with familiar people, and requires regular support.</p> <ul style="list-style-type: none"> <li>Communication about basic needs is difficult to understand or interpret even when prompted except by those who know the child's needs well</li> </ul> <p>Support is always required to facilitate communication e.g. use of choice boards, signing, communication aids.</p>	Moderate
<p>Even with frequent or significant support from carers and professionals the child is rarely able to communicate basic needs, requirements or ideas, even with familiar people.</p> <p>Communication about basic needs is difficult to understand or interpret even when prompted by those who know the child's needs well</p> <ul style="list-style-type: none"> <li>Support is always required to facilitate communication e.g. use of choice boards, signing, communication aids.</li> </ul>	High

**OR**

The child or young person demonstrates severe frustration around their communication e.g. through challenging behaviour or withdrawal

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### 3. Mobility.

Description	Level of Need
Independently mobile as appropriate for age and developmental stage (with or without mobility aids).	No additional needs
Able to stand as appropriate for developmental age, but needs some assistance and requires support to access curricular or extracurricular activities	Low
<p>Completely unable to stand but able to assist or co-operate with transfers and/or repositioning by one carer or care worker to a level appropriate for developmental age.</p> <p>OR</p> <p>Sleep deprivation due to underlying medically / mobility related need – occurring 3 times a night (at least 2 nights per week).</p>	Moderate
<p>Unable to move in a developmentally appropriate way. Cared for in one position (bed or chair) and due to risk of physical harm, loss of muscle tone, tissue viability, or pain on movement, needs careful positioning and is unable to assist or needs more than one carer to reposition or transfer.</p> <p>OR</p> <p>At a high risk of injuries, requiring a structured management plan to minimise risk, appropriate to stage of development.</p> <p>OR</p> <p>Involuntary spasms placing themselves and carers at risk.</p> <p>OR</p> <p>Extensive sleep deprivation due to underlying medically / mobility related needs occurring 1-2 hourly (at least 4 nights a week).</p>	High
<p>Completely immobile and unstable clinical condition such that on movement or transfer there is a high risk of serious physical harm.</p> <p>OR</p> <p>Where the positioning is critical to physiological functioning or life.</p>	Severe

#### 4. Nutrition, Food and Drink.

Description	Level of Need
Able to take adequate food and drink by mouth to meet all nutritional requirements. Appropriate to developmental age.	No additional needs
<p><b>Some assistance required above normal for their developmental age.</b></p> <p>OR</p> <p><b>Needs supervision, prompting and encouraging with food and drinks above the normal requirement for developmental age.</b></p> <p>OR</p> <p>Parent, carer child or young person needs support and advice about diet because of underlying condition which may create a greater chance of non-compliance, including limited understanding of consequences of food or drink intake.</p> <p>OR</p> <p>Needs feeding when this is not appropriate for developmental age, but is not time consuming.</p>	Low
<p>Needs feeding to ensure adequate intake of food and takes a long time (including liquidized feed). Specialized feeding plan developed by speech and language therapist.</p> <p>OR</p> <p>Unable to take sufficient food and drink by mouth. Most nutritional requirements taken by artificial means e.g. via a non-problematic tube feeding device, including naso-gastric tube.</p>	Moderate
<p>Dysphagia requiring a management plan with additional skilled intervention to ensure adequate nutrition or hydration and to minimize the risk of choking, aspiration and maintaining a clear airway e.g. suction.</p> <p>OR</p> <p>Problems with intake of food and drink, requiring skilled intervention to manage nutritional status. Unintended weight loss placing the individual at risk and needing skilled intervention.</p> <p>OR</p> <p>Problems relating to a feeding device that require skilled assessment and review.</p>	High

The majority of fluids and nutritional requirements are routinely taken by intravenous means.	Severe
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## 5. Continence or Elimination.

Description	Level of Need
Continent of urine and faeces (appropriate to age and development).	No additional needs
<p>Continence care is routine on a day-to-day basis and age appropriate.</p> <p>OR</p> <p>Incontinent of urine but managed by other means e.g. medication, regular toileting, pads, use of penile sheaths etc.</p> <p>OR</p> <p>Is able to maintain full control over bowel movements or has a stable stoma but may have occasional faecal incontinence.</p> <p>OR</p> <p>Has a Stoma requiring routine attention.</p>	Low
<p>Doubly incontinent but care is routine.</p> <p>OR</p> <p>Self catheterisation.</p> <p>OR</p> <p>Has a stable stoma but may have occasional faecal incontinence.</p>	Moderate
<p>Continence care is problematic and requires timely intervention by a skilled practitioner or trained carer.</p> <p>OR</p> <p>Intermittent catheterization by a trained carer or care worker.</p> <p>OR</p> <p>Has a stoma that needs extensive attention every day.</p>	High
Requires peritoneal / haemodialysis to sustain life	Priority

## 6. Skin & Tissue Viability.

Description	Level of Need
No evidence of pressure damage or condition affecting the skin.	No additional needs
<p>Evidence of pressure damage and pressure or a minor wound requiring treatment.</p> <p>OR</p> <p>Skin condition that requires clinical reassessment less than weekly.</p>	Low
<p>Open wound(s), which is (are) responding to treatment.</p> <p>OR</p> <p>Active skin condition requiring a minimum of weekly re-assessment and which is responding to treatment.</p> <p>OR</p> <p>High risk of skin breakdown which requires preventative intervention from a skilled carer or care worker several times each day without which skin integrity would break down.</p>	Moderate
<p>Open wound(s), which is (are) not responding to treatment and require a minimum of daily monitoring/reassessment.</p> <p>OR</p> <p>Active skin condition which requires a minimum of daily monitoring or reassessment.</p> <p>OR</p> <p>Specialist dressing regime, several times weekly in place, which is responding to treatment and requires regular supervision by a Consultant.</p>	High
Life threatening skin conditions or burns requiring complex, distressing dressing routines over a prolonged period.	Severe

## 7. Breathing.

Description	Level of Need
Normal breathing (age appropriate rate).	No additional needs
Routine use of inhalers, nebulisers etc.	Low
<p>Episodes of acute breathlessness, which do not respond to self-management and need specialist-recommended input.</p> <p>OR</p> <p>Requires the use of intermittent or continuous low level oxygen therapy to prevent secondary health issues.</p> <p>OR</p> <p>Has profoundly reduced mobility leading to increased susceptibility to chest infection.</p> <p>OR</p> <p>Requires daily physiotherapy to maintain optimal respiratory function.</p> <p>OR</p> <p>Breathing difficulties which require oral suction.</p>	Moderate
<p>Is able to breath unaided during the day but needs to go on to a ventilator for supportive ventilation. The ventilation can be discontinued for up to 48 hours without clinical harm.</p> <p>OR</p> <p>Is on Continuous Positive Airways Pressure (CPAP).</p>	High
<p>Has frequent hard to predict apnoeas.</p> <p>&amp;/OR</p> <p>Severe life threatening breathing difficulties, which may require essential oral &amp; / or naso phangeal suction.</p> <p>OR.</p> <p>A tracheostomy tube that requires frequent suction by a fully trained carer, to maintain a patent airway.</p> <p>&amp;/OR</p> <p>Requires ventilation at night for very poor respiratory function. Has respiratory drive and would survive accidental disconnection but would be unwell and may require hospital support.</p>	Severe

<p>Unable to breath independently and requires permanent mechanical ventilation.</p> <p>OR</p> <p>Has no respiratory drive when asleep or unconscious and requires ventilation and 1:1 support while asleep as disconnection would be fatal.</p> <p>OR</p> <p>A highly unstable tracheostomy, frequent occlusions, difficult to change tubes.</p>	Priority

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## 8. Drug Therapies and Medicines

Description	Level of Need
Parent, informal carer or self-administered medicine as age appropriate.	No additional needs
<p>Requires a suitably trained family member or formal carer, teaching assistant or nurse to administer* medicine due to:</p> <ul style="list-style-type: none"> <li>• Age</li> <li>• Non compliance</li> <li>• Type of medicine</li> <li>• Route of medicine</li> <li>• Place where medication is to be given</li> </ul> <p>*(See Appendix 1: Extract from Including Me)</p>	Low
<p>Requires administration of medicine regime by a registered nurse or formal carer or teaching assistant specifically trained for this task.</p> <p style="text-align: center;">&amp;</p> <p>Monitoring because of potential fluctuation of the medical condition that can be non-problematic to manage.</p> <p style="text-align: center;">OR</p> <p>Sleep deprivation due to essential medication management –occurring more than once a night (at least twice a week).</p>	Moderate
<p>Has a drug regime that requires management by a registered nurse (within prescription) due to a fluctuating and/or unstable condition or symptom management.</p> <p style="text-align: center;">OR</p> <p>Sleep deprivation due to severe distress due to pain requiring medication management occurring 4 times a night (4 times a week).</p> <p style="text-align: center;">OR</p> <p>Extensive sleep deprivation due to essential pain medication management occurring 1-2 hourly.</p>	High
<p>Has a medicine regime that requires daily management by a registered nurse and reference to a medical practitioner to ensure effective symptom management associated with a rapidly changing/deteriorating condition.</p> <p style="text-align: center;">&amp; / OR</p> <p>Extensive sleep deprivation due severe intractable pain requiring essential pain medication management occurring 1-2 hourly.</p>	Severe
	Priority



Has a medicine regime that requires at least daily management by a registered nurse and reference to a medical practitioner to ensure effective symptom and pain management associated with a rapidly changing/ deteriorating condition, where 1:1 monitoring of symptoms and their management is required.	
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## Psychological and Emotional Needs.

**Beyond what is normally expect from a child of this age.**

Description	Level of Need
Psychological or emotional needs apparent but age range appropriate and similar to those of peer group.	No additional needs
Periods of emotional distress (anxiety, mildly lowered mood) not dissimilar to those of age appropriate peer group which subside and are self-regulated by the young person with prompts / reassurance from peers, family members or key frontline staff within the children's workforce.	Low
<p>Requiring prompts or support to remain within existing infrastructure. Periods of variable attendance in school / college. Noticeable fluctuating levels of concentration evident. Noticeable deterioration in self-care (outside of cultural/peer group norms and trends) which often demand prolonged intervention from additional key staff.</p> <p>OR</p> <p>Evidence of low mood or depression. Reduced social functioning, increasingly solitary with a marked withdrawal from social situations. Limited response to prompts to remain within existing infrastructure (marked deterioration in attendance / concentration within lessons, deterioration in self-care outside of cultural/peer group norms and trends).</p>	Moderate
<p>Rapidly fluctuating moods of depression, anxiety or periods of distress necessitating specialist support and intervention and that have a severe impact on the child or young person's health and well-being.</p> <p>Acute and or prolonged presentation of emotional / psychological deregulation, poor impulse control placing the young person or others at serious risk and or symptoms of serious mental illness that places the young person at risk to self and others.</p> <p>OR</p> <p>Withdrawn from any attempts to engage in care plan and/or daily activities.</p>	High

## 10. Seizures.

Description	Level of Need
No evidence of seizures.	No additional needs
History of seizures but none in the past 3 months. Medication (if any) is stable.	Low
<p>Occasional seizures or periods of unconsciousness that have occurred within the last three months which require the supervision of a carer or care worker to minimise the risk of self-harm.</p> <p>OR</p> <p>Sleep deprivation due to essential seizure management – occurring 3 times a night.</p>	Moderate
<p>Seizures that result in unconsciousness and that may require frequent (more than monthly) skilled intervention to reduce the risk of harm and may require the administration of medication by a registered nurse or specially trained carer.</p> <p>OR</p> <p>Sleep deprivation due to essential seizure management occurring 4 times a night.</p>	High
Severe uncontrolled seizures daily or more resulting in unconsciousness that does not respond to treatment outlined in an established protocol and results in a high probability of risk to self or others.	Severe
Requires daily intervention by a registered nurse who will use their clinical judgement and who is required to select and implement from a range of appropriate interventions to manage seizures and treat any related risks.	Priority

**Q. Are the Domains the correct ones ( professional judgement is still important and assessors can add to/override these on a case by case basis where they can justify doing so).**

**Q. Are there any necessary Domains missing?**

**Q. Do they assist PCTs to understand their responsibilities?**

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## SUMMARY OF HARINGEY CASE

R (on the application of D and another) v Haringey London Borough Council [2005] All ER (D) 256

This case was about a 3 year old child that required, amongst other things, a tracheostomy (a tube in the throat), which needed suctioning three times a night and constant carer availability to deal with the tube if it became disconnected. Her mother was fully trained in how to clear the tube through suctioning, how to change the tapes that held the tube in place and how to change the tube.

Haringey Primary Care Trust (HPCT) provided 20 hours of respite care per week. Various assessments indicated that further respite care should be given. Haringey London Borough Council (HLBC) accepted that additional provision was required and agreed to provide an extra 10 hours a night respite, although it maintained that the service provided was a health service and should therefore be provided by HPCT. HPCT argued that HLBC did have the power to provide the service, and that the extra care was not, in its view necessary. The care was provided by qualified nurses, although it could have been provided by non-medically qualified persons if they had received the appropriate training.

Mr Justice Ouseley stated that the Coughlan criteria, used to determine whether a local authority or a Primary Care Trust should provide required services to an adult in need of NHS continuing care, applied equally to children (despite the fact that the social services care regime for children is regulated by the Children Act 1989 and not the National Assistance Act 1948). In his opinion the decisive factors were the “scale and type of nursing care”, whether its provision is incidental or ancillary to the provision of some other service which the social services authority is lawfully providing, and whether it is of a nature which such authority can be expected to provide.

Mr Justice Ouseley concluded that the service sought was not of a type which should be provided by a local authority under section 17 or paragraph 1 of Schedule 2 of the Children Act 1989. Particular important facts in this case were:

- i) the purpose of the care; although this was described as respite care and therefore might be considered social care to assist the child’s mother, its real purpose was to deal with the “continuing medical consequences of an operation, which if not met will give rise to urgent or immediate medical needs” i.e. to provide medical care for the child. The advice on management of the care was provided by a hospital and the training by medically qualified persons.
- ii) the gravity of the consequences of a failure in care and duration of the care need meant that it was more a medical service provision rather than a social services provision;

iii) with the exception of the child's mother, who had received the required training, the service had been provided by nurses who themselves required training in tracheotomy care. Therefore, whilst it was possible for others to be trained in providing the care, it was clearly an important medical procedure in which people were trained.

My Justice Ouseley therefore held that HLBC did not have a duty to provide the respite care under section 17 and paragraph 1 of Schedule 2 of the Children Act 1989 because these provisions did not extend to medical treatment of the nature envisaged. He commented that "provisions in the Children Act are not to be regarded in general as reducing or replacing the important public obligations, with their qualifications and their target nature, set out in the NHS Act 1977 (now NHS Act 2006)...Children Act nursing care provision is only that which properly falls outside the scope of the NHS". He further commented that interpreting these provisions broadly to cover what are essentially medical needs would turn the social services authority into "a substitute or additional NHS for children". With regard to sections 2 and 28A of the Chronically Sick and Disabled Persons Act 1970 Act, he commented that for the same reasoning that applied to the Children Act 1989, he did not consider that those sections "should be given so wide an interpretation as would cover day or night respite care" and that although respite care "can be seen as "practical assistance" in the home in the context of those provisions (sections 2 and 28A of the 1970 Act) and with the broad health and social services division in mind, that phrase is not apt to include this nursing care".

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