



Department  
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# National Framework for Children and Young People's Continuing Care

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## Executive summary

This Framework is intended to provide guidance for clinical commissioning groups (CCGs) when assessing the needs of children and young people whose complex needs cannot be met by universal or specialist health services.

CCGs have a legal responsibility for securing to a reasonable extent the health care which an individual needs, and this guidance is about the process which should be followed for the equitable discharge of that responsibility for children and young people with complex needs.

The Framework published in March 2010 has supported good practice locally. The principles which underpin it continue to be relevant. Recent changes however have left parts of the Framework out of date. This revision takes account of the new structures of NHS commissioning created by the Health and Social Care Act 2012 and the new integrated approach to the commissioning of services for children and young people with SEND which the Children and Families Act 2014 introduced.

In particular, where a child or young person has a special educational need or disability (SEND), which will often be the case, then CCGs and local authorities should endeavour to coordinate the assessment and agreement of the package of continuing care, as part of the process to develop the child's Education, Health and Care plan.

This guidance comprises:

- **Chapter One: Introduction** - a definition of continuing care, and the roles and responsibilities of CCGs.
- **Chapter Two: The continuing care process** - a step-by-step guide to making an assessment and decision.
- **Chapter Three: The Decision Support tool for children and young people** - a resource to support local determination of a child or young person's needs. This is also published separately as a Word® document for use locally.

We are grateful for the help of all our steering group members, both in 2010, and 2014-15, and the many individuals and organisations who responded to the public consultation held in September – October 2015. DH has endeavoured to reflect as many comments as possible in the finished guidance, and we will continue to keep this guidance under review. Comments can be sent to the address on page 2.

# 1. Introduction

## What is children and young people's continuing care?

**A continuing care package will be required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone.**

1. Some children and young people (up to their 18<sup>th</sup> birthday), may have very complex health needs. These may be the result of congenital conditions, long-term or life-limiting or life-threatening conditions, disability, or the after-effects of serious illness or injury (Annex A provides more information on these types of need).
2. These needs may be so complex, that they cannot be met by the services which are routinely available from GP practices, hospitals or in the community commissioned by clinical commissioning groups (CCGs) or NHS England.<sup>1</sup> A package of additional health support may be needed. This additional package of care has come to be known as continuing care.
3. Continuing care is not needed by children or young people whose needs can be met appropriately through existing universal or specialist services through a case management approach.
4. This framework supports CCGs in determining if a child's needs are such that they require a package of continuing care. It provides advice based on existing practice across the country on undertaking a holistic assessment of the child or young person's needs. CCGs have autonomy as to how they fulfil this function, and what process they adopt.
5. This framework covers young people up to their 18<sup>th</sup> birthday. Thereafter, the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care and the supporting guidance and tools should be used.<sup>2</sup> There are significant differences between children and young people's continuing care and NHS Continuing Healthcare for adults. Although a child or young person may be in receipt of a package of continuing care, they may not be eligible for NHS Continuing Healthcare or NHS-funded Nursing Care once they turn 18. Further information on how to support transition is given below.

## The process in brief

6. The continuing care process typically comprises three phases.
7. The **assessment** is led by a children and young people's health assessor nominated by the CCG, who will draw on the advice of other professionals. This phase may

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<sup>1</sup> For convenience, this framework refers hereafter to CCGs as the health commissioners, but it should be recognised that in some cases, for certain categories of child or young person (for example, the children of services personnel), or for specialised services, NHS England is the responsible commissioner.

<sup>2</sup> <https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care>

include a pre-assessment, to determine whether or not a full assessment is necessary. There are key four areas of evidence that should be considered in the assessment:

- the preferences of the child or young person and their family;
  - a holistic assessment of the needs of the child or young person and their family;
  - reports and risk assessments from a multidisciplinary team or evidence collated during the Education, Health and Care plan assessment; and;
  - the Decision Support Tool for children and young people.
8. The outcome of the assessment is a recommendation from the assessor as to whether or not the child or young person has continuing care needs.
  9. Diagnosis of a particular disease or condition is not in itself a determinant of a need for continuing care. A child or young person may have a rare condition which is difficult to diagnose, but will still have support needs. There should be no differentiation based on whether the health need is physical, neurological or psychological. The continuing care process should be (and be seen to be) fair, consistent, transparent, culturally sensitive, and non-discriminatory.
  10. The second phase, **decision-making** involves a multi-agency forum or panel considering the evidence and the assessor's recommendation, to reach a decision as to whether or not the child or young person has a continuing care need.
  11. This is followed by the **development of a package of care**. Commissioners will decide how the continuing care will be provided, what proportion and level of resource is required to deliver it and how much needs to be specially commissioned, again taking into account the recommendation of the assessor on nature of the child or young person's needs. Costed options may need to be separately considered by a funding panel. These options should always be considered after a decision has been made on whether or not there is a continuing care need. The establishment of a continuing care need should not be determined by the existing package of care a child or young person receives, or who provides or pays for it.
  12. Following agreement on the package of care the CCG and (where relevant), the local authority make the necessary arrangements to deliver the package of care as soon as possible. When determining what the package of care should include, commissioners will consider what additional care might need to be commissioned to fulfil their statutory duty to meet the reasonable needs of an individual.
  13. Commissioners will also keep the package of care under regular review to ensure the developing child or young person's needs continue to be supported. Any package of care which a CCG agrees should aim to be integrated or aligned with other relevant services, such as primary care.

## A multi-agency understanding of a child's needs.

15. Children with complex needs may not only need support from health services. They may also have special educational needs, and need support from social care.
16. Unless there is a good reason for this not to happen, continuing care should be part of a wider package of care, agreed and delivered by collaboration between health, education and social care.
17. Developing a multi-agency understanding of a child's needs, and then agreeing a package of care requires collaboration on the assessment process, and agreement subsequently as to who has responsibility for commissioning the different elements of the care package.
18. A CCG should endeavour to have links in place with its relevant local authorities, to ensure that multi-agency assessments can proceed led by the right agency.
19. The new arrangements for children and young people with special educational needs or disability (SEND) in particular provide a framework for outcomes-focused joint assessments involving different partners across education, health and care, and many children and young people who need continuing care will have special educational needs or disability.
20. Since September 1 2014, under section 26 of the Children and Families Act 2014, a new framework for children and young people (up to age 25) with SEND will apply in England.<sup>3</sup> At the heart of the arrangements is an integrated Education, Health and Care plan (EHC plan).
21. The EHC plan process has at its heart a co-ordinated assessment of a child or young person's needs, based on multi-professional input, and focused on the outcomes which make the most difference to the child or young person and their family. The views and aspirations of the child or young person, and of their family, are central to developing a holistic view of the child's needs.
22. Given the elements common to both the EHC plan assessment, and the continuing care process commissioners and local authorities should consider how the two processes can be brought together, to articulate a single set of needs and outcomes. There are many children and young people with special educational needs or disability without a continuing care need, and their health needs should of course be reflected in the EHC plan.
23. Local authorities and CCGs must work together to make EHC plans work, and their joint arrangements should include an agreement as to how continuing care fits with the EHC process. Although the processes are different, the same information and professionals across disciplines should be involved, in order to result in a coherent package of care across health, education and social care for children and young people who are eligible for continuing care.

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<sup>3</sup> <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>. See also *Special educational needs and disability code of practice: 0 to 25 years. Statutory guidance for organisations who work with and support children and young people with special educational needs and disabilities* (2014). <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

24. The information needed to make a decision on the continuing care package will be very similar to that needed for the health element of the EHC plan. Some form of pre-screening or decision making could determine the pathway for the process. A rapid assessment of whether or not a child is likely to have a continuing care need, could trigger the health assessor undertaking responsibility for health input to the co-ordinated process.
25. A decision by the deciding panel on the continuing care element of the EHC plan could be secured within 28 days, and the package of care commence, to be integrated subsequently with the other education and social care elements of the EHC plan as it takes shape. The health assessor's role would help facilitate the health input to the EHC plan. This would also allow a three month review to take place when the full EHC plan was considered for sign-off.
26. In line with the Haringey judgement (see Annex C), there are clear limits to what care should be funded by the local authority, which should not be a substitute for additional NHS care for children. In this case, the High Court determined that the duty under section 17 of the Children Act 1989 did not extend to meeting essential medical needs.
27. Similarly, the special educational needs support a child may require is the commissioning responsibility of the local authority, as an educational service. However, commissioners may find there is an overlap between their respective responsibilities, in relation to children with certain types of need.
28. Assessment of a child's needs should consider the extent to which a child with a learning disability, or autism may have a continuing care need due to challenging behaviour, defined by NICE as: "behaviour that is a result of the interaction between individual and environmental factors, and includes stereotypic behaviour (such as rocking or hand flapping), anger, aggression, self-injury, and disruptive or destructive behaviour. Such behaviour is seen as challenging when it affects the person's or other people's quality of life and or jeopardises their safety."<sup>4</sup>
29. Such children may require a health intervention; they may also have a special educational need. However, some health commissioners may consider that the support a child with challenging behaviour requires, is predominantly special educational needs. Equally, where the support needed is to ensure the wellbeing and health of a child with challenging behaviour, a case can be made that a health intervention is needed. It is essential that in such cases, there is a clear process agreed between commissioners for resolving issues relating to who pays.
30. Disputes about who has commissioning responsibility should be resolved through escalation to relevant executives, or through the involvement of impartial peers.
31. An assessment of a child or young person's needs may lead to a conclusion that the child's needs are being met by existing services, such as community nursing, or paediatrics. The suitability of existing provision should only be considered once a continuing care need has been established, otherwise there is a risk that a need will

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<sup>4</sup> *Autism in adults. diagnosis and management. CG142*  
<https://www.nice.org.uk/guidance/cg142/chapter/glossary>



not be recognised, because the child or young person is already in receipt of some care.

32. When considering any existing care, it is essential to test it against the wishes of the child or young person and their family, and also against the outcomes which are to be delivered. This evidence can only be obtained if the child or young person and their family are involved in every stage of the process, and the CCG, or their service provider, is active in engaging with them and documenting this evidence.
33. Commissioners should be sensitive to the needs of ensuring continuity and stability of support, and transition to different providers, or different types of care, must be planned, and carefully managed, fully involving the child or young person and their family.
34. A multi-agency assessment may also highlight that care is being commissioned inappropriately by a particular commissioner. There may of course be no need to alter the provision, provided there is an agreement behind the scenes between the commissioners (this could be an interim agreement until a suitable transition point is reached).

## Personal health budgets

35. Under the *National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) (Amendment) Regulations 2013*, the families of a child or young person eligible for continuing care have a 'right to have' a personal health budget, covering the part of their care package which would be provided by the NHS.
36. Where a child or young person (or their family) eligible for continuing care requests a personal health budget, the responsible CCG must arrange for the provision of the care by means of a personal health budget.
37. This can be achieved in one of several ways:
  - a **direct payment** made to the young person or their family;
  - the agreement of a **notional budget** to be spent by the CCG following discussions with the child or young person, and their family (or other representative) as to how best to secure the provision they need;
  - the transfer of a **real budget** agreed as above, to a person or organisation which applies the money in a way agreed between the CCG and the child or young person, and their family (or other representative).
38. CCGs must publicise and promote the availability of personal health budgets to children and young people eligible for continuing care, and provide information, advice and other support to children and young people who are eligible, and their families or representatives.
39. Personal health budgets are not restricted to children and young people eligible for continuing care. They can be offered to other children on a discretionary basis.

40. For more guidance on personal health budgets, see *Guidance on the “right to have” a Personal Health Budget in Adult NHS Continuing Healthcare and Children and Young People’s Continuing Care* (September 2014).  
[http://www.personalhealthbudgets.england.nhs.uk/library/Resources/Personalhealthbudgets/2014/Personal\\_health\\_budgets\\_right\\_to\\_have\\_guidance.pdf](http://www.personalhealthbudgets.england.nhs.uk/library/Resources/Personalhealthbudgets/2014/Personal_health_budgets_right_to_have_guidance.pdf)

## 2. The continuing care process: a step-by-step guide

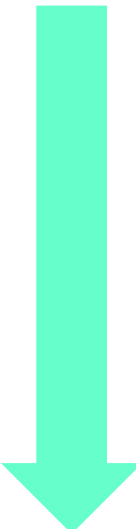
41. The CCG is responsible for leading the process of identifying if a child or young person for whom it has commissioning responsibility under section 3 of the NHS Act 2006 has a continuing care need.
42. CCGs are responsible for establishing and managing appropriate governance arrangements for the process. There should be a senior member of the CCG organisation – ideally a member of the executive – with responsibility for continuing care for children and young people, who can ensure there is effective liaison with the local authority and other partners, as well as ensuring the effective management of the process.
43. Given the clear overlap with services for children and young people with SEND, there may be value in having a single individual with oversight of both continuing care for children and young people, and the CCG's participation in local arrangements for SEND (which are led by the local authority).
44. CCGs will wish to determine for themselves what constitutes appropriate governance, and in particular, how assurance is provided to the CCG executive, and/or governing body that the arrangements for children and young people are effective and appropriate.
45. Ideally, a co-ordinator or administrator should act as a single point of contact with whom professionals can liaise wishing to discuss a child or young person with possible continuing care needs.
46. Similarly, social services and education should be able to raise easily any concern that a child may have continuing care needs. This named point of contact should hold contact details for all local nominated children and young people's health assessors, and be in touch with the Designated Medical Officer or Designated Clinical Officer (DMO / DCO) for special educational needs and disability (SEND).
47. Key points for consideration in setting the local governance arrangements are:
  - is there an appropriate local assessment process?
  - Is there a mechanism for ensuring compliance with the local process and local standards (e.g. the timetable for a decision)? How is performance reported?
  - is there a mechanism for considering high cost packages – and liaison with CCG finance and executive teams where appropriate?
  - how is the quality of packages accessed and maintained – what is the link with the CCG's performance or assurance team?

- Is there a dialogue with providers, both on the process, and in quality assuring services? This would include ensuring appropriate training and development was available for the key practitioners.
- What data is collected on the process, and on the implementation of a package of care?
- Is there local flexibility to shape strategic commissioning arrangements, to ensure that the universal and specialist services can respond to population needs (and thereby reduce the numbers of children and young people who need continuing care)?

### Timeline

48. The CCG should ensure there is a clear timeline against which progress is measured. Clear information should be available to the child or young person and their family on the process, the roles of the nominated children and young people's health assessor and multi-agency decision-making forum. There should be a process of regular updates, so that the child or young person and their family knows what point has been reached in the process.
49. It is important that a decision on whether or not a child or young person has a continuing care need can be made in a timely way. The clock starts at the point of recognition that a child or young person should have a full continuing care assessment (i.e. following any pre-assessment).
50. The pathway should aim for a decision to be given to the child or young person and their family within 6 weeks. However, given the complexity and variety of needs which a CCG may be assessing, there should be scope for flexibility – where it is not contrary to the best interests of the child or young person. For example, if an assessment is being made pending a child's discharge from hospital which is not planned for several months, other assessments may be reasonably given priority. In cases of very complex needs, there may be a number of professionals involved. As outlined above, there may also be a need for a simultaneous social care assessment.
51. A continuing care assessment should not however be delayed in order to fit within the timescale for an EHC plan assessment. A decision on whether or not a child has a continuing care need can be made by the panel, and notified to the local authority SEND co-ordinator, as part of the health advice, with the package of care developed as part of the planning process, which would provide a basis for determining which commissioner is responsible for what types of care, and reaching bipartite decisions.
52. Timescales and deadlines should always be discussed with the child or young person (where appropriate) and their family.
53. If the child or young person is being discharged from acute care or tertiary care adherence to a clear timetable increases the likelihood of the child or young person being discharged in a timely manner and reduces potential for a delayed discharge.
54. Children and young people who require fast-track assessment because of the nature of their needs (such as a palliative care need) should be identified early and the child

or young person's needs met as quickly as possible. The continuing care process should not restrict access to end-of-life care for children and young people who require immediate support over a shorter period, and should not result in any delay to appropriate treatment or care being put in place.

Phase	Step	Summary of key actions	Time-scale
Assessment	Identify	<ul style="list-style-type: none"> <li>A child or young person with a possible continuing care need is referred to the CCG.</li> </ul> <p>[Pre-assessment]</p> <ul style="list-style-type: none"> <li>A child or young person's health assessor is nominated, and the process of assessment begins.</li> </ul>	<p>Clock starts</p> 
	Assess	<ul style="list-style-type: none"> <li>The health assessor undertakes the assessment, comprising:                             <ul style="list-style-type: none"> <li>preferences of child or young person and their family;</li> <li>holistic assessment of need;</li> <li>reports from multi-disciplinary team;</li> <li>Decision Support Tool for children and young people.</li> </ul> </li> </ul>	
	Recommend	<ul style="list-style-type: none"> <li>The health assessor completes the process of assessment, and makes a recommendation.</li> </ul>	
Decision-making	Decide	<ul style="list-style-type: none"> <li>The multi-agency forum considers the recommendation and decides if the child or young person has a continuing care need.</li> </ul>	
Arrangement of provision	Inform	<ul style="list-style-type: none"> <li>The child or young person and their family are informed of the decision.</li> <li>Development of costed package of care. Any relevant organisations, such as the local authority, and key health professionals involved in the child or young person's care (e.g. GP, paediatrician) should also be notified.</li> </ul>	6 weeks
	Deliver	<ul style="list-style-type: none"> <li>Commissioning of the package of care and its provision to the child or young person.</li> <li>Ongoing monitoring / contract management for the commissioned service.</li> </ul>	
Ongoing	Review	<ul style="list-style-type: none"> <li>Reassessment of the child or young person's continuing care needs.</li> </ul>	

## Step 1: Identification

55. The continuing care process begins when there is recognition that a child or young person may have needs that require additional health services. A child or young person may be referred for assessment through a number of different routes, settings and care pathways.

56. The CCG should ensure that referrals can be made by a variety of professionals, and this should include professionals working in primary, secondary and tertiary care, Child and Adolescent Mental Health Services, community nursing teams, local authority-commissioned public health, school nursing and also education and social care.
57. Professionals in these settings should also be able to provide evidence on a child's needs to inform the continuing care assessment.
58. The CCG must have a clear local process for submitting both requests for a continuing care assessment, and for submitting professional evidence.
59. The consent of the child or young person, or their parents where necessary, must be sought. It should be made explicit to the individual what this consent covers, including the sharing of personal information between different professionals and organisations involved in their care.
60. If consent is not given, the potential effect this will have should be explained to them. The fact that an individual declines to be considered for continuing care does not, in itself, mean that a CCG has an additional responsibility to meet their needs, over and above the responsibility if consent had been given.
61. Where there are concerns that an individual may have significant ongoing needs, and that the level of appropriate support could be affected by their decision not to give consent, the CCG should discuss with the local authority the implications, as in any other case where consent for treatment is withheld. If the young person is 16 or over, the Mental Capacity Act may apply. For more information, see the glossary entries on Consent, Mental Capacity Act and Parental Responsibility.
62. In many cases, local commissioners have developed checklists for testing requests for an assessment, without undertaking a full assessment. A suggested template for this checklist is published alongside this framework. CCGs should be flexible in how they approach this; it may be appropriate to obtain professional advice to inform a pre-assessment decision.
63. A decision on whether or not a child should proceed to a formal assessment has to be made quickly, and must be robust, fully documented and where necessary, agreed with the responsible executive in the CCG (an alternative might see such a decision delegated to a relevant member of staff). This pre-assessment should not take more than a day or two – and it is likely that a relatively quick paper-based assessment will give a suitable indication if a child or young person should proceed to a full assessment.
64. Sharing information between different organisations, with different IT systems has often been a challenge, but developing a single co-ordinated plan for an individual child or young person provides a focus for practical information sharing. Consent to share information must be obtained from parents and partner agencies for all continuing care assessments. Methods for information-sharing should fully comply with local information-sharing protocols. Advice, recommendations and decisions should be recorded and stored in accordance with local recordkeeping policy.
65. Developing and agreeing the pathway could be undertaken as part of the joint arrangements between local authorities and CCGs for SEND.

66. The pathway for assessing a child or young person's needs must be understood and agreed with all partners. At a strategic level, the Health and Wellbeing Board may provide a suitable forum for securing this agreement. For transparency, the pathway should be available in a document which allows all those involved to be familiar with the process.
67. The CCG must ensure that the child or young person and their family being considered for continuing care should understand the continuing care process, receiving accessible advice and information in a timely and clear manner. Their views should be documented and taken into account, and considered alongside the benefits and risks of different types of provision as part of the assessment. Where the views of the child or young person are different from those of their family, the possibility of advocacy should be discussed.

### Step 2: Assessment

68. The nominated children and young people's health assessor should lead the assessment phase of the continuing care process on behalf of the commissioners. The assessment will obtain evidence that a child has a continuing care need. Every need considered under the Decision Support Tool should have evidence to support it, e.g. 24 hour care diaries, professional opinions, risk assessments, case notes.
69. The assessment will by its nature help to identify how those needs might be met by a package of care, but the assessment and the recommendation to the panel must be needs-based; options for care must be considered separately to any recommendation that a child or young person has a continuing care need. The assessor must exercise caution to avoid assuming a level of need, on the basis of a condition, or the existing package of care or the equipment used.
70. The assessment should make use of the evidence of previous assessments where relevant, although not to the exclusion of new assessment, or direct contact with children or young people and their families. The input of the third sector should be considered in the assessment phase as appropriate.
71. The nominated children and young people's health assessor should be a health practitioner with relevant skills and competencies to undertake children's health assessments. This role should not be undertaken by an adult practitioner.
72. It is important to recognise that it is unlikely that a single individual will have all the necessary skills or knowledge to act as an assessor for all assessments in a particular area. An assessor with the competence to assess the needs of a child or young person with complex physical needs, will not necessarily have the competence to assess a child or young person with complex behavioural or emotional needs. The assessor will collate relevant information, and liaise with the appropriate professionals to requests assessments by local authority children and young people's services on behalf of the commissioners.
73. Every assessor should as a minimum have expertise in:
  - children and young people's continuing care (and the policy in this Framework);

- child and young people's development;
- assessing children and young people and their families; and
- working with children and young people (and their families).

74. The assessor should also ideally have:

- experience and expertise in health assessment;
- well-developed leadership qualities;
- listening skills;
- an understanding of local health and social care commissioning;
- skills and competencies to level 3 safeguarding children.

75. Commissioners will need to ensure that the health assessor role is properly resourced, and that the individuals designated are not placed in a difficult position in relation to the families they support on a day-to-day basis. Commissioners will need to ensure that the health assessor is also able to make a recommendation uninhibited by their relationship with the child or young person and their family.

76. An assessor who is not known to the child or young person and their family has the advantage of independence, but will need to ensure they have the right background evidence of the child or young person's needs (and a carer's assessment is essential to this).

77. Conversely, a community nurse who regularly cares for a child or young person, and knows the family, has a significant advantage in understanding their needs, but could find that their assessment threatens the working relationship. There may be value in CCGs coordinating assessors so that a nurse does not assess a child they support (but liaises appropriately with their regular nurses). There is also scope for neighbouring CCGs to have reciprocal arrangements for assessors, so that nurses are only assessing out of area.

78. There are four broad areas of assessment, and each is important to determining the need for continuing care. The nominated children and young people's health assessor undertaking the assessment should demonstrate evidence based professional judgement in each of the four areas to support their recommendation.



## The Four Areas of Assessment

### 1. The preferences of the child or young person and their family

The child or young person and their family should be supported to be partners in the assessment process; this might include siblings and any family members involved in supporting the child or young person. Care is often highly invasive of the family home and the preferences of all family members should be sought as far as possible.

This area corresponds to section A in the Education, Health and Care plan, which captures the views, interests and aspirations of the child or young person, and their parents.

### 2. Holistic assessment of the child or young person

The nominated children and young person's health assessor undertakes a health assessment, collating existing assessments, including for social care. Where social and educational assessments have not been undertaken, the assessor should liaise with the appropriate professionals.

The health needs of other family members and the proposed environment of care should also be considered. The Decision Support Tool for children and young people provides some prompts to help shape this part of the assessment.

### 3. Reports and risk assessments from the professionals in the child's multidisciplinary team

The nominated children and young people's health assessor is responsible for collating the evidence from professionals who are involved in the care of the child or young person (across health, social and education), particularly risks assessments and reports. There may also be a need to commission healthcare risk assessments that have not already been undertaken. As in all elements of the assessment, the health assessor may need to get expert advice on this, and is not expected to act as a specialist in all areas of the child or young person's care.

This again is similar to the co-ordinated assessment of the EHC process. In many cases, the assessor will be able to receive a written report and / or risk assessment from the relevant professionals based on their notes (and often, a copy of the relevant section of the notes will suffice).

### 4. The Decision Support Tool for children and young people

The fourth area provides a means of making a summative judgement of a child or young person's needs, drawing on evidence from the other parts of the assessment. **It is not a stand-alone tool and is designed to ensure that relevant needs are assessed, captured and described in a consistent way.**

79. Everyone who contributes to an assessment should be fully aware of its intended use and distribution. The results of continuing care assessments should be shared with the child or young person and their family.
80. The assessment of children and young people for continuing care must take account of safeguarding policies and legislation, which place a duty on all agencies to safeguard and promote the welfare of children and young people.

81. Exceptionally, information may be withheld from a child or young person or someone with parental responsibility for them if the CCG considers that it would be likely to cause significant harm to the physical or mental health or condition of the child or young person or would otherwise not be in their best interests. Social services should be involved, if they are not already, where it is thought that the child is at risk of significant harm or is suffering significant harm.
82. Following the completion of the four areas of assessment, the nominated children and young people's health assessor should produce recommendations for presentation to the decision-making forum.

### Step 3: Recommendation

83. Following the completion of the four areas of assessment, the nominated children and young people's health assessor should produce recommendations for presentation to the decision-making forum. The evidence should be documented and available for the panel to consider.
84. The panel should be independent from those involved in assessment, and include key CCG and local authority professionals, and at least one clinician.

### Step 4: Decision

85. A decision should ideally be made within 6 weeks of the commencement of assessment.

### Step 5: Inform

86. Following the forum's decision, the child or young person and their family should be notified within 5 working days. Decisions should be given verbally to the child or young person and their family or their representative, to be followed by a clear written explanation for the decision.
87. Key professionals, such as the child's paediatrician, or multi-disciplinary team and their GP, and key organisations, such as their school and local authority, should also be informed.

### Resolving disputes

88. Where a child or young person is found not to have a need for continuing care, a clear written explanation of the rationale for the decision should be provided to the child or young person and family following verbal notification as above.
89. The child or young person and their family should be informed of their rights and of the complaints procedure in the case of a decision which does not meet their preferences and/or expectations. This should ideally form part of any public documentation on the continuing care process, and must be included within the published Local Offer of services for children with SEND.

90. CCGs must have complaints procedures in place to respond promptly to any request to review disagreements voiced by the child or young person or their family or carer about any aspect of the continuing care process.<sup>5</sup>
91. CCGs will already have a system for reviewing assessments or decisions 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. Any dispute with a child or young person and their family should go through this process. Any package of care should remain in place whilst a dispute is ongoing.
92. CCGs and local authorities should agree a local dispute resolution process to resolve cases where there is a dispute between NHS organisations, or between a health commissioner and a local authority, over a child or young person's continuing care needs and/or over responsibility for the funding of a package of continuing care, in a robust and timely manner. Disputes should not delay the provision of the care package, and the arrangements should be clear on how funding will be provided pending resolution of the dispute and arrangements for reimbursement to the agencies involved once the dispute is resolved.
93. Given the requirement on CCGs and local authorities to have, as part of their joint arrangements for SEND, arrangements for resolving disputes, it would be sensible for such arrangements to also cover disputes relating to continuing care. Working with the child or young person and their family on the content of their package, as with their EHC plan, is the strongest means of ensuring a plan meets the child's needs and expectations.

### Step 6: Arrangement of provision

94. The process of assessment will provide an evidence base to inform the development of options for a care package. It is essential that the panel reaches a decision first on whether or not a child has a continuing care need, before potential packages of care are considered, to avoid a provision-led decision.
95. The package of care must be shaped by the child or young person's support needs, rather than by what is offered by providers (for example, some providers have a preference for particular length of carer shifts, which may not correspond with what is needed by the child or young person and their family).
96. Multi-agency and/or multidisciplinary groups should work with the family to support the nominated children and young people's health assessor to produce the child or young person's continuing care options which are safe and effective, taking into account the child or young person's and their family's preferences. Involvement of the family is essential, not least to discuss options in relation to the parental role as carers. However, the care package should not be driven by the family's preferences where this conflicts with the needs of the child or young person, or the CCG's commissioning strategy.

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<sup>5</sup> All providers and commissioners of NHS-funded services have a statutory requirement to have in place a complaints system; the legislative framework is laid down in the Local Authority Social Services and National Health Service Complaints Regulations 2009. <http://www.legislation.gov.uk/uksi/2009/309/contents/made>

97. The domains of the Decision Support Tool for children and young people allows consideration of actual needs, how these are being met, what is working and what interventions or referrals must be made to facilitate unmet needs. There is also scope for considering the workforce and indeed, training options necessary.
98. Where the child or young person has other care packages in place, the team must have regard to these packages of care and seek to work with other teams to ensure that the care provided fits seamlessly with other care being received.
99. As noted above, joint commissioning, or bi-partite agreements may need to be arranged, to ensure health and social care needs are catered for in a package of care.
100. Care planning should begin early, consider discharge needs where appropriate, and be simplified to enable community-based services to provide home-based care wherever possible. Planning of the package of care should consider:
- the skill mix of staff (e.g. the complement of nurses/carers within the package), since this is a critical aspect of the care package in terms of quality and outcomes;
  - how continuing care integrates with SEND provision, and universal and specialist health provision;
  - sustainability and long-term outcomes (see below for transition);
  - a multi-professional approach, rather than one which focuses on venues of care;
  - the child or young person's home as the focus of care;
  - out of hours support;
  - staff competency and training of parents, staff and foster carers (including training costs);
  - equipment.
101. Decisions about residential care and other social care support must of course be made by the local authority, as lead commissioner for social care, with health working alongside to identify how the child/young person's health needs can be met. If there are concerns about home care on grounds of care, risk or capacity, interventions should be planned which will enable home care to continue whilst addressing the care, risk or capacity issues (e.g. by implementing positive behaviour support for a child with severely challenging behaviour). Residential care should be used only when other interventions have failed and/or where there are safeguarding issues and it is judged in the best interests of the child.
102. Health commissioners and local authorities will need to make the necessary logistical, funding and, in some instances, contractual arrangements to initiate the delivery of the package of continuing care.
103. A package of continuing care should be put in place as soon as possible once the decision has been made, and the child or young person and their family has been informed. In some instances there may be an unavoidable delay in implementation, such as where the outcome of a Disabled Facilities Grant panel is required, or where time is needed to ensure the competence of the workforce, but health commissioners and local authorities should ensure that delays are avoided as far as is possible. As always, the child or young person and their family should be kept informed of progress and involved in implementation.

104. Where the child or young person is found to have a need for continuing care but the proposed care package varies from the preferred option of the child or young person and their family, a clear written explanation of the rationale for the decision should be provided. Ideally, the process of engagement before this point should have enabled a consensus on the appropriate package of care.

### Step 7: Review

105. The child or young person's continuing care needs should be reviewed three months after the package of care has commenced, and then annually thereafter, or when a child or young person's health or function is known to have changed. Clearly, if there is a significant change, a full reassessment may be necessary.
106. The child or young person and their family should be able to request a review. As with any commissioned service, the CCGs is responsible for regular contract review to ensure that service specifications are being met and that the service being provided is of the required level.
107. Reviews of a child or young person's continuing care should be an opportunity for assessment of needs and how they are being addressed by the care package. It should be made clear to the child or young person and their family that reviews are designed to ensure that the child or young person's continuing care needs are being met on an ongoing basis and that they are not financially motivated. Where a child or young person has SEND, the continuing care package review, and the regular review of an EHC plan, should ideally be synchronized.
108. Any such review should be transparent, involve the child or young person and their family. Both verbal and written reports should be given to the child or young person and family as appropriate.
109. Reviews should be responsive to changes in a child or young person's fundamental need, as there will be cases where successful management of a condition has permanently reduced or removed an ongoing need. The responsibility to commission care is not indefinite as needs may change and this should be made clear to the child or young person and their family. Equally, commissioners must guard against making changes to a package of care, where the child or young person's underlying needs have not changed. As always, transparency of process, and involvement of the child or young person and their family, will be essential to maintain the fairness and consistency of the review.
110. In instances where transition back into universal or specialist health services is appropriate, the child or young person and their family should be supported throughout this transition, ideally from within their existing care team. Early engagement with other services is essential for proactive planning and ensuring a smooth move to the other service.

### Transition

111. Many children and young people provided with continuing care will remain dependent upon others for all of their care throughout their lives. The aim of providing continuing

care for this group is to enhance their quality of life and empower and support their families and carers to manage and understand their conditions and situations.

112. For those young people with the capacity to develop independence, the aim of continuing care should be to support the move from dependence to independence, with children and young people being enabled to manage their condition themselves with a full understanding of the implications of their condition.
113. Every child or young person with a package of continuing care who is approaching adulthood should have a multi-agency plan for an active transition process to adult or universal health services or to a more appropriate specialised or NHS Continuing Healthcare pathway.
114. Once a young person reaches the age of 18, they are no longer eligible for continuing care for children, but may be eligible for NHS Continuing Healthcare, which is subject to legislation and specific guidance. It is important that young people and their families are helped to understand this and its implications right from the start of transition planning. There should be a single key contact for families of a young person approaching transition
115. CCGs should ensure that they are actively involved, with their partners, in the strategic development and oversight of their local transition planning processes, and that their representation includes those who understand and can speak on behalf of adult NHS continuing healthcare. CCGs should also ensure that adult NHS continuing healthcare is appropriately represented at all transition planning meetings to do with individual young people whose needs suggest that they may be eligible for NHS Continuing Healthcare.
116. Future entitlement to adult NHS continuing healthcare should be clarified as early as possible in the transition planning process, especially if the young person's needs are likely to remain at a similar level until adulthood, and this should be accomplished by undertaking an initial screening for NHS continuing healthcare at a suitable point when aged 16-17.
117. In summary:

- At **14** years of age, the young person should be brought to the attention of the CCG as likely to need an assessment for NHS Continuing Healthcare.
- At **16 -17** years of age, screening for NHS Continuing Healthcare should be undertaken using the adult screening tool, and an agreement in principle that the young person has a primary health need, and is therefore likely to need NHS Continuing Healthcare .
- At **18** years of age, full transition to adult NHS Continuing Healthcare or to universal and specialist health services should have been made, except in instances where this is not appropriate.

118. Children's services should identify those young people for whom it is likely that adult NHS Continuing Healthcare will be necessary, and should notify whichever CCG will have responsibility for them as adults. This should occur when a young person reaches the age of 14.

119. This should be followed up by a formal referral at 16 for screening to the adult NHS Continuing Healthcare team at the relevant CCG.
120. Usually when the young person is in their 17<sup>th</sup> year, eligibility for NHS Continuing Healthcare should be determined in principle by the relevant CCG, so that, wherever applicable, effective packages of care can be commissioned in time for the individual's 18th birthday (or later, if it is agreed that it is more appropriate for responsibility to be transferred then). In order to do this staff from adult services (who are familiar with the National Framework) will need to be involved in both the assessment and care planning to ensure smooth transition to adult services. If needs are likely to change, it may be appropriate to make a provisional decision, and then to recheck it by repeating the process as adulthood approaches.
121. Entitlement to NHS Continuing Healthcare should initially be established using the decision-making process set out in the National Framework for NHS Continuing Healthcare. The health plans and other assessments and plans developed as part of the transition process will provide key evidence to be considered in the decision-making process. Any entitlement that is identified by means of these processes before a young person reaches adulthood will come into effect on their 18th birthday, subject to any change in their needs.
122. If a young person who receives children and young people's continuing care has been determined by the relevant CCG not to be eligible for a package of NHS Continuing Healthcare in respect of when they reach the age of 18, they should be advised of their non-eligibility and of their right to request an independent review, on the same basis as NHS continuing healthcare eligibility decisions regarding adults. Although these young people will cease to have a "right to have" a personal health budget, CCGs can continue to offer services via a personal health budget on a discretionary basis, to support the transition to adult services.
123. The CCG should continue to participate in the transition process, in order to ensure an appropriate transfer of responsibilities, including consideration of whether they should be commissioning, funding or providing services towards a joint package of care (for example, to deliver an EHC plan). Transition should be planned and agreed with the young person and their family or carers in good time to avoid any disruption or delay to implementing a package of care.
124. Even if a young person is not entitled to adult NHS continuing healthcare, they may have certain health needs that are the responsibility of the NHS. In such circumstances, CCGs should continue to play a full role in transition planning for the young person, and should ensure that appropriate arrangements are in place for services that meet these needs to be commissioned or provided. The focus should always be on the individual's desired outcomes and the support needed to achieve these.
125. A key aim is to ensure that a consistent package of support is provided during the years before and after the transition to adulthood. The nature of the package may change because the young person's needs or circumstances change. However, it should not change simply because of the move from children's to adult services or because of a change in the organisation with commissioning or funding responsibilities. Where change is necessary, it should be carried out in a planned

manner, in full consultation with the young person. No services or funding should be unilaterally withdrawn unless a full joint health and social care assessment has been carried out and alternative funding arrangements have been put in place.

126. The legal responsibilities for child and adult services overlap in certain circumstances. In developing individual transition plans, partners should be clear where such overlaps occur, and the plans should clearly set out who will take responsibility and why. Some local health services for children and young people are only offered up to an age short of adulthood (i.e. 16). CCGs and other partners responsible for children and young people's services should ensure that appropriate services are commissioned to meet needs through to adulthood. A gap in service provision based on age does not mean that NHS Continuing Healthcare services acquire early responsibility. Where service gaps are identified, CCGs should consider how to address these as part of their strategic commissioning responsibilities.
127. It should be noted that regulations state that, in certain circumstances, when a young person in receipt of children and young people's continuing care reaches adulthood, the care arrangements should be treated as having been made under the adult continuing care provisions. Guidance on the regulations sets out that young people approaching their 18th birthday will require a reassessment of their health and social care needs as part of their transition planning, and that, wherever possible, these young people should continue to receive their healthcare on an unchanged basis until they have been reassessed (this does not however mean that a young person in receipt of continuing care, will qualify for NHS Continuing Healthcare when they reach 18). It is therefore in the interests of the child/young person and of the CCG and LA to monitor and actively participate in the reviews of those recipients of continuing care who are approaching adulthood.
128. The regulations and guidance for NHS Continuing Healthcare can be found at: <https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care>



### 3. Decision support tool for children and young people

129. The Decision Support Tool for children and young people is intended to bring assessment information together in a concise, consistent way. It is designed to help ensure that all relevant needs are assessed and captured. A Word® version of the Tool is also available which can be used as a template locally.
130. The Tool is not stand-alone. The nominated children and young people's health assessor will have worked alongside a multi-agency or multidisciplinary team to compile the information required to complete the Tool, drawing on the three key areas of assessment already mentioned:
- the preferences of the child or young person and their family;
  - holistic assessment of the child or young person and their family;
  - reports and risk assessments from the multidisciplinary team.
131. The nominated children and young people's health assessor should use the Tool to match, as far as possible, the child/young person's level of need with the relevant description. This approach should build up a detailed analysis of individual needs, in a family context, and also provide evidence to inform the provision of a package of continuing care. The tool is not prescriptive, and evidence-based professional judgement should be exercised in all cases to ensure that the child or young person's overall level of need is correctly assessed.
132. This process and the information collected will provide the basis for recommendations to be presented to the multi-agency decision-making forum; this will inform the decision on whether or not a package of continuing care is needed.
133. The Decision Support Tool sets out children's needs across 10 care domains, divided into different levels of need:
- breathing
  - eating and drinking
  - mobility
  - continence and elimination
  - skin and tissue viability
  - communication
  - drug therapies and medicines
  - psychological and emotional needs
  - seizures
  - challenging behaviour
134. The nominated children and young people's health assessors will use their clinical skill, expertise and evidence-based professional judgement to consider what, for each care domain, is over and above what would be expected for a child or young person of that age. For example, incontinence would only become recognised as an issue when a child or young person has continence needs beyond those typical for their age.
135. The needs described in the care domains and levels of need in the Tool may not always adequately describe every child or young person and their family's circumstances. Professional judgement and clinical reasoning are paramount in ensuring that a child or young person's needs are accurately assessed, taken into

account and given due weight when making a decision regarding their continuing care needs. All four parts of the assessment process interact in defining the child or young person's overall need for continuing care.

136. There may be circumstances where a child or young person may have particular needs which do not fall within the 10 care domains described in the Tool (an example might be a child who is unable to regulate their body temperature, or who has an unstable cardiac condition). Information on these needs should of course be included as evidence in the assessment if considered significant, usually drawn from risk assessments or professional reports. Some significant health needs may not of course result in a need for continuing care, if they are already supported by outpatient or other services routinely commissioned.
137. The assessment of the level of need must recognise that where a child or young person requires constant supervision or care which is largely provided by family members, there will be a need for professional support to allow the family time off from their caring responsibilities, and this may require a social care assessment, and agreement, between the CCG and the local authority (which is usually the commissioner of respite care), of the respective contribution.
138. The Tool provides a framework for reaching a decision on levels of need. Information will need to be organised and documented to support that. Some suggested prompts are included. Note that questions may not necessarily be answerable in chronological order, and we have tried to avoid questions which would be more for a social care assessments (some questions on family circumstances have however been included). More than one section may correspond with a statutory section in an EHC plan. In every section, assessment should seek to identify needs **met and unmet**, and current need, rather than past or anticipated need.

## Child and family details

### Child / young person

- Child's name
- Date of birth
- NHS number
- Contact details
- Mother's name
- Father's name

### Assessment circumstances

- Communication
- Is an interpreter needed?
  - How can professionals best communicate with the child?

Date referred for assessment

Date of initial needs assessment / pre-assessment

- Referred by
- Give referring professional and provider organisation and relevant contact details

- Responsible CCG
- CCG of which the child or young person's GP is a member.

- Assessment start date
- Clock starts

### Family circumstances

- Family support
- Does any other member of the family have health or care needs?
  - Are siblings involved in care provision.
  - What kind of help is available in the family's circle of friends and relations?
  - Are there any other organisations or groups that support the family/carer's family?
  - Summary of parents'/carer's occupation, employment/shift patterns.
  - Effect of the child/young person's condition on the parent/carer's ability to work.
  - Has a social care assessment been made?

Housing	<ul style="list-style-type: none"> <li>• Adequacy for the child's/family's/carer's family's needs?</li> <li>• Any adaptations required?</li> </ul>
Transport	<ul style="list-style-type: none"> <li>• Is the family/carer's family reliant on public transport?</li> <li>• Are there particular difficulties in transportation (is the child receiving a mobility component of Disability Living Allowance)?</li> </ul>
Recreation and leisure	<ul style="list-style-type: none"> <li>• Is the child/young person able to choose leisure activities?</li> <li>• What is required to enable the child/young person to access leisure activities?</li> <li>• What are their interests or hobbies?</li> <li>• Are the recreational needs of siblings and other family/carer's family members being met?</li> </ul>

## Education

Name of nursery, school or college attending	<ul style="list-style-type: none"> <li>• Is the child/young person able to access an appropriate educational setting, either full or part-time?</li> </ul>
Special educational needs	<ul style="list-style-type: none"> <li>• Does the child/young person have a special educational need?</li> <li>• Does the child/ young person have a Statement of Special Educational Need, or an Education, Health and Care plan?</li> </ul>
Education and learning	<ul style="list-style-type: none"> <li>• What additional support or reasonable adjustments are required in that setting?</li> <li>• If the child/young person is too ill to access a setting, what other provision is in place to ensure continuity of learning?</li> </ul>

139. This first section should also of course include the views and aspirations of the child or young person and their family – this is the major element of Section A of the EHC plan, and should have a correspondingly prominent position in any continuing care assessment. Ideally this section should consider:

- the child/young person's issues, concerns, anxieties.
- the child/young person's preferences about care delivery.
- the family's preferences about care delivery.

## Team around the child

### Staff

Name, telephone number and location of the following where relevant:

- registered GP
- all consultants
- Designated Medical or Health Officer for SEND
- community paediatrician
- psychologist
- psychiatrist
- community children's nurse
- specialist nurse (e.g. for epilepsy).
- Nurse consultant
- CAMHS nurse
- named ward nurse
- health visitor
- school nurse
- district nurse
- social worker
- occupational therapist
- speech and language therapists
- physiotherapist
- other therapists
- SENCO
- short break services
- lead professional
- interpreter.

### Clinical details

Medical history

- Dates of significant health events/current health status.

Equipment – permanent or disposable

- Details (this might include the type of equipment, supplier, maintenance arrangements etc.)

Treatment / care needs

- Interventions; who provides and monitors the service; care plans.
- Symptom management and pain control.
- How are the child/young person and family/carers supported?
- Does the family have adequate information on the child/young person's condition/future?
- What is the 24-hour daily care routine?
- Competencies required to care for the child/young person.
- Is there a lead professional, and is this working well?

140. Assessment should consider the emotional support needs of a child, young person and their family.

- What is the effect of the child/young person's condition on each member of the family?
- What times of the day/events are stressful?

- How does the family cope?
- Who does the family call on for support at these times?
- Are there times when the child or young person need particular support?
- How do they communicate as a family?
- What is the child/young person's understanding of his/her condition?
- What understanding do siblings have of the child/young person's condition?
- Is an assessment by child and adolescent mental health services required?

## Outcomes

141. The assessment of a child's continuing care needs must consider the outcomes necessary to enable the child or young person to get the best from life, and outcomes relating to transition (where the child is 14 years or older).
142. They should be specific, deliverable and linked directly to the child's wishes. They should include where appropriate, outcomes for transition, through key changes in a child or young person's life, such as changing schools, moving from children's to adult care and/or from paediatric services to adult health, or moving on from further education to adulthood.
143. Key issues would include:
- Maintaining a safe environment (including vulnerability to exploitation)
  - Communicating
  - Breathing
  - Eating and drinking
  - Elimination
  - Personal cleaning and dressing
  - Controlling body temperature
  - Mobility
  - Leisure
  - Learning
  - Expressing individuality
  - Sleeping
  - Employment
  - Independence
  - Further education
  - Emergency care
  - End of life.
  - Pain management

## Interpreting the level of need using the domains

144. Health assessors should consider the needs of the child or young person across the following 10 domains of care. Care has been taken to avoid duplicating needs in two separate domains. However, assessors should consider how different but inter-related needs across more than one domain can complicate the child or young person's overall care needs and result in sufficient complexity, intensity or risk to demonstrate continuing care needs.
145. In each domain, a number of different descriptors are given, separated by **or**; this does not necessarily preclude more than one descriptor being relevant to the child or young person's needs.

146. It is essential that clear evidence is obtained to support assessments in the relevant domains, and that this evidence is recorded as part of the continuing care assessment, and included in any subsequent care plan.
147. In order to help with interpretation, some examples have been included to clarify certain types of need, although these have been used sparingly. However, the fact that a child has a condition or symptom which is mentioned, is not in itself an indicator of the level of need (for example, the fact that a child has a tracheostomy, does not automatically mean they have a priority need under the Breathing domain).
148. A child is likely to have continuing care needs if assessed as having a severe or priority level of need in at least one domain of care, or a high level of need in three domains of care.
149. 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 a picture of overall care needs across all domains. 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 – that needs assessed as 'moderate' in two domains are the equivalent of one 'high' level of need, for example. In presenting recommendations to a multi-agency forum, nominated children and young people's health assessors should consider the level of need identified in **all** care domains in order to gain the overall picture.
150. Nominated children and young people's health assessors should be mindful that even if the child or young person is assessed as not having continuing care needs, they may require other healthcare input from universal services or community children/young person's nursing or other specialist services.
151. An assessment may identify behaviours under **Challenging behaviour** which cannot be met by health services or which would be more appropriately met by special educational support, or social care. In such cases, there should be a dialogue with the local authority, and if necessary, agreement of a joint package of care, in line with respective commissioning policies. Where a child has a Statement of SEN or an Education, Health and Care plan, there may of course be a pre-existing package of educational support which requires no additional support from health or social care services. It is preferable that the assessment gives an honest appraisal of a child or young person's needs, to be followed by a discussion as to who provides the necessary support, than that the assessment attempts to pre-empt this, and ignores potentially relevant evidence.

**Breathing**

Description	Level of need
Breathing typical for age and development.	No additional needs
Routine use of inhalers, nebulisers, etc.; <b>or</b> care plan or management plan in place to reduce the risk of aspiration.	Low
Episodes of acute breathlessness, which do not respond to self-management and need specialist-recommended input; <b>or</b> intermittent or continuous low-level oxygen therapy is needed to prevent secondary health issues; <b>or</b> supportive but not dependent non-invasive ventilation which may include oxygen therapy which does not cause life-threatening difficulties if disconnected; <b>or</b> child or young person has profoundly reduced mobility or other conditions which lead to increased susceptibility to chest infection (Gastroesophageal Reflux Disease and Dysphagia); <b>or</b> requires daily physiotherapy to maintain optimal respiratory function; <b>or</b> requires oral suction (at least weekly) due to the risk of aspiration and breathing difficulties; <b>or</b> has a history within the last three to six months of recurring aspiration/chest infections.	Moderate
Requires high flow air / oxygen to maintain respiratory function overnight or for the majority of the day and night; <b>or</b> is able to breath unaided during the day but needs to go onto a ventilator for supportive ventilation. The ventilation can be discontinued for up to 24 hours without clinical harm; <b>or</b> requires continuous high level oxygen dependency, determined by clinical need; <b>or</b> has a need for daily oral pharyngeal and/or nasopharyngeal suction with a management plan undertaken by a specialist practitioner; <b>or</b> stable tracheostomy that can be managed by the child or young person or only requires minimal and predictable suction / care from a carer.	High
Has frequent, hard-to-predict apnoea (not related to seizures); <b>or</b> severe, life-threatening breathing difficulties, which require essential oral pharyngeal and/or nasopharyngeal suction, day or night; <b>or</b>	Severe



<p>a tracheostomy tube that requires frequent essential interventions (additional to routine care) by a fully trained carer, to maintain an airway;  <b>or</b>                  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>	
<p>Unable to breath independently and requires permanent mechanical ventilation;  <b>or</b>                  has no respiratory drive when asleep or unconscious and requires ventilation, disconnection of which could be fatal;  <b>or</b>                  a highly unstable tracheostomy, frequent occlusions and difficult to change tubes.</p>	<p>Priority</p>

**Eating and drinking**

Description	Level of need
<b>Able to take adequate food and drink by mouth, to meet all nutritional requirements, typical of age.</b>	No additional needs
Some assistance required above what is typical for their age; <b>or</b> needs supervision, prompting and encouragement with food and drinks above the typical requirement for their age; <b>or</b> needs support and advice about diet because the underlying condition gives greater chance of non-compliance, including limited understanding of the consequences of food or drink intake; <b>or</b> needs feeding when this is not typical for age, but is not time consuming or not unsafe if general guidance is adhered to.	Low
Needs feeding to ensure safe and adequate intake of food; feeding (including liquidised feed) is lengthy; specialised feeding plan developed by speech and language therapist; <b>or</b> unable to take sufficient food and drink by mouth, with most nutritional requirements taken by artificial means, for example, via a non-problematic tube feeding device, including nasogastric tubes.	Moderate
Faltering growth, despite following specialised feeding plan by a speech and language therapist and/or dietician to manage nutritional status,. <b>or</b> dysphagia, requiring a specialised management plan developed by the speech and language therapist and multi-disciplinary team, with additional skilled intervention to ensure adequate nutrition or hydration and to minimise the risk of choking, aspiration and to maintain a clear airway (for example through suction); <b>or</b> problems with intake of food and drink (which could include vomiting), requiring skilled intervention to manage nutritional status; weaning from tube feeding dependency and / recognised eating disorder, with self-imposed dietary regime or self-neglect, for example, anxiety and/or depression leading to intake problems placing the child/young person at risk and needing skilled intervention; <b>or</b> problems relating to a feeding device (e.g. nasogastric tube) which require a risk-assessment and management plan undertaken by a speech and language therapist and multidisciplinary team and requiring regular review and reassessment. Despite the plan, there remains a risk of choking and/or aspiration.	High
The majority of fluids and nutritional requirements are routinely taken by intravenous means.	Severe

**Mobility**

Description	Level of need
Mobility typical for age and development.	No additional needs
<p>Able to stand, bear their weight and move with some assistance, and mobility aids.</p> <p><b>or</b></p> <p>moves with difficulty (e.g. unsteady, ataxic); irregular gait.</p>	Low
<p>Difficulties in standing or moving even with aids, although some mobility with assistance.</p> <p><b>or</b></p> <p>sleep deprivation (as opposed to wakefulness) due to underlying medical related need (such as muscle spasms, dystonia), occurring three times a night, several nights per week;</p> <p><b>or</b></p> <p>unable to move in a way typical for age; cared for in single position, or a limited number of positions (e.g. bed, supportive chair) due to the risk of physical harm, loss of muscle tone, tissue viability, or pain on movement, but is able to assist.</p>	Moderate
<p>Unable to move in a way typical for age; cared for in single position, or a limited number of positions (e.g. bed, supportive chair) due to the 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><b>or</b></p> <p>at a high risk of fracture due to poor bone density, requiring a structured management plan to minimise risk, appropriate to stage of development;</p> <p><b>or</b></p> <p>involuntary spasms placing themselves and carers at risk;</p> <p><b>or</b></p> <p>extensive sleep deprivation due to underlying medical/mobility related needs, occurring every one to two hours (and at least four nights a week).</p>	High
<p>Completely immobile and with an unstable clinical condition such that on movement or transfer there is a high risk of serious physical harm;</p> <p><b>or</b></p> <p>positioning is critical to physiological functioning or life.</p>	Severe

**Continence or elimination**

Description	Level of need
Continence care is routine and typical of age.	No additional needs
Incontinent of urine but managed by other means, for example, medication, regular toileting, pads, use of penile sheaths; <b>or</b> is usually able to maintain control over bowel movements but may have occasional faecal incontinence.	Low
Has a stoma requiring routine attention, <b>or</b> doubly incontinent but care is routine; <b>or</b> self-catheterisation; <b>or</b> difficulties in toileting due to constipation, or irritable bowel syndrome; requires encouragement and support.	Moderate
Continence care is problematic and requires timely intervention by a skilled practitioner or trained carer; <b>or</b> intermittent catheterisation by a trained carer or care worker; <b>or</b> has a stoma that needs extensive attention every day. <b>or</b> requires haemodialysis in hospital to sustain life.	High
Requires dialysis in the home to sustain life.	Severe

**Skin and tissue viability.**

Interpretation point: where a child or young person has a stoma, only the management of the stoma itself as an opening in the tissue should be considered here (i.e. a tracheostomy should only be considered here where there are issues relating to the opening; the use of the tracheostomy to aid breathing, and its management should be considered under **Breathing**.)

Description	Level of need
No evidence of pressure damage or a condition affecting the skin.	No additional needs
Evidence of pressure damage or a minor wound requiring treatment; <b>or</b> skin condition that requires clinical reassessment less than weekly; <b>or</b> well established stoma which requires routine care; <b>or</b> has a tissue viability plan which requires regular review.	Low
Open wound(s), which is (are) responding to treatment; <b>or</b> active skin condition requiring a minimum of weekly reassessment and which is responding to treatment; <b>or</b> high risk of skin breakdown that requires preventative intervention from a skilled carer several times a day, without which skin integrity would break down; <b>or</b> high risk of tissue breakdown because of a stoma (e.g. gastrostomy, tracheostomy, or colostomy stomas) which require skilled care to maintain skin integrity.	Moderate
Open wound(s), which is (are) not responding to treatment and require a minimum of daily monitoring/reassessment; <b>or</b> active long-term skin condition, which requires a minimum of daily monitoring or reassessment; <b>or</b> specialist dressing regime, several times weekly, which is responding to treatment and requires regular supervision.	High
Life-threatening skin conditions or burns requiring complex, painful dressing routines over a prolonged period.	Severe

## Communication

Description	Level of need
<p>Able to understand or communicate clearly, verbally or non-verbally, within their primary language, appropriate to their developmental level. The child/young person's ability to understand or communicate is appropriate for their age and developmental level within their first language.</p>	No additional needs
<p>Needs prompting or assistance to communicate their needs. Special effort may be needed to ensure accurate interpretation of needs, or may need additional support visually – either through touch or with hearing.</p> <p>Family/carers may be able to anticipate needs through non-verbal signs due to familiarity with the individual.</p>	Low
<p>Communication of emotions and fundamental needs is difficult to understand or interpret, even when prompted, unless with familiar people, and requires regular support. Family/carers may be able to anticipate and interpret the child/ young person's needs due to familiarity.</p> <p><b>or</b></p> <p>support is <b>always</b> required to facilitate communication, for example, the use of choice boards, signing and communication aids.</p> <p><b>or</b></p> <p>ability to communicate basic needs is variable depending on fluctuating mood; the child/young person demonstrates severe frustration about their communication, for example, through withdrawal.</p>	Moderate
<p>Even with frequent or significant support from family/carers and professionals, the child or young person is rarely able to communicate basic needs, requirements or ideas.</p>	High

**Drug therapies and medication**

Description	Level of need
Medicine administered by parent, carer, or self, as appropriate for age.	No additional needs
<p>Requires a suitably trained family member, formal carer, teaching assistant, nurse or appropriately trained other 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; and/or</li> <li>• site of medication administration</li> </ul>	Low
<p>Requires administration of medicine regime by a registered nurse, formal employed carer, teaching assistant or family member specifically trained for this task, or appropriately trained others;</p> <p><b>or</b></p> <p>monitoring because of potential fluctuation of the medical condition that can be non-problematic to manage;</p> <p><b>or</b></p> <p>sleep deprivation due to essential medication management – occurring more than once a night (and at least twice a week).</p>	Moderate
<p>Drug regime requires management by a registered nurse at least weekly, due to a fluctuating and/or unstable condition;</p> <p><b>or</b></p> <p>sleep deprivation caused by severe distress due to pain requiring medication management – occurring four times a night (and four times a week).</p> <p><b>or</b></p> <p>requires monitoring and intervention for autonomic storming episodes.</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><b>or</b></p> <p>extensive sleep deprivation caused by severe intractable pain requiring essential pain medication management – occurring every one to two hours</p> <p><b>or</b></p> <p>requires continuous intravenous medication, which if stopped would be life threatening (e.g. epoprostenol infusion).</p>	Severe
<p>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 one-to-one monitoring of symptoms and their management is essential.</p>	Priority

**Psychological and emotional needs (beyond what would typically be expected from a child or young person of their age).**

Interpretation point: a separate domain considers **Challenging Behaviour**, and assessors should avoid double counting the same need.

Description	Level of need
Psychological or emotional needs are apparent but typical of age and similar to those of peer group.	No additional needs
Periods of emotional distress (anxiety, mildly lowered mood) not dissimilar to those typical of age and peer group, which subside and are self-regulated by the child/young person, with prompts/ reassurance from peers, family members, carers and/or staff within the workforce.	Low
Requires prompts or significant support to remain within existing infrastructure; periods of variable attendance in school/college; noticeably fluctuating levels of concentration. Self-care is notably lacking (and falls outside of cultural/peer group norms and trends), which may demand prolonged intervention from additional key staff; self-harm, but not generally high risk; <b>or</b> evidence of low moods, depression, anxiety or periods of distress; reduced social functioning and increasingly solitary, with a marked withdrawal from social situations; limited response to prompts to remain within existing infrastructure (marked deterioration in attendance/attainment / deterioration in self-care outside of cultural/peer group norms and trends).	Moderate
Rapidly fluctuating moods of depression, necessitating specialist support and intervention, which have a severe impact on the child/young person's health and well-being to such an extent that the individual cannot engage with daily activities such as eating, drinking, sleeping or which place the individual or others at risk; <b>or</b> 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 individual or others at risk; this will include high-risk, self-harm.	High



**Seizures**

Description	Level of need
No evidence of seizures.	No additional needs
History of seizures but none in the last three months; medication (if any) is stable; <b>or</b> occasional absent seizures and there is a low risk of harm.	Low
Occasional seizures including absences that have occurred with the last three months which require the supervision of a carer to minimise the risk of harm; <b>or</b> up to three tonic-clonic seizures every night requiring regular supervision.	Moderate
Tonic-clonic seizures requiring rescue medication on a weekly basis; <b>or</b> 4 or more tonic-clonic seizures at night.	High
Severe uncontrolled seizures, occurring at least daily. Seizures often do not respond to rescue medication and the child or young person needs hospital treatment on a regular basis. This results in a high probability of risk to his/her self.	Severe

**Challenging behaviour**

Description	Level of need
No incidents of behaviour which challenge parents/carers/staff.	No additional needs
Some incidents of behaviour which challenge parents/carers/staff but which do not exceed expected behaviours for age or stage of development and which can be managed within mainstream services (e.g. early years support, health visiting, school).	Low
Occasional challenging behaviours which are more frequent, more intense or more unusual than those expected for age or stage of development, which are having a negative impact on the child and their family / everyday life.	Moderate
Regular challenging behaviours such as aggression (e.g. hitting, kicking, biting, hair-pulling), destruction (e.g. ripping clothes, breaking windows, throwing objects), self-injury (e.g. head banging, self-biting, skin picking), or other behaviours (e.g. running away, eating inedible objects), despite specialist health intervention and which have a negative impact on the child and their family / everyday life.	High
Frequent, intense behaviours such as aggression, destruction, self-injury, despite intense multi-agency support, which have a profoundly negative impact on quality of life for the child and their family, and risk exclusion from the home or school.	Severe
Challenging behaviours of high frequency and intensity, despite intense multi-agency support, which threaten the immediate safety of the child or those around them and restrict every day activities (e.g. exclusion from school or home environment).	Priority

## Annex A. Types of need

Generally, a child or young person will develop continuing care needs for one of the following reasons:

### **Congenital**

In instances where a child is born with either a diagnosed or an undiagnosed congenital condition that is likely to necessitate a continuing care need.

### **Long-term deteriorating conditions**

Continuing care referrals that arise for children and young people with complex, deteriorating conditions will usually be initiated by multi-agency decision-making forums. CCGs need to ensure that there are agreements in place with local authorities around when and how to include continuing care in the process, so that the child or young person can move seamlessly from universal and specialist care into continuing care.

### **Life-limiting conditions**

These are conditions for which there is no reasonable hope of cure and from which people are expected to die. Life-threatening conditions or episodes are those for which curative treatment may be feasible but can fail. People with life-limiting conditions need continuing palliative care throughout the trajectory of their illness.

Life-limiting and life-threatening conditions in children and young people can be defined by the following four categories:

1. Life-threatening conditions for which curative treatment may be feasible but can fail - such as cancer or congenital heart disease.
2. Conditions where premature death is inevitable but where there may be prolonged periods where the child is well - such as Duchenne muscular dystrophy.
3. Progressive conditions without curative treatment options, such as Batten disease.
4. Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death – such as severe brain injury

### **Sudden unexpected need**

Accidents or after-effects of serious illness or injury can result in a child or young person suddenly developing continuing care needs. In instances where a sudden unexpected need has necessitated care in a tertiary setting, the child or young person and their family will require a package of continuing care to return home. It is important that CCGs and specialist children's hospitals work in partnership, in order to help children and young people and families to consider all options for continuing care provision.

The continuing care needs of the specific groups listed below may require additional consideration.

### **Mental health needs**

Children or young people with mental health needs are likely to have a range of needs requiring assistance or intervention. Some needs are consistent and predictable, while others are less predictable. The latter will generally be most pronounced in the psychological/emotional and communication domains of the Decision Support Tool for children and young people.

### **Learning disabilities**

A learning disability may mean that the child/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. It is important that the nominated children and young people's health assessor considers the totality of the four areas of assessment for the child or young person and their family's needs, and how they inter-relate, in order to inform and co-ordinate their care: communication and behaviour are complex issues for this care group.

### **Autistic spectrum disorder (ASD)**

ASD may have a detrimental effect on the interplay of domains outlined in the Decision Support Tool for children and young people. Children or young people with ASD may also have mental health needs. The nominated children and young people's health assessor should ensure that the assessment recognises the impact of ASD on the child or young person's continuing care needs.

### **End-of-life care**

Where a child or young person has needs that require the input of end-of life services, they should be referred to the specialist palliative services for an assessment. Children and young people with a rapidly deteriorating condition and expected short-term life expectancy should be able to receive continuing care immediately. Strict time limits are not relevant for end-of-life cases, and should not be imposed; the nominated children and young people's health assessor should identify such cases.

### **Rare / genetic conditions**

There will be cases where there is a lack of definitive clinical diagnosis (or a definitive diagnosis cannot be made in a timely way). It is essential that assessment is based on the specific needs of the child and young person, and draws on evidence presented by the family and carers in such cases.

## Annex B. Glossary of key terms

**Adult continuing healthcare**  
(see **NHS Continuing Healthcare**)

### **Assessment**

A multi-agency process in which the needs of a child or young person and their family are identified and their impact on daily living and quality of life is evaluated. The nominated children and young people's health assessor is responsible for undertaking a health assessment and collating existing assessments by local authority children's and young people's services on behalf of the commissioners to present a holistic picture of the child or young person's continuing care needs.

If there is no existing assessment, the nominated health assessor should liaise with the appropriate professionals to instigate assessments by local authority children and young people's services on behalf of the commissioners and then use these reports to inform the holistic assessment of the child or young person's continuing care needs.

### **Challenging behaviour**

Defined by NICE as: "behaviour that is a result of the interaction between individual and environmental factors, and includes stereotypic behaviour (such as rocking or hand flapping), anger, aggression, self-injury, and disruptive or destructive behaviour. Such behaviour is seen as challenging when it affects the person's or other people's quality of life and or jeopardises their safety."

<https://www.nice.org.uk/guidance/cg142/chapter/glossary>

### **Children and young people's continuing care**

A package of continuing care needed over an extended period of time for children or young people with continuing care needs that arise because of disability, accident or illness, which cannot be met by universal or specialist services alone. Children and young people's continuing care is likely to require services from health and local authority children and young people's services.

### **Children's palliative care**

An active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

### **Consent**

If a child who is under 16 does not have the capacity to give consent, someone with parental responsibility can consent for them, but that person must have the capacity to give consent.

If one person with parental responsibility gives consent and another does not, the healthcare professionals can choose to accept the consent and perform the treatment in most cases. If the people with parental responsibility disagree about what is in the child's best interests, the courts can make a decision. If a parent refuses to give consent to a particular treatment, this decision can be overruled by the courts if treatment is thought to be in the best interests of the child.

If the local authority has reason to believe that the child is suffering or likely to suffer significant harm, they could apply to the court under the Children Act 1989 for either:

- an emergency protection order on the basis that the significant harm would occur should the child not receive care;
- an interim care order if the harm or likely harm could be attributed to the care given by the parents.

Young people with SEND have the right to make decisions for themselves, when they reach the end of the academic year in which they turn 16, rather than their parents making decisions for them (although their family can continue to provide support if the young person agrees). The right of young people to make a decision is subject to their capacity to do so, as set out in the Mental Capacity Act 2005. See also the entry on **Parental responsibility**.

### **Continuing care needs**

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

### **Designated medical officer / clinical officer**

The designated medical officer, or clinical officer supports the CCG in meeting its statutory responsibilities for children and young people with SEND by providing a point of contact for local partners, when notifying parents and local authorities about children and young people they believe have, or may have, SEN or a disability, and when seeking advice on SEN or disabilities.

The officer provides a point of contact for local authorities, schools and colleges seeking health advice on children and young people who may have SEN or disabilities, and provides a contact (or contacts) for CCGs or health providers so that appropriate notification can be given to the local authority of children under compulsory school age who they think may have SEN or disabilities.

The DMO or DCO should have an appropriate level of clinical expertise to enable them to exercise these functions effectively, and is usually a paediatrician, but there is local flexibility for the role to be undertaken by a suitably competent nurse or other health professional.

### **Education, health and care plan**

At the heart of the new arrangements for children and young people with SEND introduced by the Children and Families Act 2014 is the concept of a single plan for each child with SEND, which covers their education, health and social care needs. A local authority must conduct an assessment of education, health and care needs when it considers that it may be necessary for special educational provision to be made for the child or young person.

CCGs and local authorities will work together to

- establish and record the views, interests and aspirations of the parents and child or young person;
- provide a full description of the child or young person's special educational needs and any health and social care needs;

- establish outcomes across education, health and social care based on the child or young person's needs and aspirations;
- specify the provision required and how education, health and care services will work together to meet the child or young person's needs and support the achievement of the agreed outcomes.

The Code of Practice is the statutory guide to the EHC process and covers all the legal requirements and important good practice. *Special educational needs and disability code of practice: 0 to 25 years. Statutory guidance for organisations who work with and support children and young people with special educational needs and disabilities* (2014).

<https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

### Lead professional

Where a child or young person with continuing care needs requires support from more than one practitioner, the lead professional is someone who:

- acts as a single point of contact for the child or young person and their family, serving as someone whom the child or young person and their family can trust, and who is able to support them in making choices and in navigating their way through the system;
- ensures that they get appropriate interventions when needed, which are well planned, regularly reviewed and effectively delivered; and
- reduces overlap and inconsistency among other practitioners.

Evidence from practice suggests that the lead professional role is to effective frontline delivery of integrated services. It ensures that professional involvement is rationalised, co-ordinated and communicated effectively, and results in a better experience for children, young people and their families involved with a range of agencies.

### Mental Capacity Act

The Mental Capacity Act (MCA) is designed to protect and empower individuals who may lack the mental capacity to make their own decisions about their care and treatment. It is a law that applies to individuals aged 16 and over.

The MCA sets out a two-stage test of capacity.

- 1) Does the individual concerned have an impairment of, or a disturbance in the functioning of, their mind or brain, whether as a result of a condition, illness, or external factors such as alcohol or drug use?
- 2) Does the impairment or disturbance mean the individual is unable to make a specific decision when they need to? Individuals can lack capacity to make some decisions but have capacity to make others, so it is vital to consider whether the individual lacks capacity to make the specific decision.

Also, capacity can fluctuate with time – an individual may lack capacity at one point in time, but may be able to make the same decision at a later point in time. Where appropriate, individuals should be allowed the time to make a decision themselves.

In relation to the second question, the MCA says a person is unable to make a decision if they cannot:

- understand the information relevant to the decision
- retain that information
- use or weigh up that information as part of the process of making the decision

If they are notable to do any of the above three things or communicate their decision (by talking, using sign language, or through any other means), the MCA says they will be treated as unable to make the specific decision in question.

More information can be obtained from <http://www.nhs.uk/conditions/social-care-and-support-guide/pages/mental-capacity.aspx>

### **Multi-agency decision-making forum / panel**

The multi-agency decision-making forum will comprise professionals from different disciplines, i.e. from both health commissioners and local authorities. The forum will take into consideration the recommendations and proposed options for packages of continuing care. If a continuing care need is identified, it is for the health commissioners and the local authority to decide what services each will commission and fund.

### **NHS Continuing Healthcare**

A package of ongoing care that is arranged and funded solely by the NHS where the individual has been found to have a 'primary health need' as set out in the statutory guidance (as opposed to a need for local authority care). Such care is provided to an individual aged 18 or over, to meet needs that have arisen as a result of disability, accident or illness. Where an individual has a primary health need and is therefore eligible for NHS continuing healthcare, the NHS is responsible for providing all of that individual's assessed health and social care needs – including accommodation, if that is part of the overall need. The full guidance can be found at <https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care>

### **Nominated children and young people's health assessor**

A health practitioner experienced in children and young people's health and skilled in the health assessment of children who leads on the assessment phase of the continuing care process. Following the completion of the assessment phase, the nominated children and young people's health assessor will produce recommendations for presentation to a multi-agency decision-making forum for them to reach a decision on whether continuing care is needed and, if so, what package of continuing care to provide. If a continuing care need is identified it is for health commissioners and the local authority to decide what services each will commission and fund.

### **Package of continuing care**

A combination of resources, planning, co-ordination and support designed to meet a child or young person's assessed needs for continuing care.

### **Parental responsibility**

As defined by the Children Act 1989 (see <http://www.legislation.gov.uk/ukpga/1989/41>) a person with parental responsibility for a child could be:

- the child's parents;
- the child's special guardian (under a special guardianship order);
- the child's legally appointed guardian
- a person named in a child arrangements order as a person with whom the child is to live;
- a local authority designated to care for the child (under a care order); or
- a local authority or person with an emergency protection order for the child.

### **Responsible commissioner**



The organisation that discharges the statutory duty to secure care for an individual. For health services, the duty is that of Sections 3 to 6 of the NHS Act 2006, and accompanying regulations. Most health services for an individual are usually commissioned by the CCG of which their GP practice is a member, but specialised services and health care for some specific groups is commissioned by NHS England. Public health services are usually commissioned by local authorities or Public Health England.

For information on who has responsibility for making payments to providers, see *Who Pays? Determining responsibility for payments to providers* (August, 2013) <http://www.england.nhs.uk/wp-content/uploads/2014/05/who-pays.pdf>

### **Special educational needs and disability (SEND)**

The Children and Families Act 2014 states that a child or young person has SEND if he or she has a learning difficulty or disability which calls for special educational provision to be made for him or her.

A child of compulsory school age or a young person has a learning difficulty or disability if he or she:

- has a significantly greater difficulty in learning than the majority of others of the same age, or
- has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions.

A child *under* compulsory school age has a learning difficulty or disability if he or she is likely to be within the above categories (or would be likely to be if no special educational provision were made).

Post-16 institutions often use the term learning difficulties and disabilities (LDD). The term SEND is used in this Code across the 0-25 age range but includes LDD.

Section 3 of the Children and Families Act 2014 introduced from September 2014 a new statutory framework for how local authorities and CCGs should work together to ensure children and young people with SEND get the education, health and care services they need (see also 'Education, health and care plan' in this glossary). The key points are described in Chapter 1 above. The full Act is available at: <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

CCGs will work with their local authority, to develop and publish a Local Offer, setting out in one place information about the range of education, health and social care services available for children and young people in their area who have SEN or are disabled, including those who do not have EHC plans, and how they can be accessed. The published local offer should include details of continuing care services and how one accesses continuing care, and would provide a suitable location for publicising the continuing care process.

### **Specialised services**

Specialised services are those less common interventions needed by a relatively small group of patients, which require a clinical team with very specific training and often, equipment, which it would be impractical to commission or provide at a local level. These services are usually located in specialised hospital trusts that can recruit a team of staff

with the appropriate expertise and enable them to develop their skills needed. Examples include Tier 4 Child & Adolescent Mental Health Services and specialist neuroscience services for children and young people, including neurosurgery. Most specialised services are commissioned by NHS England directly, but some elements of a specialised service may be commissioned by local CCGs, or work closely with CCG commissioned services.

For information on all specialised services identified as such by NHS England, and how they are commissioned, see the *Manual for Prescribed Specialised Services 2013/14*

<http://www.england.nhs.uk/wp-content/uploads/2014/01/pss-manual.pdf> For more information on Specialised Services in general, see: <http://www.england.nhs.uk/ourwork/commissioning/spec-services/>

### **Universal services**

Health services which are available to all of the population of England from birth, including primary care provided by GP practices, health visiting for new born children, school nursing and Accident and Emergency services.

## Annex C. Summary of the Haringey case

The following summary of the judgment in *R (on the application of D and another) v Haringey London Borough Council* ('the Haringey case') is presented here for reference, as case law relevant to children and young people's continuing care, which CCGs and local authorities should take into account in their processes for deciding on and putting in place packages of continuing care.

The Haringey case considered the scope of a local authority's duties under the Children Act 1989 to provide nursing care for a disabled child in order to offer respite for the child's mother, and the case clarified the divide between health provision and social care provision in that context.

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

This case concerned a 3-year-old child who required, among 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. The child's 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 of respite care, 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, in its view, not necessary. The care was provided by qualified nurses, although it could have been provided by non-medically qualified people if they had received the appropriate training.

Mr Justice Ouseley was willing to apply the Coughlan criteria, used to determine whether a local authority or a PCT should provide required services to an adult in need of continuing care, equally to children (despite the fact that the social services care regime for children was regulated by the Children Act 1989 and not the National Assistance Act 1948). In his opinion, relevant 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 an 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 Schedule 2 to the Children Act 1989.

Of particular importance in this case were the following points.

- 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.

- The gravity of the consequences of a failure in care and the duration of the care need meant that it was more a medical service provision than a social services provision.

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 tracheostomy care. Therefore, while it was possible for others to be trained in providing the care, it was clearly an important medical procedure in which people were trained.

Mr Justice Ouseley therefore held that HLBC did not have a duty to provide the respite care under section 17 of Schedule 2 to 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 the NHS Act 2006, as amended by the Health and Social Care Act 2012].

'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, 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 the 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'.