



Department  
of Health

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

2015

FOR CONSULTATION

September 2015

<b>Title:</b> National Framework for Children and Young People’s Continuing Care
<b>Author:</b> SCLGCP/CMHI/IDC/14100
<b>Document Purpose:</b> Guidance (draft for consultation)
<b>Publication date:</b> Draft for consultation published in September 2015
<b>Target audience:</b> public, clinical commissioning groups, local authorities, health and wellbeing boards, health and care professionals.
<b>Contact details:</b> Gareth James Disabled and Ill Child Services Team Social Care, Local Government and Care Partnerships Directorate 2E60, Department of Health, Quarry House, Quarry Hill, Leeds, LS2 7UE  <a href="mailto:gareth.james@dh.gsi.gov.uk">gareth.james@dh.gsi.gov.uk</a>

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

2015/16

Prepared by the Disabled and Ill Child Services Team, Department of Health

# Contents

Contents .....	4
Executive summary .....	5
1. Introduction .....	6
What is children and young people’s continuing care? .....	6
Eligibility .....	7
The role of the CCG .....	9
Personal health budgets .....	10
Joint commissioning for special educational needs and disability (SEND) .....	11
2. The continuing care process: a step-by-.....	13
step guide .....	13
Step 1: Identification .....	14
Step 2: Assessment .....	15
Step 3: Recommendation .....	18
Step 4: Decision making .....	18
Step 5: Inform .....	19
Step 6: Arrangement of provision .....	20
Step 7: Review .....	20
Transition .....	21
3. Children’s decision support tool .....	24
Child and family details .....	25
Medical history .....	27
Outcomes .....	28
Care domains .....	31
Annex A. Types of need .....	42
Annex B. Glossary of key terms .....	44

## Executive summary

This Framework is intended to provide guidance for clinical commissioning groups (CCGs) and local authorities on the process for assessing, deciding and agreeing packages of continuing care for children and young people, whose needs cannot be met by universal or specialised services.

In particular, where a child 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 Framework sets out the principles and the process which should be followed by local commissioners. CCGs have a legal responsibility for securing the long-term health care which an individual needs to a reasonable extent, and this guidance is about the process which should be followed for the equitable discharge of that responsibility.

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, the new integrated approach to the commissioning of services for children with SEND which the Children and Families Act 2014 has introduced, and the changes to adult social care introduced by the Care Act 2014.

We have retained relevant material from the earlier framework, but have attempted to remove duplication. We have integrated the Children's Decision Support tool, previously given as an Annex, within the main text. 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 Children's Decision Support tool** - a resource to support local determination of packages of continuing care.

We are grateful for the help of our steering group members, both in 2010, and 2014. 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?

**Continuing care is required when the child or young person's health needs cannot be met by existing universal or specialist services.**

1. Continuing care for children and young people is needed where a child or young person (under 18) has complex needs which cannot be met from the health services routinely commissioned by clinical commissioning groups (CCGs) or NHS England. It has been defined in recent regulations as:

*'a package of care which is arranged and funded by a relevant body for a person aged 17 or under to meet needs which have arisen as a result of disability, accident or illness.'*<sup>1</sup>

2. The care needed may be resource intensive, and long-term, with a significant element of nursing care. It may be provided in a number of settings and may involve more than one provider.
3. This framework is designed to support CCGs in determining if a child's needs are such that they can only be met through a package of continuing care. The fundamental principle of this framework is that continuing care needs should be identified, and the package of care agreed, as part of a holistic assessment of the child or young person's needs.
4. There can be many different factors which result in a child having a need for continuing care. These include congenital conditions, long-term and life-limiting conditions, disability, or the after-effects of serious illness or injury (Annex A provides more information on types of need).
5. Assessment of a child's needs should also consider the extent to which a child may have a continuing care need due to challenging behaviour – that is culturally abnormal behaviour of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in jeopardy, or behaviour which is likely to seriously limit use of or result in the person being denied access to ordinary community facilities.
6. Challenging behaviour in this sense is not to be confused with a health condition which by its nature is problematic or taxing for a professional or a family. A child's frustration in struggling to communicate may be challenging, but the need is related to Communication. Similarly, a child's problems in Sleeping may prove challenging for them and their family, but the need in question falls into the domain of Sleeping.
7. A decision on whether or not continuing care is needed must be informed by a clinical understanding of a child or young person's condition and an understanding of the way in which their needs affect their lives and those of their family. The emphasis should

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<sup>1</sup> *The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) (Amendment) Regulations 2013.*  
[http://www.legislation.gov.uk/ukxi/2013/2891/pdfs/ukxi\\_20132891\\_en.pdf](http://www.legislation.gov.uk/ukxi/2013/2891/pdfs/ukxi_20132891_en.pdf)

be on understanding the outcomes which would make the biggest difference to the child or young person and their family, and how health services can support delivery of those aims.

8. Where appropriate, continuing care should be part of a wider package of care, agreed and delivered by collaboration between health, education and social care. The new arrangements for children 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. For the implications of the new SEND framework see the section below on *Joint commissioning for special educational needs or disability*.
9. This framework covers birth to 17 years. For adults - aged 18 and over - the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care and the supporting guidance and tools should be used.  
<https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care>

## Eligibility

10. The continuing care process determines if a child's needs can be met by existing universal or specialised services, and if not, what additional care would be needed.
11. Diagnosis of a particular disease or condition is not in itself a determinant of a need for continuing care.
12. Similarly, the establishment of a continuing care need should not be determined by the setting where care is provided or by the characteristics of the professional who delivers the care.
13. There should be no differentiation based on whether the health need is physical, mental or psychological. The continuing care process should be (and be seen to be) fair, consistent, transparent, culturally sensitive, and non-discriminatory.
14. Commissioners must ensure they adopt an appropriate focus on those outcomes which make a difference to the child or young person, and their family, and consider their wishes, expectations and preferences as regards how and where care is delivered and its impact. 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.
15. The full continuing care process typically comprises **assessment**, **decision-making**, and **provision**. There must be a clear timetable, and a process of regular updates, so that the child, young person and their family knows what point has been reached in the process. A dedicated single point of contact and advice should be considered. The roles of the nominated children and young people's health assessor and multi-agency decision-making forum should be clear.
16. The **assessment phase** is led by a children and young people's health assessor nominated by the CCG. There are 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, including carer assessment;
  - reports and risk assessments from the multidisciplinary team, or evidence collated during the Education, Health and Care plan assessment; and;
  - the Children's Decision Support Tool.
17. 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 that cannot be met by existing universal or specialist services.
  18. The **decision-making phase** involves a multidisciplinary, multi-agency forum or panel making a decision as to whether or not the child or young person has a continuing care need. They decide on the recommendations and costed options put forward by the assessor. The CCG must ensure that the panel has the input of the local authority and other key partners.
  19. Commissioners will then 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.
  20. When determining what the package of care should include, commissioners will need to consider what their existing local offer of services comprises, and flexibility for commissioning any additional care, to fulfil their statutory duty to meet the reasonable needs of an individual.
  21. A decision on the package of continuing care that may be provided should not be budget or finance-led: the primary consideration should be supporting the child or young person's assessed needs and outcomes.
  22. Decisions should be given verbally to the child or young person and their family or their representative, followed by formal written notification. A clear written explanation for the decision must be given. Meeting face to face, and giving clear reasons is particularly important where the child or young person and their family have expressed preferences that have not been met.
  23. Following a decision being made and communicated to the child or young person and their family, if the decision is to provide continuing care, **the arrangement of provision** begins, during which the CCG and the local authority should use commissioning resources to make the necessary logistical, contractual and funding arrangements to ensure that the provision of the package of continuing care is in place as soon as possible. They will also keep the package of care under regular review to ensure the developing child's needs continue to be supported.
  24. Following notification of the decision, the child or young person and their family should be involved in discussions on the next steps and time-frames to implement the package of continuing care. The opportunity for them to provide regular feedback will of course be a fundamental part of the ongoing review of the care package.



25. It should be understood that there are significant differences between children's continuing care and NHS Continuing Healthcare for adults, which is subject to a statutory process. 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 role of the CCG

26. The CCG is responsible for leading the process of identifying the continuing care needs of a child or young person for whom it has commissioning responsibility under section 3 of the NHS Act 2006. For ease of reference, this framework refers 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 will be the responsible commissioner.
27. However, a child or young person with continuing care needs may require services commissioned by the local authority, and other partners. Where a child or young person requires services commissioned by multiple organisations, the CCG is responsible for leading the commissioning care process, involving the local authority and other partners as appropriate.
28. CCGs should identify a named first point of contact for the commissioning of the children and young people's continuing care process. The role of the named individual is to act as a point of contact for professionals from the community, acute or tertiary settings wishing to discuss a child or young person with possible continuing care needs. The named point of contact should hold contact details for all local nominated children and young people's health assessors.
29. CCGs are also responsible for establishing and managing appropriate governance arrangements for their children and young people's continuing care process. 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.
30. 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. Given the clear overlap with services for children 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, led by the local authority.
31. 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 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 who need continuing care)?
32. All partners are responsible for funding their own contributions to the continuing care package - including short breaks and social care - in line with their statutory responsibility for care.
33. Any package of care which a CCG agrees should be sustainable for the duration of the child or young person's needs, and should be integrated or aligned with other relevant services, such as primary care.

## Personal health budgets

34. 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.
35. 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.
36. 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).
37. 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.

38. 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.
39. 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)

## Joint commissioning for special educational needs and disability (SEND)

40. 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>2</sup> All new entrants to the system will be supported via these arrangements, and children and young people with existing statements of special educational needs will transfer to the new arrangements over a three year period.<sup>3</sup> At the heart of the arrangements is an integrated Education, Health and Care plan (EHC plan).
41. 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.
42. A child or young person with a continuing care need will often also have SEND. Where this is the case, the child or young person’s continuing care needs, and package of care should at the very least feature as part of the integrated package of care in their EHC plan. 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.
43. 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.

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<sup>2</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>

<sup>3</sup> For full details of the transition arrangements, see *Transition to the new 0 to 25 special educational needs and disability system. Statutory guidance for local authorities and organisations providing services to children and young people with SEN* (2014).  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/348591/Transition\\_to\\_the\\_new\\_0\\_to\\_25\\_special\\_educational\\_needs\\_and\\_disability\\_system\\_statutory\\_guidance\\_for\\_local\\_authorities.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/348591/Transition_to_the_new_0_to_25_special_educational_needs_and_disability_system_statutory_guidance_for_local_authorities.pdf)

44. 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.
45. 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. The EHC plan assessment has a longer-timetable than the continuing care assessment ((20 weeks as opposed to 28 days), and the process is led by the local authority rather than the CCG. It will not therefore usually be of benefit to completely integrate the two processes (and certainly not appropriate if it delays a decision on a package of continuing care.)
46. 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 social care and health input to the co-ordinated process.
47. A decision by the deciding panel could be secured within 28 days on the continuing care element of the EHC plan, 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.
48. As the new SEND arrangements extend up to age 25, there will be young people aged 18-25, who are assessed as having a primary health need under the NHS Continuing Healthcare framework. This means that the NHS is responsible for providing all of the individual's assessed health and social care needs – including accommodation, if that is part of the overall need. The local authority may not have any responsibility towards the young person. The local authority would still take the lead in co-ordinating the EHC plan but the services they were ultimately responsible for securing would be negligible.
49. CCGs and local authorities may wish for the same oversight arrangements to apply to both the continuing healthcare process and EHC plans.

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

50. There are seven stages a child or young person with possible continuing care needs will pass through during the continuing care process. The CCG should ensure there is a clear timeline from referral through completion of assessment to decision, and that progress is measured against this.
51. This continuing care pathway should aim to link children, young people and their families with community services, hospital-based services, local authority children's and young people's services and the third sector to ensure a joined-up and integrated approach to meeting needs.

Phase	Step	Summary of key actions	Timescale	Cumulative timescale
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> <li>A child or young person's health assessor is nominated, and the process of assessment begins.</li> </ul>	1 working day	1 working day
	Assess	<ul style="list-style-type: none"> <li>The health assessor completes the process of 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>Children's Decision Support Tool.</li> </ul> </li> </ul>		
	Recommend	<ul style="list-style-type: none"> <li>The health assessor completes the process of assessment, and makes a costed recommendation.</li> </ul>	9 working days	10 working days
Decision-making	Decide	<ul style="list-style-type: none"> <li>The multi-agency forum considers the recommendation and decides on the package of care needed.</li> </ul>	14 working days	23 working days
Arrangement of provision	Inform	<ul style="list-style-type: none"> <li>The child or young person and their family (and any relevant organisations, such as the local authority) are informed of the decision.</li> </ul>	5 working days	28 working days
	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>	As soon as possible.	
Ongoing	Review	<ul style="list-style-type: none"> <li>Reassessment of the child or young person's continuing care needs.</li> </ul>	Initial review 3 months after implementation, than reviews at least annually.	

## Step 1: Identification

52. The continuing care process begins when there is recognition that a child or young person may have needs that cannot be met through existing universal or specialist services alone. A child or young person may be referred for assessment through a number of different routes, settings and care pathways.
53. 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.
54. Professionals in these settings should also be able to provide evidence to inform the continuing care process.
55. The CCG must have a clear local process in place for submitting requests for a continuing care assessment, and professional evidence to support an assessment, and ideally, a single point of contact with whom professionals can liaise, at least initially, before an assessor has been assigned to an individual. The named point of contact should hold contact details for all local nominated children and young people's health assessors.
56. The Designated Medical Officer or Designated Clinical Officer for SEND should be able to signpost referrals to this contact point; it may be sensible for this Officer to act as that point of contact.
57. Clearly, there will need to be a quick pre-assessment process, which considers the necessity of carrying out a full-continuing care assessment. CCGs should be flexible in how they approach this.
58. A sensible process for this would draw on elements of the formal process: considering the evidence of the child or young person's needs as presented by professional advice, considering where those needs might lie in the Children's Decision Support Tool, and examining their existing package of care. 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.
59. The clock starts at the point of recognition that a child or young person should have a full continuing care assessment. The pathway should aim for a decision to be given to the child or young person and their family within 6 weeks.
60. 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 should 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.

61. Developing and agreeing the pathway could be undertaken as part of the joint arrangements between local authorities and CCGs for SEND. The designated medical or health officer role for SEND may in particular provide a focus for advising or offering information on continuing care to local partners, in the same way that they provide a point of contact on SEND issues for local health services.
62. The pathway for assessing a child or young person's needs, and agreeing the package of care 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 in the process to orient themselves. In particular, there should be a clear timetable set out.
63. 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.
64. 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.
65. 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.

## Step 2: Assessment

66. Every child or young person referred with possible continuing care needs should be offered a comprehensive assessment, carried out by a nominated children and young people's health assessor within eight working days of identification. The consent of the child or young person, or their parents where appropriate, should be sought.
67. It should be made explicit to the individual as for what their consent is being sought, including the sharing of personal information between different professionals and organisations involved in their care.
68. If a young person, or those responsible for them, does not consent to an assessment of eligibility for continuing care, the potential effect this will have should be explained to them. 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. 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 LA the implications. For more information, see the glossary entries on Consent and Parental Responsibility.

69. 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 involve a clear, reasoned evidence base from a range of sources that takes account of the child's particular needs in a holistic and family-centred context. They will collate relevant information, and liaise with the appropriate professionals to requests assessments by local authority children's and young people's services on behalf of the commissioners.
70. Assessment should be a process, not a one-off event. Most children or young people with continuing care needs will have had multiple assessments, such as an assessment of special educational needs, although this may not always be the case if the continuing care need has arisen due to a sudden trauma or injury. A continuing care assessment should build on previous assessments, 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.
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. There may be a need for several individuals to collaborate on an assessment of a child's needs, where they are complex.
73. Every assessor should as a minimum have expertise in:
  - children and young people's continuing care;
  - 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;
  - a thorough working knowledge of the policy in this Framework;
  - well-developed leadership qualities;
  - listening skills;
  - an understanding of local health and social care commissioning.
75. Children and young people's continuing care needs should be assessed consistently and fairly, irrespective of the reason for their needs or the nature of those needs. There are four elements to the assessment phase, which health commissioners, local authorities and their partners should ensure are reflected in the local process



76. Each of the four areas of assessment 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(s).

#### **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 includes siblings and working partners. Care is often highly invasive of the family home and the preferences of all family members should be sought as far as possible.

##### **2. Holistic assessment of the child or young person and their family, including carer assessment**

The assessment phase is an integral part of the continuing care process, and questioning by a professional can give valuable insight into a child or young person's needs but also reinforce feelings of self-worth in the parents. The carer's assessment should consider the family capacity for resilience; this relates to a family's ability to provide care for the child or young person and is not a judgement on parenting ability. Family circumstances, the health needs of other family members and the proposed environment of care should also be considered.

##### **3. Reports and risk assessments from the multidisciplinary team**

The nominated children and young people's health assessor is responsible for undertaking any necessary healthcare risk assessments that have not already been undertaken and collating the relevant risk assessments and reports (health, social and education).

##### **4. The Children's Decision Support Tool (see Chapter 3).**

The fourth area brings together the assessment information from the three other areas. **It is not a stand-alone tool and is designed to ensure that relevant needs are assessed, captured and described in a consistent way.**

77. The assessment phase should be undertaken in a systematic and consistent way to ensure equity and transparency. The results of continuing care assessments should be shared with the child or young person and their family. Everyone who contributes to an assessment should be fully aware of its intended use and distribution.
78. The assessment of children and young people for continuing care must account of safeguarding policies and legislation, which place a duty on all agencies to safeguard and promote the welfare of children and young people.
79. 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.
80. Following the completion of the four areas of assessment, the nominated children and young people's health assessor should produce recommendations, including costed options, for presentation to a multi-agency decision-making forum.

### Step 3: Recommendation

81. Following the completion of the assessment by a nominated children and young people's health assessor, recommendations and costed options should be produced for consideration at a multi-agency decision-making forum. The four areas of assessment should provide the evidence for options.
82. 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, taking into account the child or young person's and their family's preferences, which are safe and effective. Where the child or young person is already 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.
83. 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:
  - how continuing care integrates with SEND provision, and existing universal and specialist providers;
  - 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. When home care options have been fully considered and ruled out on care, risk or capacity grounds and/or family choice, then residential care should be considered to support home care or to replace it;
  - out of hours support;
  - staff competency and training of parents, staff and foster carers (including training costs) should be considered as appropriate.
84. A decision to include long-term residential care in a child or young person's package of care must never be made on financial grounds.

### Step 4: Decision making

85. Following the assessment phase, the nominated children and young people's health assessor should produce recommendations and costed options for a multi-agency decision-making forum to decide whether continuing care is needed and, if so, what package of continuing care should be provided.
86. The multi-agency forum should:
  - be independent from those involved in assessment;
  - be made up of key health commissioner and local authority professionals, including commissioners and clinical advisers;
  - consider the expressed wishes of the child or young person and their family and the care options that meet the assessed needs of the child or young person and their family;

- take into account local authority children's and young people's services' requirements.
- be allocated dedicated time to support this process.

87. A decision should be made within 14 working days of receipt of the assessment documentation.

## Step 5: Inform

88. Following the forum's decision, the child or young person and their family should be notified within 5 working days. Key professionals, such as the child's paediatrician, or multi-disciplinary team or GP, and key organisations, such as their school and local authority, should also be informed.

### Resolving disputes

89. 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. In this instance, their needs should be addressed through existing universal and specialist services.

90. 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.

91. 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.

92. 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>4</sup>

93. 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.

94. 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

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<sup>4</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>

pending resolution of the dispute and arrangements for reimbursement to the agencies involved once the dispute is resolved.

95. 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

96. Provision of a package of continuing care should begin as soon as possible once the decision has been made, and the child or young person and their family has been informed.
97. 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.
98. In some instances there may be an unavoidable delay in implementation, such as where the outcome of a Disabled Facilities Grant panel is required, 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.

## Step 7: Review

99. The child or young person's continuing care needs should be reviewed three months after the panel decision, and then at least annually thereafter. If the child or young person's circumstances are known to have changed, this should also trigger a review, and the child or young person and their family should be able to request a review. The commissioners of the care package are responsible for regular contract review to ensure that service specifications are being met and the service being provided is of the required level.
100. 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.
101. 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.
102. 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.

103. In instances where transition back into universal or specialist 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

104. As far as possible, the aim of providing continuing care should be to support the move from dependence to independence, with children and young people being enabled to manage their condition themselves with a full understanding of the implications of their condition.
105. 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 services or to a more appropriate specialised or NHS Continuing Care pathway.
106. 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.
107. 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 there may be potential eligibility.
108. It is desirable and best practice that 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.
109. In summary:

- At **14** years of age, the young person should be brought to the attention of adult continuing care services.
- At **16** years of age, screening for NHS continuing healthcare should be undertaken using the adult screening tool.

- At **17** years of age, an agreement in principle for adult NHS continuing healthcare should have been made.
- At **18** years of age, full transition to adult NHS continuing healthcare or to universal and specialist services should have been made, except in instances where this is not appropriate.

110. 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.
111. This should be followed up by a formal referral for screening at age 16 to the adult NHS continuing healthcare team at the relevant CCG.
112. At the age of 17, eligibility for adult 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.
113. Entitlement to adult NHS continuing healthcare should initially be established using the decision-making process set out in the National Framework, including the Checklist and the Children's Decision Support Tool. 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.
114. If a young person who receives children's continuing care has been determined by the relevant CCG not to be eligible for a package of adult 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. 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).
115. Children and young people eligible for continuing care who have a personal health budget may not be eligible for NHS Continuing Healthcare when they reach 18. 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. 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.

116. 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.
117. 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.
118. 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 adult 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.
119. It should be noted that regulations state that, in certain circumstances, when a young person in receipt of children'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. 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.
120. 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. Children's decision support tool

121. The Children's Decision Support Tool has been developed to bring assessment information together and present it in a concise, consistent way. It is designed to help ensure that all relevant needs are assessed and captured to inform local decisions about the care needed. The domains and supporting information are given in this framework, and a separate Word® version of the Decision Support Tool is also available which can be used as a template for undertaking assessments if required.
122. The Children's Decision Support 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 Children's Decision Support 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, including the carer assessment;
  - reports and risk assessments from the multidisciplinary team.
123. The nominated children and young people's health assessor should use the Children's Decision Support 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 provide the evidence to inform the decision on the provision of a package of continuing care.
124. 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.
125. This process and the information collected will provide the basis for recommendations and costed options to be presented to the multi-agency decision-making forum; this will inform the decision on whether a package of continuing care is needed. The decision on whether continuing care is needed will be taken at the multi-agency decision-making forum, where each party will decide their contribution to the package of continuing care.
126. The Children's Decision Support Tool sets out children's needs across 11 care domains, divided into different levels of need:
- communication
  - mobility
  - nutrition, food and drink (including vomiting)
  - continence and elimination
  - skin and tissue viability
  - breathing
  - drug therapies and medicines
  - psychological and emotional
  - seizures
  - challenging behaviour
  - other
127. 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 expected at his or her age.

128. The needs described collectively in the care domains and levels of need in the Children's Decision Support 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 care.
129. Assessors should have evidence to support all assessments, and should avoid simply cutting and pasting the text in a domain. In completing the tool, care should be taken to make sure that needs are not duplicated in different domains.
130. There may be circumstances where a child or young person may have particular needs that cannot reasonably be included in the first 10 specific care domains described in the Children's Decision Support Tool. In this situation, the final 'Other' domain may be used to capture high or severe needs. The nominated children and young people's health assessor, either in conjunction with other members of the multidisciplinary team or by taking into account recent assessments and/or reports, should determine the nature and extent of these needs .
131. 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. Respite care is usually the commissioning responsibility of the local authority, but where a clinical professional is needed (for example, to oversee continuous intravenous medication, the CCG should ensure this is provided).
132. The Tool provides a framework for a reaching a decision. 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 (for example, judging the adequacy of the child and their family's accommodation for their needs), and that 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**.

## Child and family details

### Child / young person

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

### Assessment circumstances

- Communication
- Is an interpreter needed?

- How can professionals best communicate with the child?

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Date referred for assessment

Date of initial needs assessment

- This should be considered the Clock start for the assessment process.

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Referred by

- Give referring professional and provider organisation and relevant contact details

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Responsible CCG

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

### 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.
- Any difficulty meeting bills/financial commitments?
- Has the child/young person's condition affected the family/carer's family's finances?
- Is the family/carer's family in receipt of all benefit entitlements?
- Do they need extra support from Family Fund or other voluntary organisation?

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Housing

- Owned or rented?
- Adequacy for the child's/family's/carer's family's needs?
- Any adaptations required?

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Transport

- Is the family/carer's family reliant on public transport?
- Accessing hospital appointments, etc.

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Recreation and leisure

- Is the child/young person able to choose leisure activities?

- What is required to enable the child/young person to access leisure activities?
- What are their interests or hobbies?
- Are the recreational needs of siblings and other family/carer's family members being met?

## Education

Name of nursery, school or college attending

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

Education and learning

- What additional support or reasonable adjustments are required in that setting?
- If the child/young person is too ill to access a setting, what other provision is in place to ensure continuity of learning?

133. 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.

## Medical history

### Health Professionals

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

- |  |  |
|--|--|
| <ul style="list-style-type: none"> <li>• registered GP</li> <li>• all consultants</li> <li>• Designated Medical or Health Officer for SEND</li> <li>• community paediatrician</li> <li>• psychologist</li> <li>• psychiatrist</li> <li>• community children's nurse</li> <li>• specialist nurse (e.g. for epilepsy).</li> <li>• Nurse consultant</li> <li>• CAMHS nurse</li> <li>• named ward nurse</li> </ul> | <ul style="list-style-type: none"> <li>• health visitor</li> <li>• school nurse</li> <li>• district nurse</li> <li>• social worker</li> <li>• occupational therapist</li> <li>• speech and language therapists</li> <li>• physiotherapist</li> <li>• other therapists</li> <li>• teacher</li> <li>• short break services</li> <li>• lead professional</li> <li>• interpreter.</li> </ul> |
|--|--|

### Clinical details

Medical history	<ul style="list-style-type: none"> <li>Dates of significant health events/current health status.</li> </ul>
Medication	<ul style="list-style-type: none"> <li>Current medication; allergies.</li> </ul>
Equipment - disposable	<ul style="list-style-type: none"> <li>Type, manufacturer/ supplier ; distributor / quantity and frequency etc. Collection method.</li> </ul>
Equipment – permanent	<ul style="list-style-type: none"> <li>Type, manufacturer/ supplier; distributor / quantity, maintenance.</li> </ul>
Treatment / care needs	<ul style="list-style-type: none"> <li>Interventions; who provides and monitors the service; care plans.</li> <li>Symptom management and pain control.</li> <li>What is the 24-hour daily care routine?</li> <li>How are the child/young person and family/carers supported?</li> <li>Does the family have adequate information on the child/young person's condition/future?</li> <li>What is the 24-hour daily care routine?</li> <li>Competencies required to care for the child/young person.</li> <li>Is there a lead professional, and is this working well?</li> </ul>

134. 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 the child and adolescent mental health service required?

## Outcomes

135. 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), identifying unmet need.
136. 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.
137. Key issues would include:
- Maintaining a safe environment.
  - Communicating.
  - Breathing.
  - Eating and drinking.
  - Elimination.
  - Personal cleaning and dressing.
  - Controlling body temperature.
  - Mobilising.
  - Playing.
  - Learning.
  - Expressing individuality.
  - Sleeping.
  - Employment
  - Independence
  - Further education
  - Emergency care
  - End of life.
  - Pain management

## Care domains

138. Health assessors should consider the needs of the child or young person across the following 11 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. Examples of this might include the relationship between skin integrity and continence, or cognitive impairment and behaviour and/or communication.
139. 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.
140. It is the responsibility of assessors to advise, and panels to decide, eligibility for continuing care. 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 at least three domains of care.
141. 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 and costed options 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.

142. 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.

## 1. Communication

Description	Level of need
<p>Communicates clearly, verbally or non-verbally, appropriate to developmental needs. Has a good understanding of their primary language. May require translation if English is not their first language.</p> <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 to communicate their needs. The child/young person's ability to understand and communicate is appropriate for their age and recognised developmental milestones. Special effort may be needed to ensure accurate interpretation of needs, or may need additional support visually – either through touch or with hearing. Family/carers may be able to anticipate needs through non-verbal signs due to familiarity with the individual. Expressive or receptive language.</p> <p>The child/young person's ability to understand or communicate is appropriate for their age and developmental level.</p> <p><b>However</b>, special effort may be needed to ensure accurate interpretation of their needs; for example:</p> <ul style="list-style-type: none"> <li>• the child/young person may need prompting to communicate their needs; and/or</li> <li>• the child/young person may need additional support – visual support such as symbols, signing or support with hearing, e.g. use of hearing aids.</li> </ul>	Low
<p>Communication about basic needs is difficult to understand or interpret, even when prompted, unless with familiar people, and requires regular support. Family/carers may be able to anticipate and interpret the child/young person's needs due to familiarity.</p> <p>Support is <b>always</b> required to facilitate communication, for example, the use of choice boards, signing and communication aids.</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 or withdrawal.</p>	Moderate
<p>Even with frequent or significant support from family/carers and professionals, the child/young person is rarely able to communicate basic needs, requirements or ideas, even with familiar people.</p>	High

## 2. Mobility

Description	Level of need
Independently mobile as appropriate for age and development.	No additional needs
Able to stand and move with mobility aids.	Low
<p>Difficulties in standing or moving even with aids; need support to access curricular or extracurricular activities.</p> <p><b>and/or</b></p> <p>sleep deprivation due to underlying medically/mobility related needs – occurring three times a night (and at least two nights per week).</p>	Moderate
<p>Unable to move in a developmentally appropriate way; cared for in one position (bed or chair) and due to risk of physical harm, loss of muscle tone, tissue viability, or pain on movement; needs careful positioning and is unable to assist or needs more than one carer to reposition or transfer;</p> <p><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 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>where positioning is critical to physiological functioning or life.</p>	Severe



### 3. Nutrition, food and drink (including vomiting)

Description	Level of need
Able to take adequate food and drink by mouth, to meet all nutritional requirements. Appropriate to developmental age.	No additional needs
<p>Some assistance required above what is appropriate for their developmental age;</p> <p><b>or</b></p> <p>needs supervision, prompting and encouragement with food and drinks above the normal requirement for developmental age;</p> <p><b>or</b></p> <p>parent/carer and/or child/young person 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;</p> <p><b>or</b></p> <p>needs feeding when this is not appropriate for developmental age, but is not time consuming.</p>	Low
<p>Needs feeding to ensure adequate intake of food and takes a long time (including liquidised feed); specialised feeding plan developed by speech and language therapist;</p> <p><b>or</b></p> <p>unable to take sufficient food and drink by mouth – most nutritional requirements taken by artificial means, for example, via a non-problematic tube feeding device, including nasogastric tubes.</p>	Moderate
<p>Dysphagia, requiring a management plan 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, suction;</p> <p><b>or</b></p> <p>problems with intake of food and drink, requiring skilled intervention to manage nutritional status; recognised eating disorder, with self-imposed dietary regime or self-neglect, for example, depression leading to intake problems placing the child/young person at risk and needing skilled intervention;</p> <p><b>or</b></p> <p>problems relating to a feeding device (e.g. nasogastric tube feeding) which require a risk-assessment and management plan undertaken by a speech and language professional, and requiring regular review and reassessment. Despite the plan, there remains a risk of choking.</p>	High
The majority of fluids and nutritional requirements are routinely taken by intravenous means.	Severe

**4. Continence or elimination**

Description	Level of need
Continent of urine and faeces (appropriate to age and development).	No additional needs
Continence care is routine on a day-to-day basis and age appropriate; <b>or</b> incontinent of urine but managed by other means, for example, medication, regular toileting, pads, use of penile sheaths; <b>or</b> is able to maintain full control over bowel movements or has a stable stoma, but may have occasional faecal incontinence; <b>or</b> has a stoma requiring routine attention.	Low
Doubly incontinent but care is routine; <b>or</b> self-catheterisation; <b>or</b> has a stable stoma but may have occasional faecal incontinence.	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.	High
Requires peritoneal dialysis or haemodialysis to sustain life.	Priority

**5. Skin and tissue viability.**

(Stomas should be considered under 5. Continence or elimination; tracheostomies under 7. Breathing).

Description	Level of need
No evidence of pressure damage or condition affecting the skin.	No additional needs
Evidence of pressure damage and pressure, 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.	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 or care worker several times each day, without which skin integrity would break down; <b>or</b> tracheostomy requiring routine care.	Moderate
Open wound(s), which is (are) not responding to treatment and require a minimum of daily monitoring/reassessment; <b>or</b> active 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

## 6. Breathing

Description	Level of need
Normal breathing (age-appropriate rate).	No additional needs
Routine use of inhalers, nebulisers, etc.	Low
<p>Episodes of acute breathlessness, which do not respond to self-management and need specialist-recommended input;</p> <p><b>or</b></p> <p>requires the use of intermittent or continuous low-level oxygen therapy to prevent secondary health issues;</p> <p><b>or</b></p> <p>has profoundly reduced mobility leading to increased susceptibility to chest infection;</p> <p><b>or</b></p> <p>requires daily physiotherapy to maintain optimal respiratory function;</p> <p><b>or</b></p> <p>breathing difficulties, which require oral suction.</p>	Moderate
<p>Requires high flow air / oxygen to maintain respiratory function overnight or for the majority of the day and night (i.e. CPAP / BIPAP).</p> <p>Requires continuous high level oxygen dependency, determined by clinical need.</p> <p><b>or</b></p> <p>has a need for regular oral pharyngeal and/or nasopharyngeal suction (e.g. more than weekly), with a management plan undertaken by a specialist practitioner.</p>	High
<p>Has frequent, hard-to-predict apnoea;</p> <p><b>and/or</b></p> <p>continuous airway monitoring and positioning of head and neck to maintain airway;</p> <p><b>and/or</b></p> <p>severe, life-threatening breathing difficulties, which may require essential oral pharyngeal and/or nasopharyngeal suction, day or night;</p> <p><b>or</b></p> <p>a tracheostomy tube that requires essential suction by a fully trained carer, to maintain a patent airway;</p> <p><b>and/or</b></p> <p>requires ventilation at night for very poor respiratory function; has respiratory drive and would survive accidental disconnection, but would be unwell and may require hospital support.</p>	Severe
<p>Unable to breath independently and requires permanent mechanical ventilation;</p> <p><b>or</b></p> <p>has no respiratory drive when asleep or unconscious and requires ventilation and one-to-one support while asleep, as disconnection would be fatal;</p> <p><b>or</b></p> <p>a highly unstable tracheostomy, frequent occlusions and difficult to change tubes.</p>	Priority

## 7. Drug therapies and medication

Description	Level of need
Parent, informal carer or self-administered medicine as age appropriate.	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>and</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>Has a drug regime that requires management by a registered nurse (within prescription) at least weekly, due to a fluctuating and/or unstable condition or symptom management;</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>	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>and/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>and/or</b></p> <p>requires continuous intravenous medication, which if stopped would have a detrimental effect to underlying medical condition (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 required.</p>	Priority

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

(Note that Domain 10 separately considers Challenging Behaviour).

Description	Level of need
Psychological or emotional needs are apparent but age appropriate and similar to those of peer group.	No additional needs
Periods of emotional distress (anxiety, mildly lowered mood) not dissimilar to those of age-appropriate peer group, which subside and are self-regulated by the child/young person, with prompts/ reassurance from peers, family members, carers and/or staff within the workforce.	Low
<p>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; intentional self-harm, but not generally high risk;</p> <p><b>or</b></p> <p>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/concentration within lessons and deterioration in self-care outside of cultural/peer group norms and trends).</p>	Moderate
<p>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 at risk;</p> <p><b>or</b></p> <p>acute and/or prolonged presentation of emotional/psychological deregulation, poor impulse control placing the young person or others at serious risk, and/or symptoms of serious mental illness that places the young person at risk to his/her self and others; this will include high-risk, intentional self-harming behaviour.</p>	High

## 9. 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.	Low
Occasional seizures or periods of unconsciousness that have occurred within the last three months which require the supervision of a carer or care worker to minimise the risk of self-harm; <b>or</b> sleep deprivation due to essential seizure management – occurring three times a night.	Moderate
Seizures that result in unconsciousness and that may require frequent (more than monthly) skilled intervention to reduce the risk of harm and may require the administration of medication by a registered nurse or specially trained carer; <b>or</b> sleep deprivation due to essential seizure management – occurring four times a night; <b>or</b> Requires monitoring and intervention for autonomic storming episodes (e.g. using infusion pumps).	High
Severe uncontrolled seizures, daily or more, resulting in unconsciousness that does not respond to treatment outlined in an established protocol, and results in a high probability of risk to his/her self or others.	Severe
Requires daily intervention by a registered nurse who will use clinical judgement to select and implement from a range of appropriate interventions to manage seizures and treat any related risks.	Priority

## 10. Challenging behaviour

Description	Level of need
Functioning within current environment without further specific specialist training of carers/professionals.	No additional needs
Some incidents of behaviour that do not pose a significant risk or barrier to intervention but require some additional direct/indirect input from identified resources/professionals within frontline services.	Low
Challenging behaviour that follows a predictable pattern and that does not pose a risk to self or others; <b>or</b> behaviours that indicate a marked difficulty in self-regulating his/ her behaviours. This may include impulsive behaviours and/or self-neglect (self-neglect differs from parental neglect and is more applicable to adolescents). This is also separate from peer or cultural trends/uniform or identity.	Moderate
Demonstrates a fluctuating poor ability to self-regulate behaviours in maintaining personal safety and development, despite specialist health intervention. Likely to require intense multi-agency involvement to maintain existing infrastructure, and additional high-level support from several agencies.	High
Demonstrates a consistent poor ability to self-regulate behaviours in maintaining personal safety and development, despite specialist health intervention. Likely to require ongoing, intense multi-agency involvement to maintain any infrastructure, and additional high-level support from several agencies. Usually requires direct specialist clinical assessment, treatment and review from specialist healthcare professionals in addition to those of frontline service.	Severe
Demonstrates a consistent poor ability to self-regulate behaviours in maintaining personal safety and development, despite specialist health intervention, whereby the physical health and safety of the person or others is likely to be placed in serious jeopardy; <b>and</b> behaviours that create a barrier to intervention, requiring direct, urgent and intensive specialist clinical assessment, treatment and review from specialist healthcare professionals in addition to those of frontline services; <b>and</b> sustained behaviours that demonstrate the impairment of a child/young person's personal growth and development through an inability to access necessary resources.	Priority



### 11. Other significant care needs

This final section is intended for particular needs which do not easily fall within the preceding domains, or which are not adequately reflected. Assessors should endeavour to include here any relevant high or severe levels of need, using their professional judgement and evidence presented by relevant contributors to inform a decision as to the level of need, and its impact on the individual's wellbeing. Only high or severe needs should be considered under this domain.

It is essential that this domain is used with discretion and judgement, to ensure consistency with the levels of need in the other domains. CCGs will want to ensure that this domain is not used as a means to circumvent low levels of need in the other domains.

Description	Level of need
	High
	Severe

## 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, the continuing care process should be initiated as soon as possible.

### **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.

### **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 or acquired brain injury**

Children or young people with mental health needs, such as acquired brain injury or neuro-cognitive problems, who are being considered for continuing care, 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 Children's Decision Support Tool.

### **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. A learning disability may have a detrimental effect on the interplay of domains outlined in the Children's Decision Support Tool. The nominated children and young people's health assessor should ensure that the assessment recognises the impact of a learning disability on the child or young person's continuing care needs.

**End-of-life and palliative care**

Where a child or young person has needs that require the input of end-of life and/or palliative care 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.

## 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's 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.

### **Care**

Support provided to a child or young person to enable him or her to live as independently as possible, including anything done to help a child or young person live with ill health, disability, physical frailty or a learning difficulty, and to participate as fully as possible in family, school and community activities. This encompasses health, social care and education.

### **Care plan**

A document agreed between the relevant care professionals and the child or young person and their family, setting out the package of continuing care needed, and its intended outcomes.

### **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's and young people's services.

### **Clinical commissioning group (CCG)**

The 211 clinical commissioning groups are the local organisations with responsibility for commissioning most NHS services. Every GP practice is a member of a local CCG, and each CCG has responsibility for anyone who is registered with one of their member practices, and anyone usually resident in the group's area who is not registered with any practice (a similar principle determined the responsibility of primary care trusts). A list and map of CCGs can be found at: <http://www.england.nhs.uk/wp-content/uploads/2014/02/ccg-map-Feb2014.pdf>

Under section 3 of the NHS Act 2006, a CCG has a duty to arrange for the provision of health services to such extent as it considers necessary to meet the reasonable requirements of the persons for whom it has responsibility. Note that some services are not the responsibility of CCGs (e.g. services commissioned by NHS England, such as primary care and dentistry, services commissioned by other bodies, such as Public Health

England, or public health services commissioned by local authorities). The act sets requirements about how CCGs are established, and operate, and how they are held to account by NHS England in an annual performance assessment.

CCGs have a range of additional statutory duties relating to how they carry out their commissioning function, set out in sections 14P to 14Z2 of the NHS Act 2006.

<http://www.legislation.gov.uk/ukpga/2012/7/section/26/enacted>

### **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.

### **Continuing care pathway**

The continuing care pathway describes the journey undertaken by a child or young person with possible continuing care needs from the point of referral through to the provision of a package of care. There are seven stages of this pathway which a child or young person with possible continuing care needs will pass through.

### **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.

### **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>

### **NHS-funded nursing care**

The funding provided by the NHS to homes providing nursing to support the provision of nursing care by a registered nurse. Since 2007 NHS-funded nursing care has been based on a single band rate. In all cases individuals should be considered for eligibility for NHS continuing healthcare before a decision is reached about the need for NHS-funded nursing care.

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

A health practitioner experienced in children'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, including costed options, 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.

### **Personal health budget**

An amount of money allocated to meet a child or young person's health and wellbeing needs. A personal health budget allows someone with a condition such as a long-term condition, learning disability, continuing healthcare or mental health needs to have more choice, flexibility and control over the services and care they receive, enabling them to better meet their desired health outcomes.

### **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>

### **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.