

National Framework for Children and Young People's Continuing Care



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National Framework for Children and Young People's Continuing Care

Foreword

This National Framework for Children and Young People's Continuing Care ('the Framework') sets out an equitable, transparent and timely process for assessing, deciding and agreeing bespoke continuing care packages for children and young people whose needs in this area cannot be met by existing universal and specialist services. It has been produced in consultation with a wide range of stakeholders, including practitioners and commissioners from both the NHS and local authority children's services. Children, young people and parents have been involved throughout the development of the Framework.

The focus of the Framework is the process by which nominated healthcare assessors carry out holistic assessments of children and young people's continuing care needs and the related needs of their families. These needs generally arise from congenital conditions, long-term deteriorating conditions, accidents or the after effects of serious illness or injury. They will typically be one or more of the following: challenging behaviour, communication, mobility, nutrition, continence or elimination, skin and tissue viability, breathing, drug therapies and medicines, psychological and emotional needs, or seizures. Assessment of these needs and the delivery of bespoke packages of care to meet them will take place alongside services to meet other needs, including education and social care.

Publication of the Framework is a key part of delivering the vision and standards for the care of disabled children and young people and those with complex health needs set out in Standard 8 of the National Service Framework for Children, Young People and Maternity Services. It is an important step forward in meeting the holistic needs of children and young people with long-term conditions, disability or palliative care needs.

The Framework also lays the foundations for further developments to improve the transition to adult continuing care arrangements, and needs to be seen in the context of ongoing work to streamline assessment arrangements for children and young people. The Department of Health and the Department for Children, Schools and Families look forward to ongoing dialogue on these issues with children, young people, parents, commissioners and practitioners across health, social care and education, and other stakeholders.

The Department of Health will also explore how best to evaluate the impact the Framework has on improving the lives of children and young people with continuing care needs and of their families to inform future developments.

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Executive summary

This National Framework for Children and Young People's Continuing Care ('the Framework') is designed to be read by all those commissioning and providing children's continuing care services in primary care trusts (PCTs) and local authorities and their partners. It describes the process, led by PCTs, that organisations should go through in assessing needs and putting in place bespoke packages of continuing care for those children and young people who require it because their needs cannot be met by existing universal or specialist services alone.

Annex A details the assessment phase of the process and is particularly relevant to nominated children and young people's health assessors and those making decisions about continuing care packages. Annex B describes the care pathway as it should be experienced by a child or young person with possible continuing care needs and their family. Annex C sets out the legal framework for children and young people's continuing care.

This Framework sets out a children and young people's continuing care process that should:

- > adhere to a set of core values, key principles and timetables;
- > make the child or young person and their family the focus of the continuing care process and facilitate the provision of personalised packages of care;
- > be developed and owned locally by a multi-agency team;
- > cross organisational and inter-agency boundaries, thus reducing the possibility of fragmented care; and
- > include measurement of outcomes and promote continuous quality improvement.

The Framework has been produced in consultation with a wide range of stakeholders, including NHS practitioners and commissioners. Children, young people and parents have been involved throughout its development, particularly during the consultation process. Key concerns expressed were the complexity of healthcare needs for these children and young people; the critical role played by families in providing the majority of their care and supporting them to live at home; and the need for children, young people and their families to be partners in the continuing care process. Another strong theme was the importance of providing support that is high quality, responsive and well co-ordinated across the relevant agencies. These principles are central to the Framework.

This Framework does not aim to give guidance on the content or funding of the actual packages of continuing care. It is not designed to be a prescriptive tool, nor to replace the need for strong local processes and dialogue regarding the continuing care needs of individual children and young people. Local decision-making should be based on the assessed needs of the individual child or young person. Rather, use of the Framework will ensure that:

- > children, young people and their families are actively engaged in the continuing care process;
- > the continuing care process is co-ordinated and consistent between organisations; and
- > health and social care practitioners, including those working in the independent and third sectors, and the public understand the continuing care process.

1. Introduction

1. This Framework sets out an equitable, transparent and timely process for assessing, deciding and agreeing bespoke packages of continuing care for those children and young people under the age of 18 who have continuing care needs that cannot be met by existing universal and specialist services alone. It describes how local organisations, including PCTs and local authorities, should work together to assess need and put in place packages of continuing care. It should be read by all those with responsibility for commissioning and providing continuing care to children and young people.
2. In some areas, strong local co-ordination of the continuing care process is already happening. This Framework is designed to support and strengthen existing good practice and to provide clear guidance for areas where processes and partnerships are less well developed.
3. If a robust process is in place, the child or young person with continuing care needs should have a clearly structured care pathway. More detail on the pathway, and how it should be experienced by the child or young person and their family, is at Annex B.
4. The National Framework consists of the following:
 - > **a continuing care process** which outlines the principles, timelines and the phases involved in assessing and arranging provision of packages of continuing care. It also considers the process from child to adult services;
 - > **an assessment toolkit** to aid identification of continuing care needs in children and young people and a children and young people's Decision Support Tool to inform local decision-making about the care that is needed;
 - > **a continuing care pathway** to help plan, design and deliver services. This care pathway is based on the Association for Children's Palliative Care Integrated Care Pathway for Children and Young People with Life-Threatening or Life-Limiting Conditions and their Families;
 - > details of the **legal framework** for children and young people's continuing care; and
 - > **a summary of the Haringey case** which determined that the *Coughlan* criteria, used to determine whether a local authority or a primary care trust should provide required services to an adult in need of NHS continuing care, applied equally to children.

1.1 What is continuing care?

5. A continuing care package will be required when a child or young person has needs arising from disability, accident or illness¹ that cannot be met by existing universal or specialist services alone. Continuing care does not cover children and young people with care needs that may be met appropriately through existing universal or specialist health services. In this instance, their needs should be addressed using a case management approach.
6. The Framework pilot study found limited information available around the numbers of children and young people receiving packages of continuing care. It included estimates of around 5,000–6,000 assessments nationally per year. Where a need for continuing care is established bespoke commissioning will be required.
7. Continuing care is organised differently for children and young people than for adults. Continuing care for adults is governed by the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care. That framework gives guidance on putting in place complete packages of care where an adult has been assessed as having a primary health need. It means that the provision of all their resulting care needs, whether at home or in a care home, is the responsibility of the NHS.²
8. However, childhood and youth is a period of rapidly changing physical, intellectual and emotional maturation alongside social and educational development. All children of compulsory school age (5 to 16) should receive suitable education, either by regular attendance at school or through other arrangements. There may also be social care needs. Most care for children and young people is provided by families at home, and maintaining relationships between the child or young person, their family and other carers, and professionals, is a particularly important aspect.³
9. This means that a wider range of agencies is likely to be involved in the case of a child or young person with continuing care needs than in the case of an adult. Children and young people's continuing care needs are best addressed holistically by all the agencies that are involved in providing them with public

¹ The National Health Service Act 2006: 'Illness' includes mental disorder within the meaning of the Mental Health Act 1983 (c. 20) and any injury or disability requiring medical or dental treatment or nursing.

² DH (revised 2009) *The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care* London: DH.

³ The term 'family' refers to mothers, fathers, carers and other adults with responsibility for caring for a child, and includes the child's siblings, even if they may be looked after.

services or care: predominantly health, social care and education.⁴ It is likely that a continuing care package will include a range of services commissioned by PCTs, local authority children's services and sometimes others.⁵

1.2 The leadership role of the primary care trust

10. Primary legislation governing the health service does not use the expression 'continuing care'. However, section 1 of the National Health Service Act 2006 requires the Secretary of State to continue the promotion in England of a comprehensive health service, designed to secure improvement in:
 - > the physical and mental health of the people of England; and
 - > the prevention, diagnosis and treatment of illness.
11. Furthermore, the Secretary of State is under a duty to provide services for 'the care of persons suffering from illness and the after-care of persons who have suffered from illness' throughout England, to whatever extent he or she considers necessary to meet all reasonable requirements.
12. PCTs are responsible for leading the continuing care process set out in this Framework. However, a child or young person with continuing care needs may require services commissioned by the PCT, the local authority, and other partners. Where a child or young person requires services commissioned by multiple organisations, the PCT is responsible for leading the commissioning care process, involving the local authority and other partners as appropriate.
13. PCTs are also responsible for establishing and managing governance arrangements for the children and young people's continuing care process. Key points for consideration are as follows:
 - > implementing and maintaining good practice;
 - > ensuring that quality standards are met and sustained;
 - > providing training and development opportunities for practitioners, including supervision;
 - > identifying and acting on issues arising in the provision of children and young people's continuing care;

⁴ HM Treasury (2003) *Every Child Matters* (Cm 5860). London: The Stationery Office.

⁵ In the context of this Framework, PCTs are commissioners of health services that are delivered by a wide range of providers. Local authorities can both commission and provide social and education services, referred to as local authority children's and young people's services. More rarely, other organisations, such as GP practices and schools, may also commission services.

- > promoting awareness of the Framework; and
 - > ensuring flexibility to shape strategic commissioning arrangements and the design of services in instances where a consistent and transparent children and young people's continuing care process highlights repeated issues, e.g. several children with the same continuing care needs.
14. Commissioners have responsibility for ensuring that commissioning resources are turned into service provision in a flexible way. The actual services provided as part of the package for children and young people with continuing care needs will be arranged by the NHS, local authorities and their partners as appropriate, enabling the child or young person to function optimally within their family, community or care setting.
15. All partners are responsible for funding their own contributions to the continuing care package in line with their statutory functions. Ideally this should happen through pooled or shared funding, as part of a Children's Trust arrangement, resulting in seamless commissioning. Through their Children's Trust partnership arrangements, PCTs, local authorities and their partners should consider how the principles and processes in this Framework relate to their current practice.
16. The Operating Framework for the NHS in England 2010/11 encourages personal budgets, and these can be offered from childhood for people with complex care needs.⁶ A personal health budget involves:
- > an individual knowing how much money can be spent on their healthcare (their budget);
 - > a discussion between the patient and the PCT about the care and services they want; and
 - > a care plan (also known by other names, such as support plan) being agreed, which sets out:
 - the individual's health needs and desired health outcomes;
 - the amount of money in their budget;
 - how this money will be spent to meet the individuals needs/outcomes (the money should fully meet the cost of the care plan); and
 - a regular review of the care plan and monitoring of how the money is spent.

⁶ DH (2009) *The NHS Operating Framework for England for 2010/11*. London: DH.

PCTs should consider, on a case-by-case basis, whether continuing care needs could best be funded via a personal budget.

17. Strategic health authorities (SHAs) and Government offices should work with PCTs and local authorities to ensure that satisfactory arrangements are in place for assessing and meeting the continuing care needs of children and young people.
18. Nominated children and young people's health assessors are responsible for ensuring that the assessment of a child or young person with possible continuing care needs, and their families, takes place in a consistent and open manner.

2. The continuing care process

19. This section describes the process by which service commissioners and providers should design and deliver a continuing care pathway for a child or young person. It gives an overview, then the principles by which the process should operate, and goes on to describe in detail each phase of the process.
20. This Framework is principally concerned with describing the continuing care process. A fuller description of the continuing care pathway – how the process should look to the child or young person and their family – is available at Annex A.

2.1 Overview

21. The **continuing care process** is a three-phase activity which PCTs, local authorities and their partners undertake in order to deliver a **continuing care pathway** for children and young people with continuing care needs. The three phases are assessment, decision-making, and arrangement of provision.
22. The **assessment phase** is the first stage of the continuing care process and is led by a nominated children and young people's health assessor. There are four areas that should be considered in the assessment. The first three are:
 - > the preferences of the child or young person and their family;
 - > holistic assessment of the child or young person and their family, including carer assessment; and
 - > reports and risk assessments from the multidisciplinary team.The evidence and outcomes of assessment in these three areas are then collated in the fourth area:
 - > the children and young people's Decision Support Tool (see Annex B).
23. The outcome of the assessment phase will be a recommendation from the nominated children and young people's health assessor as to whether the child or young person has continuing care needs that cannot be met by existing universal or specialist services and will therefore require a package of continuing care involving bespoke commissioning and funding arrangements. More detailed guidance on the assessment phase is on pages 20–23.

24. The **decision-making phase** follows the assessment phase and usually involves a multidisciplinary, multi-agency forum such as a joint funding panel, part of a Children's Trust or an alternative local arrangement. This forum or panel will make 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 nominated children and young people's health assessor. 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 nominated children and young people's health assessor.
25. The **arrangement of provision phase** follows the decision-making phase. After a decision has been taken regarding a package of continuing care, the PCT, local authority and their partners will undertake the planning and commissioning processes required to put in place a package of continuing care. When the care is being delivered, they will also need to keep the package under regular review to ensure that the child's evolving needs are met.

2.2 Principles

26. This section sets out the core values and key principles which PCTs, local authorities and their partners should consider in undertaking the children and young people's continuing care process. Implementation of, or alignment to, the principles and processes of this Framework at a local level will require clear arrangements to ensure multi-agency input for primary and secondary care and other children's services, and to smooth the transition to adult services.
27. The children and young people's continuing care process should meet the vision of *High Quality Care For All* and should include:
 - > clinical effectiveness;
 - > patient safety; and
 - > the experience of the child or young person and their family.⁷
28. The continuing care process should focus on the child or young person in the context of their family, moving towards a more individual person-centred process during transition from childhood to adulthood. This means that the perception of the child or young person and their family of their support needs, and their preferences in having those needs met, should be at the heart of the continuing care process. Their wishes and expectations of how and where

⁷ Darzi, Lord (2008) *High Quality Care For All: NHS Next Stage Review Final Report*. London: DH.

care is delivered should be documented and taken into account, and their preferences should be considered alongside the benefits and risks of different types of provision.

29. The child or young person and their family being considered for continuing care should understand the continuing care process, receiving advice and information in a timely and clear manner. This will maximise their ability to participate in informed decision-making about their future.
30. Generally, parents, as experts in their child or young person's care and as primary carers, provide the majority of care to the child or young person. Parents or other primary carers need to be supported to:
 - > be skilled and confident in their caring;
 - > manage the risks; and
 - > ensure that quality of life is maintained for the family as a whole.
31. Where the views of the child or young person are different from those of their family, the possibility of advocacy should be discussed.
32. The continuing care process should meet the standards of the Aiming High for Disabled Children Core Offer.⁸ There should be no differentiation based on whether the health need is physical, mental or psychological. The continuing care process should be:
 - > fair
 - > consistent
 - > transparent
 - > culturally sensitive, and
 - > non-discriminatory.
33. Decisions about a child or young person's continuing care should be based on an assessment of their needs. The diagnosis of a particular disease or condition is not in itself a determinant of a need for continuing care.
34. 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.

⁸ www.everychildmatters.gov.uk/socialcare/ahdc/coreoffer

35. Wherever possible, continuing care should be provided in the child or young person's home, but it may be provided in another setting such as a residential school, residential placement or hospice. Establishment of a continuing care need is not determined either by the setting where the care is provided or by the characteristics of the person who delivers the care.
36. The children and young people's continuing care process requires a whole-system approach that should be reflected in an integrated continuing care pathway. This will ensure that:
 - > primary, secondary or tertiary care is co-ordinated;
 - > the need to refer to local authority children's and young people's services is identified, if not being met already; and
 - > appropriate referrals to or input from specialist assessments, such as those by Child and Adolescent Mental Health Services, are made.
37. PCTs 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.
38. Children and young people who require fast-tracking because of the nature of their needs, such as a prognosis indicating end-of-life care needs, 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.
39. Where a child or young person is found not to have a need for continuing care, a clear 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 using a case management approach.
40. Where the child or young person is found to have a need for continuing care but the proposed care package is not the child or young person and their family's preferred option for either delivery or content, a clear explanation of the rationale for the decision should be provided. If the child or young person and their family do not agree with the decision and explanation provided, they should follow their PCT's local complaints procedure.

41. The assessment phase should take into consideration the effect an effective regime of care may have on a child or young person's continuing care needs. Regular reviews need to be built into the process to ensure that the care package continues to meet the child or young person's ongoing needs. The responsibility to commission care is not indefinite as needs may change; this should be made clear to the child or young person and their family.
42. In instances where the successful management of a continuing care need has permanently reduced or removed an ongoing need, this will have a bearing on the child or young person's need for continuing care. However, the continuing care process should not marginalise a need just because it is being successfully managed but where the underlying need continues unreduced.

2.3 Resolution of disputes

43. PCTs will have a local complaints procedure 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. PCTs will already have a system for review of 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. In instances where the complaint relates specifically to local authority children's and young people's services, the PCT will act as the designated first point of contact for children or young people and their families and co-ordinate as appropriate.
44. Guidance around local dispute resolution, between NHS organisations or between a PCT and a local authority, could operate in a similar way to the panels established under the Community Care (Delayed Discharges etc.) Act 2003. *Who Pays?*⁹ sets out guidelines for when there is a dispute between PCTs as to responsibility. Paragraph 2 of the guiding principles states: 'The underlying principle is that there should be no gaps in responsibility – no treatment should be refused or delayed due to uncertainty or ambiguity as to which PCT is responsible for funding an individual's healthcare provision.'
 - > PCTs and local authorities in each local area should agree a local disputes resolution process to resolve cases where there is a dispute between NHS organisations, or between a PCT and a local authority, about a child or young person's continuing care needs and/or about the apportionment of funding of a package of continuing care.

⁹ DH (2007) *Who Pays? Establishing the responsible commissioner*. London: DH.

- > Disputes should not delay the provision of the care package, and protocol should make clear how funding will be provided pending resolution of the dispute.
- > Where disputes involve PCTs and local authorities in different geographical areas, the relevant PCT and local authority should agree a dispute resolution process to ensure resolution in a robust and timely manner. This should include agreement on how funding will be provided during the dispute, and arrangements for reimbursement to the agencies involved once the dispute is resolved.
- > SHAs should be mindful of their role in resolving disputes, as set out in *Who Pays?*

2.4 Timelines

45. A clear timetable is important because it is in the best interest of the child or young person and their family for the outcome to be known as soon as possible. If the child or young person is being discharged from acute care or tertiary care,¹⁰ 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.
46. Provision of a package of continuing care should occur as soon as possible following a decision being made at a multi-agency decision-making panel and the child or young person and family being informed.
47. Timelines for the continuing care pathway should be in line with those outlined below, with appropriate flexibilities to fast-track children and young people thought to be approaching the final weeks and days of life.
48. Diagram 2 in Annex B outlines the indicative timescales for each phase of the children and young people's continuing care pathway.

¹⁰ Council for Disabled Children (2010) *Guidelines on the discharge from hospital of children and young people with high support needs*. London: Council for Disabled Children.

2.5 Assessment phase

49. The continuing care process begins when there is an emerging recognition that a child or young person may have continuing care needs that cannot be met through existing universal or specialist services alone. Children and young people can be referred for assessment through a number of different routes, settings and care pathways. More detail on the types of needs that such children and young people may have, and how these are assessed, is given in the assessment toolkit at Annex A.
50. Every child or young person referred with possible continuing care needs should be offered a comprehensive assessment. The assessment will be health-led but will include an assessment of health, social care and education needs. 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.¹¹ Children with continuing care needs will often have had a range of other individual assessments, for example from the Common Assessment Framework or specialist assessments.^{12,13} The results of these should inform both the assessment and decision-making processes of the child or young person's continuing care assessment.
51. 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 nominated children and young people's health assessor should be a health practitioner experienced in children and young people's health who also has experience and expertise in health assessment, a thorough working knowledge of the policy on the Framework, and well-developed leadership qualities. To ensure appropriate, fair and consistent assessment, the nominated children and young people's health assessor should have relevant skills and competencies 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.

The assessor should also have highly developed listening skills and an understanding of commissioning.

¹¹ The term 'family' refers to mothers, fathers, carers and other adults with responsibility for caring for a child, and includes the child's siblings, even if they may be looked after.

¹² Children's Workforce Development Council (CWDC) (2009) *Common Assessment Framework: Practitioners' and Managers' Guides*. London: CWDC.

¹³ Department for Education and Skills (DfES) (2006) *Common Assessment Framework for Children and Young People: Supporting Tools*. London: DfES.

52. It is important that children and young people and their families understand:
- > why a continuing care assessment is being undertaken
 - > what it will involve
 - > where it will take place
 - > their input into the process.
53. There are four areas of the assessment phase, which PCTs, local authorities and their partners should ensure that their processes reflect. The first three are:
- > the preferences of the child or young person and their family;
 - > holistic assessment of the child or young person and their family, including carer assessment; and
 - > reports and risk assessments from the multidisciplinary team.

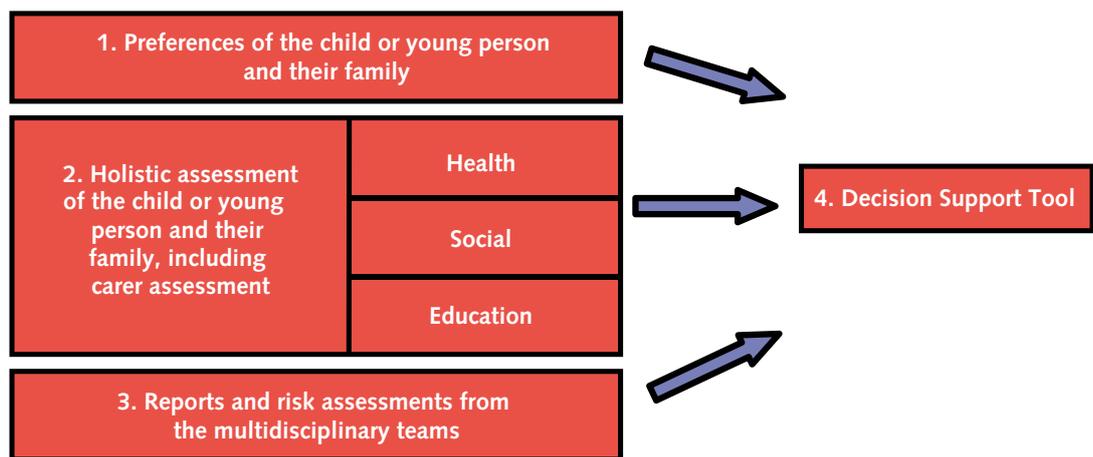
The evidence and outcomes of these three areas are then collated in the fourth area:

- > the children and young people's Decision Support Tool (see Annex B).
54. Each of the four areas of assessment is important to the determination of a 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).
- > **Area 1 – The preferences of the child or young person and their family**
In the first area the nominated children and young people's health assessor is responsible for capturing the child or young person's and their family's preferences.
 - > **Area 2 – Holistic assessment of the child or young person and their family, including carer assessment**
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. In instances where social and education assessments have not already been undertaken, the nominated children and young people's health assessor should liaise with the appropriate professionals to instigate an assessment in these areas and then use these reports to inform the holistic assessment of the child or young person's continuing care needs.

- > **Area 3 – Reports and risk assessments from the multidisciplinary team**
In the third area, 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).
- > **Area 4 – The children and young people's Decision Support Tool**
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.

55. **Diagram 1** shows how the first three areas of the assessment phase feed into the fourth area, the Decision Support Tool.

Diagram 1: The four areas of the assessment phase



56. 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.
57. Holistic multi-agency and multidisciplinary approaches, which also address the child or young person's and their family's emotional needs, are key. 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.

58. The input of the third sector should be considered in the assessment phase, as appropriate.
59. Continuing care assessments should draw on other assessments but not to the exclusion of direct assessment of and contact with children or young people and their families.
60. Assessment should be a process, not a one-off event. A continuing care assessment should build on previous assessments. Most children or young people with continuing care needs will have had multiple assessments, although this may not always be the case if the continuing care need has arisen due to a sudden trauma or injury. Children and young people's needs change quickly, so review is an essential part of the continuing care process.
61. 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.
62. Exceptionally, information may be withheld from a child or young person or someone with parental responsibility for him/her if the PCT considers that it would be likely to cause significant harm to the physical or mental health or condition of the child or young person or would otherwise not be in their best interests. Social services should be involved, if they are not already, where it is thought that the child is at risk of significant harm or is suffering significant harm.
63. Consent to share information should be obtained from partner agencies for all continuing care assessments. Methods for information-sharing should fully comply with local information-sharing protocols.
64. 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.

2.6 Decision-making phase

65. Decisions about the commissioning of packages of care should be made with reference to a multidisciplinary, multi-agency team assessment by the nominated health assessor to ensure provision of a holistic package of continuing care.

66. The recommendations and costed options presented by the nominated children and young people's health assessor to the multi-agency decision-making forum will form the basis for a commissioning decision to be made by the forum regarding the need for, and the package of, continuing care. In instances where a continuing care need is identified, the multi-agency decision-making forum should consider the preferences of the child or young person and their family (area 1 of the assessment phase) when deciding on packages of care. It is important that PCTs and local authorities plan the co-ordination of their care and support, taking into account local authority children's and young people's services' requirements.
67. Once a decision has been made at a multi-agency decision-making forum, the child or young person and their family should be informed of the decision within five working days. Packages of continuing care should be recorded in a care plan and worded so they are understandable to the child or young person, their family and the different agencies involved in the decision-making process and/or the continuing care of the child or young person. The decision should also be communicated to the child or young person and their family, the NHS multidisciplinary team, the local authority and the school. If the identified needs require fast-tracking, the decision should be communicated immediately.
68. 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 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.

2.7 Arrangement of provision phase

69. After a decision has been taken and communicated, PCTs and/or local authorities, as appropriate, will need to make the necessary logistical, funding and, in some instances, contractual arrangements to initiate the delivery of provision of the package of continuing care.
70. During the arrangement of provision phase, PCTs and local authorities should adhere to Standard 3 of the National Service Framework (NSF) for Children, Young People and Maternity Services Core Standards,¹⁴ which outlines best practice in planning and commissioning services for children, young people and their families.
71. Provision of a package of continuing care should begin as soon as possible following a decision being made and the child or young person and their

¹⁴ DH (2004) *National Service Framework for Children, Young People and Maternity Services: Core Standards*. London: DH.

family being informed. In some instances there may be an unavoidable delay in implementation, such as where the outcome of a Disabled Facilities Grant panel is required, but PCTs and local authorities should ensure that delays are avoided as far as is possible. Arrangement of provision should adhere to section 10 – Planning and Commissioning – within Standard 3 of the NSF Core Standards.

Review

72. The continuing care process does not end with the provision of a package of continuing care. Ongoing case management is required for those children or young people in receipt of continuing care, and reviewing the package of care is an important part of the arrangement of provision phase. A lead professional will be able to co-ordinate effectively all the various agencies involved in providing care.
73. All children and young people's continuing care packages should be reviewed on a regular basis. A recommended minimum is three months after the initial assessment and then annually or more frequently depending on the continuing care needs of the child or young person. The child or young person, or their family, can request a review as appropriate. The commissioners of the care package are responsible for making necessary arrangements for regular contract review to ensure that service specifications are being met and the service being provided is of the required level.
74. If the nature or level of needs changes significantly, the scheduled review of the child or young person's needs should be brought forward as the package may need to be increased or may no longer be required.
75. Reviews of a child or young person's continuing care needs should be an opportunity for assessment of needs and how they are being addressed by the package of continuing care provided. 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 and that they are not financially motivated.
76. Any such review should be transparent, involve the child or young person and their family and be supported by a rationale/explanation of the decision. Both verbal and written reports should be given to the child or young person and family as appropriate. All reviews should adhere to the key principles for the continuing care process.
77. In instances where a child or young person's continuing care needs have decreased so that transition back into universal or specialist services is appropriate, the child or young person and their family should be supported throughout this transition.

2.8 Transition from child to adult services

78. The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care and the supporting guidance and tools only applies to people aged 18 or over. It is important that both the adult and children's frameworks consider transition.
79. It is important to remember that the legislation and the respective responsibilities of the NHS, social care and other services are different in children's and adult services. As noted previously, the terms 'continuing care' (in relation to children's services) and 'NHS continuing healthcare' (in relation to adults) also have different meanings. It is important that young people and their families are helped to understand this difference and its implications from the start of transition planning.
80. *Transition: moving on well*¹⁵ sets out good practice for health professionals and their partners in transition planning for young people with complex health needs or disabilities. A *transition guide for all services*¹⁶ explains how all relevant services should work together with a young person to identify how they can best support them to help achieve their desired outcomes. All transition planning for young people should take full account of the approaches set out in these documents.
81. All PCTs should ensure that they are actively involved in the strategic development and oversight of their local transition planning processes with their partners, and that their representation includes those who understand and can represent adult NHS continuing healthcare. PCTs should also ensure that adult NHS continuing healthcare is appropriately represented in all transition planning meetings regarding individual young people wherever the individual's needs suggest that there may be potential eligibility. PCTs and local authorities should have systems in place to ensure that appropriate referrals are made when either organisation is supporting a young person who may have a need for services from the other agency on reaching adulthood.
82. It is desirable and best practice that future entitlement to adult NHS continuing healthcare should be clarified at as early a stage as possible in the transition planning process, especially when the young person's needs are likely to remain at a similar level until adulthood.

¹⁵ Department for Children, Schools and Families (DCSF) and DH (2008) *Transition: moving on well – A good practice guide*. London: DH.

¹⁶ DCSF and DH (2007) *A transition guide for all services: key information for professionals about the transition process for disabled young people*. London: DCSF.

83. Children's continuing care teams should identify those young people for whom it is likely that adult NHS continuing healthcare will be necessary and notify the relevant PCT who will hold adult responsibility for them. Such young people should be identified when they reach the age of 14.
84. This should be followed up by a formal referral for screening at age 16 to the adult NHS continuing healthcare team at the relevant PCT.
85. By the age of 17, an individual's eligibility for adult NHS continuing healthcare should be decided in principle by the relevant PCT in order that, where applicable, effective packages of care can be commissioned in time for the individual's 18th birthday (or a later date if it is jointly agreed that it is more appropriate for responsibility to transfer at that time). Where needs may change, it may be appropriate to make a provisional decision and then re-check it through repeating the process as adulthood approaches.
86. Entitlement for adult NHS continuing healthcare should initially be established through use of the decision-making process set out in the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care, including use of the checklist and the Decision Support Tool. The eligibility decision should be made using the relevant PCT's usual adult NHS continuing healthcare decision-making processes. Health plans, and other assessments developed as part of the transition process, will be key evidence to consider in the decision-making process. Any entitlement identified through carrying out these processes prior to a young person reaching adulthood will come into effect on their 18th birthday, subject to any change in their needs.
87. If a young person receiving children's continuing care has been determined by the relevant PCT not to be eligible for adult NHS continuing healthcare, they should be advised of their non-eligibility and of their rights to request an independent review on the same basis as NHS continuing healthcare eligibility decisions regarding adults. The PCT should continue to participate in the transition process to ensure an appropriate transfer of responsibilities, including consideration of whether the PCT should be commissioning, funding or providing services towards a joint package of continuing care.
88. Where a young person is receiving support via a placement outside of the PCT's area, it is important that there is clear agreement between all relevant PCTs at an early stage in the transition planning process as to who the responsible commissioner presently is and to any potential future changes to the arrangement. This should be determined by applying the principles set out in *Who Pays?*. All PCTs with present or future responsibilities should be actively represented in the transition planning process. A dispute or lack of clarity over commissioner responsibilities should not lead to a lack of appropriate input in the transition process.

89. Even where a young person is not entitled to adult NHS continuing healthcare, they may have some health needs that fall within the responsibilities of the NHS. In such circumstances, PCTs should continue to play a full role in transition planning for the young person and 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 help achieve them.
90. 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 a move from children's to adult services or a move between organisations with commissioning or funding responsibilities. Where change is necessary, it should be carried out in a phased manner in full consultation with the young person. No services or funding should be withdrawn unless a full assessment has been carried out in respect of need for adult health and social care services, including funding responsibilities.
91. The legal responsibilities for children's 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 the reasons why. Some local health services for children and young people are only offered up to an age short of adulthood (i.e. 16). PCTs and 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, PCTs should consider how to address these as part of their strategic commissioning responsibilities.
92. It should be noted that regulations state that, in certain circumstances, when a young person in receipt of children and young people's continuing care reaches adulthood, the care arrangements should be treated as having been made under the adult continuing care provisions.¹⁷ 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. 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 child or young person's and the PCT's and local authority's interests to monitor and actively participate in the reviews of those recipients of continuing care who are approaching adulthood.

¹⁷ The National Health Service (Functions of Strategic Health Authorities and Primary Care Trusts and Administration Arrangements) (England) (Amendment No. 2) Regulations 2007.

Annex A: Assessment toolkit (including Decision Support Tool) for children and young people's continuing care

Introduction

1. This annex gives detailed advice on how to implement the assessment phase of the continuing care process. It should be used by nominated health assessors to guide their work in this phase, and by commissioners and those on decision-making panels to guide their decisions. Step-by-step guidance on areas 1 to 3 is followed by the Decision Support Tool (area 4), which brings all the areas together to facilitate a holistic assessment of the needs of the child or young person.
2. Generally, a child or young person will develop continuing care needs for one of the three 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. Primary care trusts (PCTs) 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 PCTs 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.

3. 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 and young people'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 and young people'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.
4. Assessment for continuing care should meet the National Service Framework for Children, Young People and Maternity Services (2004) standards, particularly the following:
 - > Standard 3 – 'Children/young people and their families receive high quality services which are co-ordinated around their individual needs and take account of their views.'

- > Standard 8 – ‘Children and young people who are disabled or who have complex health needs, receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, enable them and their family to live ordinary lives.’

*Aiming high for disabled children: better support for families*¹⁸ reinforces the commitment made in NSF Standard 8.

Area 1: Preferences and views of the child, young person and their family

5. The assessment phase is the first stage in which the process focuses on the views and preferences of the child or young person and their family; each family member has a contribution to the understanding of a whole family's needs. There should be involvement of children or young people and their families in designing their packages of care, as prioritised in *Aiming high for disabled children*.
6. Key factors that may add or detract from gaining the views and preferences of the whole family during the assessment phase are as follows:
 - > Timing – if conducted exclusively in working hours, the assessment is likely to exclude working partners and siblings.
 - > Location – assessments carried out in hospital or clinical environments will often exclude family members.
 - > Communication skills – practitioners skilled in family-centred care and assessment are more likely to effectively involve children, young people, parents and siblings in the identification of needs and in developing appropriate packages of care.
 - > Communication aids – involvement of speech and language therapists and/or special needs teachers can support children or young people with continuing care needs to express their opinions and perceptions of their needs.
7. Skilled interpreters are essential in order to gain views from families where English is not a first language for some or all family members. Parents with learning disabilities or communication difficulties require appropriate support from adult services.

¹⁸ Department for Education and Skills (DfES) (2007) *Aiming high for disabled children: better support for families*. London: DfES.

8. Where advanced planning techniques have been used and a family has been engaged by professionals in expressing its preferences and proactively planning for its future needs, this information can usefully inform the continuing care assessment, ensuring the information dovetails with existing advanced care planning processes.

Area 2: Holistic child or young person and family-centred assessment, including carer's assessment

9. The assessment phase should capture and give due consideration to the needs of the whole family. The preferences and views of the child or young person and their family should be at the centre of the assessment phase. The nominated children and young people's health assessor is responsible for undertaking a health assessment and collating existing assessments by local authority children and young people's services on behalf of the commissioners, in order to present a holistic picture of the child or young person's continuing care needs. In instances where social and education assessments have not already been undertaken, the nominated children and young people's health assessor should liaise with the appropriate professionals to instigate an assessment in these areas and then use these reports to inform the holistic assessment of the child or young person's continuing care needs.
10. The assessment phase of the children and young person's continuing care process will have a very different focus from the adult continuing care assessment, for reasons outlined previously in this Framework.

Area 3: Reports and risk assessments from the multidisciplinary team

11. Reports from health and local authority children and young people's services provide an important part of the evidence base for making an assessment of continuing care needs and the package of continuing care. The nominated children and young people's health assessor should undertake a healthcare risk assessment and prepare a report. Where other reports from local authority children and young people's services exist, it is the role of the nominated children and young people's health assessor to collate them. If they do not exist, the nominated children and young people's health assessor should liaise with the appropriate professionals to instigate relevant risk assessments.
12. Children or young people with long-standing continuing care needs may have extensive reports and notes. For the purposes of children and young people's continuing care, reports that demonstrate the frequency, intensity, unpredictability, deterioration and/or instability of social or educational needs of the child or young person or their family are relevant.

13. In compiling the relevant reports and in preparing their final recommendations, including costed options, the nominated children and young people's health assessor should demonstrate the effectiveness of the preferred package of continuing care.
14. Multidisciplinary reports may be obtained from the following:
 - > hospital consultants/specialists
 - > specialist nurses
 - > therapists
 - > general practitioners
 - > community children's nurses
 - > learning disability teams
 - > psychologists
 - > child and adolescent mental health services (CAMHS) reports
 - > Child Development Centres.
15. Multi-agency reports which should be accessed are as follows:
 - > the Common Assessment Framework
 - > the core or initial assessment report
 - > the carer's assessment
 - > the family/carer assessment plan
 - > educational statement of special educational needs, and annual reviews
 - > 'team around the child or young person' review.
16. Records:
 - > care intervention/evaluation records
 - > overnight assessments from short break centres
 - > family/carer diaries of care interventions.
17. Independent reports may be available from:
 - > consultants/specialists;
 - > outside nursing teams; and
 - > external children/young person's continuing care experts.

Risk assessment

18. Risk assessment should be undertaken during the assessment phase and should be used for appraising options for delivery of care. In continuing care, risk assessment can be used to make informed decisions about staffing levels, workforce numbers, equipment and back-up services. Risk management can be used to assess either clinical or environmental risk, as care, support and education will be provided in a variety of settings. Risk management has the potential to enable inclusion. *The dignity of risk*¹⁹ and *Including me*²⁰ are key texts in using risk management to enable, rather than exclude, in social care and educational environments.
19. Risk assessments may influence assessment of need or care package design in the following areas:
 - > clinical risk
 - > staffing levels
 - > equipment
 - > care environment
 - > moving and handling.
20. Risk assessment should be used to demonstrate whether there is a significant risk in terms of frequency, intensity, unpredictability, deterioration and instability of need where this may not be fully captured in the children and young people's Decision Support Tool.
21. PCTs should ensure that nominated children and young people's health assessors are aware of locally agreed risk assessment processes in their area. Risk management leads from PCTs should work with nominated children and young people's health assessors to develop and integrate risk management into local risk assessment strategies.

¹⁹ Council for Disabled Children (2004) *The dignity of risk: a practical handbook for professionals working with disabled children and their families*. London: Council for Disabled Children.

²⁰ Carlin J (2005) *Including me: managing complex health needs in schools and early years settings*. London: Council for Disabled Children.

Area 4: Children and young people's Decision Support Tool

22. The children and young people's Decision Support Tool below has been developed to bring assessment information together and present it in a concise, consistent way. The Decision Support Tool is not a stand-alone tool and should be used to pull together the other three key areas of assessment:
 - > the preferences of the child or young person and their family
 - > holistic assessment of the child or young person and their family, including carer assessment
 - > reports and risk assessments from multidisciplinary team.
23. It is designed to help ensure that all relevant needs are assessed and captured and to describe and record an overall picture to inform local decisions about the care needed. The children and young people's Decision Support Tool is not intended to provide a process that results in uniform decisions about what continuing care should be provided to children and young people.
24. The nominated children and young people's health assessor will have worked alongside a multi-agency team to compile the information required to complete the children and young people's Decision Support Tool. This will include a child or young person and family-centred assessment, the child or young person's and their family's views and relevant professional and risk assessments. The nominated children and young people's health assessor should use the Decision Support Tool to match, as far as possible, the child/young person's level of need with the description that most closely relates to their specific needs. This approach should build up a detailed analysis of individual needs, in a family context, and provide the evidence to inform the decision on the provision of a package of continuing care.
25. 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.
26. 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.

27. The children and young people's Decision Support Tool brings together needs from across 10 care domains, as follows:
 - > challenging behaviour
 - > communication
 - > mobility
 - > nutrition, food and drink
 - > continence and elimination
 - > skin and tissue viability
 - > breathing
 - > drug therapies and medicines
 - > psychological and emotional
 - > seizures.
28. Each care domain can have up to five levels of need, based on a mixture of complexity, intensity, unpredictability of need and risk to the child/young person:
 - > priority
 - > severe
 - > high
 - > medium
 - > low.
29. 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, continence would only become recognised as an issue when a child or young person has continence needs beyond those expected at his or her age.
30. Where a child or young person's care needs to be fast-tracked, such as instances of rapid deterioration or where there is a need for end-of-life care, the assessment phase should not delay this process. These needs should be met first, and then, where appropriate, followed up with a continuing care assessment.

31. The needs described collectively in the care domains and levels of need in the children or young people'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.
32. There may be circumstances, on a case-by-case basis, where a child or young person may have particular needs that do not appear to match the care domains described in the children and young people's Decision Support Tool. In this situation 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 any other needs.

Child/young person's details	Family's details
Name, date of birth, address, telephone number, religion, ethnicity, first language and gender.	Mother's name, father's name and work telephone numbers.
Next of kin.	First language, interpreter if required.
Primary diagnosis, secondary diagnosis and allergies.	Sibling's names, dates of birth and health statuses.
Name and address of nursery, school or college attending.	Names of significant others, relationship, addresses and telephone numbers.
Name and address of short break care and frequency.	Family structure.
Date referred to service and who referred.	Parental responsibility.
Date of initial needs assessment.	Parental disabilities.
Names of nurse and other professionals undertaking assessment.	

<p>Professionals and services involved – contact sheet</p> <p>Name, telephone and location of the following:</p> <ul style="list-style-type: none"> > registered GP (determines responsible PCT) > all consultants > community paediatrician > psychologist > psychiatrist > community children's nurse > CAMHS nurse > named ward nurse > health visitor > school nurse > district nurse > social worker > occupational therapist > speech and language therapists > physiotherapist > other therapists > teacher > short break services > lead professional > interpreter. 	<p>Medical details</p> <p>Health biography – dates of significant health events/current issues/medications.</p> <p>Disposable equipment – type, manufacturer, who responsible, collection method.</p> <p>Hard equipment – type, manufacturer, issue date, supplier, service date, owned by.</p> <hr/> <p>Nursing and care needs</p> <p>Treatment and care needs and who meets these needs.</p> <p>Equipment needs.</p> <p>Symptom management and pain control.</p> <p>How are the child/young person and family/carers supported?</p> <p>Does the family have adequate information on the child/young person's condition/future?</p> <p>What is the 24-hour daily care routine?</p> <p>Competencies required to care for the child/young person.</p> <p>Identify met and unmet needs.</p>
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<p>Activities of living²¹</p> <p>Maintaining a safe environment.</p> <p>Communicating.</p> <p>Breathing.</p> <p>Eating and drinking.</p> <p>Elimination.</p> <p>Personal cleaning and dressing.</p> <p>Controlling body temperature.</p> <p>Mobilising.</p> <p>Playing.</p> <p>Learning.</p> <p>Expressing individuality.</p> <p>Sleeping.</p> <p>End of life.</p>	<p>Young people (those aged 14 years and older)</p> <p>Has transition commenced?</p> <p>Lead professional.</p> <p>Lead professional designate.</p> <p>Future plans:</p> <ul style="list-style-type: none"> > Education/employment. > Accommodation care package. > Can they be assisted to achieve independent living? > Are their views different to their parents'? > Will their parents or main carers need extra emotional and practical support? > Is there consent to share information with other agencies?
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33. The children and young people's Decision Support Tool takes care to ensure that a specific need is not duplicated in two separate care 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.
34. 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 two 'moderates' equal one 'high', 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.
35. Either three 'high' ratings, one 'severe' rating or one 'priority' rating is likely to indicate continuing care needs.

²¹ *Activities of Living*, Roper, Logan and Tierney, orig. 1980, rev. 1998.

36. These guidelines should not be used in a restrictive way. 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.

Challenging behaviour

37. 'Challenging behaviour' is culturally abnormal behaviours 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.

Emotional support needs	Current service provision
What is the effect of the child/young person's condition on each member of the family?	The child/young person's issues, concerns, anxieties.
What times of the day/events are stressful?	The child/young person's preferences about care delivery.
How does the family cope?	The family's preferences about care delivery.
Who does the family call on for support at these times?	Services involved (statutory, voluntary sector, private).
Are there times when the child or young person need particular support?	Carers and the child/young person's perception of these.
How do they communicate as a family?	Any problems with the education of the child/young person or siblings?
What is the child/young person's understanding of his/her condition?	Co-ordination and communication between professionals?
What understanding do siblings have of the child/young person's condition?	Is there a lead professional, and is this working well?
Is an assessment by the child and adolescent mental health service required?	Advice or training needs.
	What information do professionals need?
	How can professionals improve the family's quality of life?
	Does any other member of the family have health or service needs?
	Are siblings involved in care?
	Identify met and unmet needs.

Family/carer's family circumstances

The family's wider community:

- > What kind of help is available in the family's circle of friends and relations?
- > Are there any other organisations or groups that support the family/carer's family?

Housing:

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

Transport:

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

Education and learning:

- > Is the child/young person able to access an appropriate educational setting, either full or part-time?
- > What effect does their condition have on their ability to access the curriculum?
- > 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?

Employment:

- > 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?

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?

Parent and siblings' views.

Child/young person's views.

Identify areas for action.

Care domains

1. 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
<p>Challenging behaviour that follows a predictable pattern and that does not pose a risk to self or others;</p> <p>or</p> <p>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.</p>	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

Description	Level of need
<p>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;</p> <p>and</p> <p>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;</p> <p>and</p> <p>sustained behaviours that demonstrate the impairment of a child/young person's personal growth and development through an inability to access necessary resources.</p>	Priority

2. 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. Able to understand or communicate clearly, verbally or non-verbally, within their primary language, appropriate to their developmental level.</p> <p>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

Description	Level of need
<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>However:</p> <p>Special effort may be needed to ensure accurate interpretation of their needs; for example:</p> <ul style="list-style-type: none"> > the child/young person may need prompting to communicate their needs; and/or > the child/young person may need additional support – visual support such as symbols, signing or support with hearing, e.g. use of hearing aids. <p>Family/carers may be able to anticipate and interpret the child/young person's needs due to familiarity.</p>	Low
<p>Communication about basic needs is difficult to understand or interpret, even when prompted, unless with familiar people, and requires regular support.</p> <p>Support is always 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 or level of pain;</p> <p>or</p> <p>the child/young person demonstrates severe frustration about their communication, for example, through challenging behaviour 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

3. Mobility

Description	Level of need
Independently mobile as appropriate for age and developmental stage (with or without mobility aids).	No additional needs
Able to stand as appropriate for developmental age, but needs some assistance and requires support to access curricular or extracurricular activities.	Low
<p>Completely unable to stand but able to assist or co-operate with transfers and/or repositioning by one carer or care worker to a level appropriate for developmental age;</p> <p>or</p> <p>sleep deprivation due to underlying medically/mobility related 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>or</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>or</p> <p>involuntary spasms placing themselves and carers at risk;</p> <p>or</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>or</p> <p>where positioning is critical to physiological functioning or life.</p>	Severe

4. Nutrition, food and drink

Description	Level of need
Able to take adequate food and drink by mouth, to meet all nutritional requirements. Appropriate to developmental age.	No additional needs
<p>Some assistance required above what is appropriate for their developmental age;</p> <p>or</p> <p>needs supervision, prompting and encouragement with food and drinks above the normal requirement for developmental age;</p> <p>or</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>or</p> <p>needs feeding when this is not appropriate for developmental age, but is not time consuming.</p>	Low
<p>Needs feeding to ensure adequate intake of food and takes a long time (including liquidised feed); specialised feeding plan developed by speech and language therapist;</p> <p>or</p> <p>unable to take sufficient food and drink by mouth – most nutritional requirements taken by artificial means, for example, via a non-problematic tube feeding device, including naso-gastric tubes.</p>	Moderate

Description	Level of need
<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>or</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>or</p> <p>problems relating to a feeding device which require skilled assessment and review.</p>	High
<p>The majority of fluids and nutritional requirements are routinely taken by intravenous means.</p>	Severe

5. Continence or elimination

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

Description	Level of need
Doubly incontinent but care is routine; or self-catheterisation; or 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; or intermittent catheterisation by a trained carer or care worker; or has a stoma that needs extensive attention every day.	High
Requires peritoneal dialysis or haemodialysis to sustain life.	Priority

6. Skin and tissue viability

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; or skin condition that requires clinical reassessment less than weekly.	Low
Open wound(s), which is (are) responding to treatment; or active skin condition requiring a minimum of weekly reassessment and which is responding to treatment; or 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.	Moderate

Description	Level of need
<p>Open wound(s), which is (are) not responding to treatment and require a minimum of daily monitoring/reassessment;</p> <p>or</p> <p>active skin condition, which requires a minimum of daily monitoring or reassessment;</p> <p>or</p> <p>specialist dressing regime, several times weekly, which is responding to treatment and requires regular supervision.</p>	High
Life-threatening skin conditions or burns requiring complex, painful dressing routines over a prolonged period.	Severe

7. Breathing

Description	Level of need
Normal breathing (age-appropriate rate).	No additional needs
Routine use of inhalers, nebulisers, etc.	Low
<p>Episodes of acute breathlessness, which do not respond to self-management and need specialist-recommended input;</p> <p>or</p> <p>requires the use of intermittent or continuous low-level oxygen therapy to prevent secondary health issues;</p> <p>or</p> <p>has profoundly reduced mobility leading to increased susceptibility to chest infection;</p> <p>or</p> <p>requires daily physiotherapy to maintain optimal respiratory function;</p> <p>or</p> <p>breathing difficulties, which require oral suction.</p>	Moderate
Is able to breath unaided during the day but needs to go onto a ventilator for supportive ventilation. The ventilation can be discontinued for up to 24 hours without clinical harm.	High

Description	Level of need
<p>Has frequent, hard-to-predict apnoeas; and/or severe, life-threatening breathing difficulties, which may require essential oral pharyngeal and/or naso pharyngeal suction, day or night; or a tracheostomy tube that requires essential suction by a fully trained carer, to maintain a patent airway; and/or 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; or has no respiratory drive when asleep or unconscious and requires ventilation and one-to-one support while asleep, as disconnection would be fatal; or a highly unstable tracheostomy, frequent occlusions and difficult to change tubes.</p>	Priority

8. Drug therapies and medicines

Description	Level of need
Parent, informal carer or self-administered medicine as age appropriate.	No additional needs
<p>Requires a suitably trained family member, formal carer, teaching assistant, nurse or appropriately trained other to administer medicine due to:</p> <ul style="list-style-type: none"> > age; > non-compliance; > type of medicine; > route of medicine; and/or > site of medication administration. 	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>and</p> <p>monitoring because of potential fluctuation of the medical condition that can be non-problematic to manage;</p> <p>or</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>or</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

Description	Level of need
<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>and/or</p> <p>extensive sleep deprivation caused by severe intractable pain requiring essential pain medication management – occurring every one to two hours.</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

9. Psychological and emotional needs

(Beyond what is normally expected from a child/young person of this age.)

Description	Level of need
<p>Psychological or emotional needs apparent but age appropriate and similar to those of peer group.</p>	No additional needs
<p>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 key frontline staff within the children and young people's workforce.</p>	Low

Description	Level of need
<p>Require prompts or support to remain within existing infrastructure; periods of variable attendance in school/college; noticeably fluctuating levels of concentration; noticeable deterioration in self-care (outside of cultural/peer group norms and trends) which often demands prolonged intervention from additional key staff; intentional self-harm, but not generally high risk;</p> <p>or</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>or</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

10. Seizures

(This encompasses the whole range of types of seizures and any associated risks.)

Description	Level of need
No evidence of seizures.	No additional needs
History of seizures but none in the past three months; medication (if any) is stable.	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; or 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; or sleep deprivation due to essential seizure management – occurring four times a night.	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

38. The process of drawing on a range of multidisciplinary assessments, the wishes of the child/young person and their family, and the multi-agency application of the assessment phase including the children and young people's Decision Support Tool will provide an indication of the child/young person's need for continuing care. If a decision has been made that a child or young person has continuing care needs, the PCT and local authority should each decide on what service each will provide, and the decision should be notified to the child or young person and their family and referrer.

Annex B: Continuing care pathway for children and young people

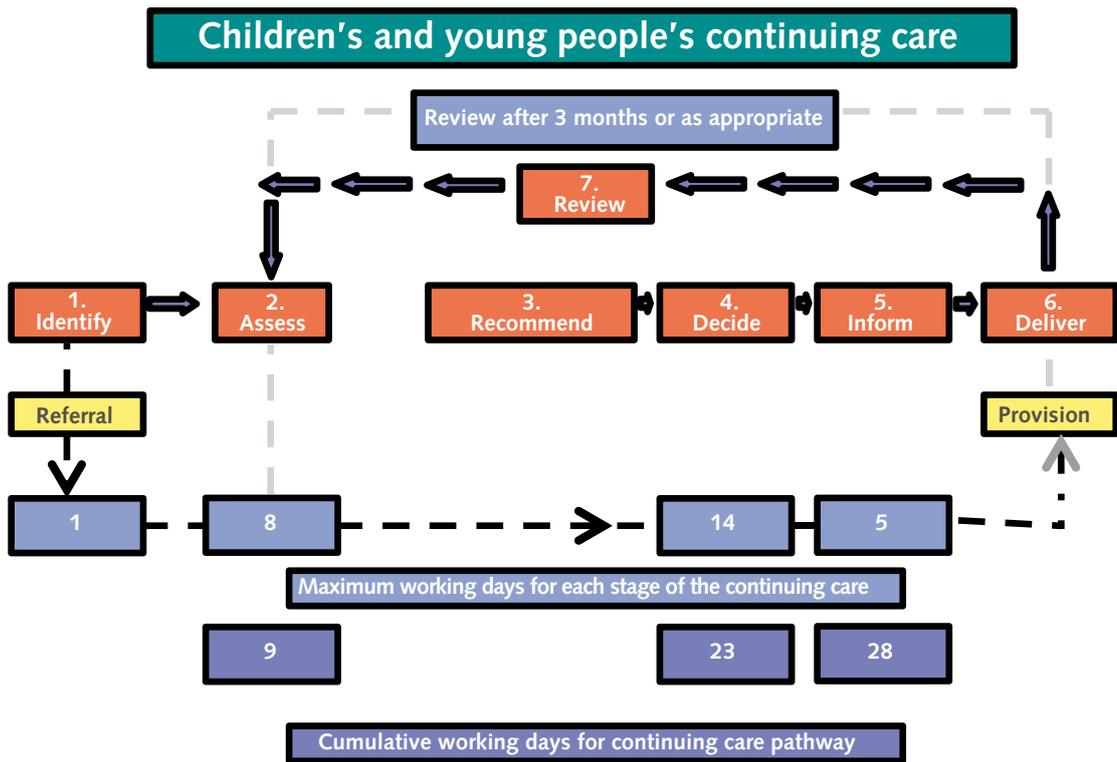
Introduction

39. This annex describes the continuing care pathway for children and young people. It should be referred to by assessors and others involved in decision-making about the possible continuing care needs of a child or young person, or in providing care to meet those needs. The pathway shows how the continuing care process should look from the perspective of the child or young person and their family.
40. Care pathways have been developed to ensure that services are more patient-focused, and they often concentrate on the treatment and care of people with specific diagnoses. While a child or young person's continuing care needs are not determined by a specific diagnosis, the identification of a possible continuing care need prompts entry to the continuing care pathway. This continuing care pathway builds on the Association for Children's Palliative Care *Integrated Care Pathway for Children and Young People with Life-Threatening or Life-Limiting Conditions and their Families*.²² It aims 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 the continuing care needs of children and young people.
41. The pathway maps 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 continuing care. There are seven stages of this pathway which a child or young person with possible continuing care needs will pass through during the continuing care process, from entry through to living with continuing care needs and moving into adult services. Each stage has a principle and set of goals to help children, young people and their families involved in the continuing care pathway understand what should be happening

²² Association for Children's Palliative Care (ACT) (2004) *Integrated Care Pathway for Children and Young People with Life-Threatening or Life-Limiting Conditions and their Families*. Bristol: ACT.

and what they should expect at each stage. There is potential for children or young people with continuing care needs to move in and out of the continuing care pathway, as levels of need can change over time. Diagram 2 gives an overview of the pathway, while pages 57–65 describe each stage in more detail.

Diagram 2: Overview of the pathway, including timescales



Key:
Grey line = review process

The stages in detail

Diagram 3 sets out the stages of the continuing care pathway with a summary of the key actions to be undertaken in each. It also shows how these stages relate to the overarching continuing care process described in the main text of this Framework.

Diagram 3: Summary of the continuing care pathway

Phases of the continuing care process	Stage of care pathway	Summary of key actions	Timescales	Cumulative timescales
Assessment phase	1) Identify	Child or young person with possible continuing care needs identified through effective referral. Fast-track if necessary.	1 working day	1 working day
	2) Assess	Nominated children's and young people's health assessor completes four areas of assessment.		
Decision-making phase	3) Recommend	Nominated children's and young people's health assessor prepares recommendations and costed options.	8 working days	9 working days
	4) Decide	Multi-agency forum considers recommendations and costed options and decides on package of continuing care for child or young person where continuing care need is identified.	14 working days	23 working days
Arrangement of provision phase	5) Inform	Child or young person and family, referrer and relevant organisations informed of decision.	5 working days	28 working days
	6) Deliver	Identify provider(s) for package of continuing care/commissioning and implementation of package of continuing care/ongoing training, support and monitoring.	Dependent on complexity, commissioning, Disabled Facilities Grant Funding processes and/or national exemplars	
	7) Review	Re-assessment of child or young person's continuing care needs and appropriateness of package of continuing care should occur three months after initial assessment, then annually as a minimum or sooner as appropriate.	3 months/annually/ as appropriate	

More detailed guidance on each stage of the pathway follows.

STAGE 1: IDENTIFY

A child or young person may reach this stage in a variety of different ways: through sudden unexpected need, through deterioration of a long-term condition or through a congenital disease.

Best practice principle: Identification

Every child or young person with possible continuing care needs requiring a continuing care assessment is identified through an effective referral process. For children and young people who require immediate care, such as end-of-life or palliative care, there is a fast-track process to ensure that their care is not delayed.

Goals

- > Referral can be made from a variety of settings by a variety of people.
- > Children or young people who require fast-tracking because of the nature of their needs, such as a prognosis indicating end-of-life care needs, are identified and referred early, to make sure their needs are met as quickly as possible without having to undergo a full continuing care assessment in the first instance.
- > There is full and active involvement of children, young people and their families in the process.
- > Information should be available for families, and age-appropriate information should be available for children or young people and their families to clarify the process of referral.
- > Families should receive information, training and support to empower and enable them to understand and accept the implications of the child or young person's care needs and to participate in their care.
- > For children or young people being discharged from acute settings, early consideration should be given to whether there is a continuing care need and planning should be developed in collaboration with local care providers.
- > The process should allow for fast-tracking to other more appropriate pathways, e.g. disease-specific pathways.

STAGE 2: ASSESS

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

Best practice principle: Assessment of care needs

Every child or young person should receive an assessment of their holistic care needs carried out by a nominated children and young people's health assessor after it is recognised that they may have continuing care within eight working days of identification.

Goals

- > The assessment will include a health assessment by the nominated children and young people's health assessor who will also collate, or should liaise with the appropriate professionals to instigate, assessments by local authority children's and young people's services on behalf of the commissioners. The holistic assessment of the child or young person and family is based on the outcomes of the health, social and education assessments and carer assessment.
- > The results of any relevant assessments that the child or young person may have undergone already, such as the Common Assessment Framework or specialist assessments, are included in this process.
- > There is identification of children and young people who should be fast-tracked to immediate care.
- > There is full and active involvement of children or young people and their families in the process.
- > Information is available to enable all those involved to understand what is likely to happen. This should be accessible to the child or young person and their family as well as to professionals.
- > Children and young people's continuing care needs are assessed consistently and fairly, irrespective of the reason for their needs or the nature of those needs.
- > Children and young people and their families are kept informed throughout the process, and know the outcome of and reasons behind the assessment.
- > Children, young people and their families are kept informed about the next steps and time-frames to implement the package of continuing care.
- > Assessment of children and young people for continuing care takes account of safeguarding policies and legislation, including the Children Act 2004, which places a duty on all agencies to safeguard and promote the welfare of children and young people.
- > Clear time-frames from referral through completion of assessment to decision within this policy are implemented locally, and targets are audited through local processes.

STAGE 3: RECOMMEND

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.

Best practice principle: Preparation of recommendations

A child or young person and family-centred process that recognises home as the centre of caring, and focuses on the needs of the child or young person and their family and considers sustainability, ongoing training and development, is followed. Costed options for sustainable packages of care should be fully compatible with children and young people's legislation and policy.

Goals

- > The four areas of assessment should provide the base and evidence for each option.
- > Multi-agency and/or multidisciplinary groups should work with the family to support the nominated children and young people's health assessor to produce child or young person and family-centred continuing care options, taking into account the child or young person's and their family's preferences, which are safe and effective.
- > Options considered should be in line with the principles of *Every Child Matters*, the NSF for Children, Young People and Maternity Services, the Children Act 2004 and, where appropriate, *Aiming high for disabled children: better support for families* and *Better Care: Better Lives*.²³
- > Planning of care should be fully integrated and fully utilise existing universal and specialist provision; sustainability of options should be a top priority in option appraisal.
- > Planning should take a team around the child or young person approach rather than focusing on venues of care.
- > In developing options the principle that the home is the centre of caring should be the starting point. 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 should be considered in each proposal.
- > Training costs should be fully considered in setting the care package up and in subsequent years.

²³ DH (2008) *Better Care: Better Lives – Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions*. London: DH.

Best practice principle: Involvement in decision-making

Children or young people and their families should be facilitated to fully take part in decision-making. This includes information giving, listening, discussion and negotiation, and the outcome of the process should be communicated clearly to the family and followed up in writing.

Goals

- > The child or young person and their family should be enabled to contribute their knowledge and experience to the assessment process. There is full and active involvement of the child, young person and their family in the process.
- > The child or young person and their siblings should have access to information appropriate to their age and understanding.
- > Advocates should be readily available to support children or young people to take part in decision-making.
- > Where a child or young person and their family express preferences that are not met, clear reasons should be given to them.
- > Decisions should be given formally in writing to the child or young person and their family or their representative, and should provide a clear rationale and explanation for the decision.
- > The child or young person and their family should be supported to understand the information they receive.
- > The child or young person and their family should have access to interpreters, if needed.
- > The roles of the nominated children and young people's health assessor and multi-agency decision-making forum should be clear.
- > The process should support the personalisation agenda and should be flexible to meet individual needs, while also acknowledging equitable and fair use of resources.

STAGE 4: DECIDE

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. The nominated children and young people's health assessor should also match the four areas of assessment, as far as possible, to the description in the children and young people's Decision Support Tool that most closely relates to the child or young person's specific continuing care needs. This enables the nominated children and young people's health assessor to build up a detailed understanding of the child or young person's needs and provide the evidence to inform the decision on continuing care provision. The children and young people's Decision Support Tool is not prescriptive, and professional judgment should be exercised in all cases to ensure that the child or young person's overall level of need is correctly assessed and that appropriate decisions are made.

Best practice principle: Informing about decisions

Decisions about a child or young person's continuing care are made by a multi-agency decision-making forum and are based on the recommendations and costed options produced by the nominated children and young people's health assessor; the process ensures transparency and equity. A decision should be made within 14 working days of receipt of assessment documentation. Notification of the outcome should be made to family and key professionals within five working days.

Goals

- > The multi-agency decision-making forum should be independent from those involved in assessment.
- > The multi-agency decision-making forum is made up of key PCT and local authority professionals, including commissioners and clinical advisers.
- > The multi-agency decision-making forum should 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.
- > The multi-agency decision-making forum should be allocated dedicated time to support this process.
- > The sustainability of each care option should be considered.
- > Full integration with existing universal and specialist services is a key requisite to be demonstrated by the chosen option.

- > Schools and early years settings should be involved appropriately in the process and informed of the outcome of the assessment.
- > In considering options, the principle that 'home is the centre of caring' should be the starting point. When home care options have been fully considered, including home or residential short-break support, 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.
- > The decision reached should be notified to the child or young person and their family and professionals involved in the process within five working days of the decision being made.
- > Verbal and written reports should be given to the child or young person and their family in user-friendly, non-technical language.
- > Decisions should be recorded and stored in accordance with local record-keeping policy.

STAGES 5 AND 6: INFORM AND DELIVER

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 phase begins, during which the PCT and the local authority should use commissioning resources to make the necessary logistical, contractual and funding arrangements to ensure that provision of the package of continuing care is in place as soon as possible.

Best practice principle: Delivery of care package

Care packages should be sustainable and integrated with existing universal and specialist provision, provided in a timely manner and adaptable to future care needs.

Goals

- > Integration with existing universal and specialist services is a key requisite, which should enhance sustainability and reduce fragmentation of service delivery.
- > Sustainability of services should be constantly considered and reviewed. Early indications from work being undertaken by DH on community children's nursing has demonstrated the advantages of large, multifaceted children's teams in delivering sustainable services.
- > Care management should be integral to care packages.

- > Training of parents, staff and foster carers should be considered as appropriate.
- > Care planning should begin early, consider discharge needs, and be simplified to enable community-based services to provide home-based care wherever possible.

STAGE 7: REVIEW

The child or young person should be reviewed three months after the commissioning decision to establish whether their continuing care needs have changed. Exit from the continuing care pathway occurs in one of two ways: either the child or young person returns to universal or specialist services, including end-of-life services, or they are in transition to adult services.

In instances where the level of continuing care needs has decreased so that transition back into universal or specialist services is appropriate, the child or young person and their family should be supported throughout this transition. As far as possible, the aim throughout the continuing care pathway should be to 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, how it can be treated and how this will affect other areas of their life.

Where a continuing care need is ongoing and the young person is aged 14 or above, transition to adult services should begin to be considered.

Best practice principle: Re-assessing continuing care needs

Every child or young person will be reviewed at a minimum of three months after assessment and then yearly or more often as appropriate. Every child or young person will have, where appropriate, a co-ordinated multi-agency plan for an active transition process to adult or universal services or to a more appropriate care pathway, such as a universal or disease-specific pathway or an end-of-life care pathway, to take place within an agreed time-frame. A care plan is developed to meet the child or young person's individual continuing care needs. A key worker and key worker designate are identified to work alongside the child or young person and their family to facilitate this process.

Goals

- > Children or young people are listened to, involved, encouraged to ask questions and express opinions, and supported to make decisions.
- > When the nature or level of needs changes significantly, a review of the child or young person's needs is made.
- > A multidisciplinary approach is essential.
- > A key worker should be appointed from within the existing care team to manage the process of moving services.
- > Where a child or young person has continuing care needs that require the input of other specialist services, they should be referred to that service for an assessment.
- > Early engagement with other services is essential for proactive planning and ensuring a smooth move to the other service.
- > There is good inter-agency and interdisciplinary co-ordination across statutory, third and independent sectors, and a range of universal, targeted and specialist services.
- > At 14 years of age, the young person is flagged up to adult services.
- > At 16 years of age, screening for adult 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.
- > Full transition to adult NHS continuing healthcare or to adult universal and specialist services should have been made by 18 years of age, except in instances where this is not appropriate as detailed in the section on transition (see page 26).

Annex C: Legal framework

1. Introduction

This section is for reference by commissioners. Its purpose is to identify the main responsibilities of the NHS, primary care trusts (PCTs) and local authorities that are contained in legislation.

1.1 Primary care trust commissioning responsibilities

Primary legislation governing the health service does not use the expression 'continuing care'. However, section 1 of the National Health Service Act 2006 requires the Secretary of State to continue the promotion in England of a comprehensive health service, designed to secure improvement in:

- > the physical and mental health of the people of England; and
- > the prevention, diagnosis and treatment of illness.

Furthermore, the Secretary of State is under a duty to provide services for 'the care of persons suffering from illness and the after-care of persons who have suffered from illness' throughout England, to whatever extent he/she considers necessary to meet all reasonable requirements.

Secondary care commissioning responsibilities have been delegated to PCTs by Regulation 3 of the National Health Service (Functions of Strategic Health Authorities and Primary Care Trusts and Administration Arrangements)(England) (Amendment No. 2) Regulations 2007. *Who Pays? Establishing the responsible commissioner*²⁴ provides guidance on the application of the legal framework to PCTs' secondary care commissioning responsibilities.

PCTs must also have regard to guidance given by the Secretary of State in exercising their functions relating to co-operation with children's services in certain arrangements relating to improving child health well-being. The voices of children, young people and their families are expected to inform local design and delivery arrangements of services. This is re-inforced in *Aiming high for disabled children: better support for families* and in the Local Government and Public Involvement in Health Act 2007.

²⁴ DH (2007) *Who Pays? Establishing the responsible commissioner*. London: DH.

1.2 Children's services

Social services for children in need are mostly provided under section 17 of the Children Act 1989, following an assessment under the *Framework for the Assessment of Children in Need and their Families*.²⁵ The guidance for children under 3 years old who are disabled²⁶ or have complex health needs,²⁷ the *National Service Framework for Children, Young People and Maternity Services*,²⁸ and the *Framework for the Assessment of Children in Need and their Families* expect a comprehensive multidisciplinary needs assessment and joint planning of care with integrated provision to help maximise children and young people's development and achievement in life.

2. Integrated working

2.1 Joint commissioning

The *Joint Planning and Commissioning Framework for Children, Young People and Maternity Services*²⁹ introduces a framework to help local commissioners (both PCTs and local authorities) to design a unified system in each local area for a joined-up picture of children and young people's needs and for collaboration to achieve best use of joint resources for better outcomes. This is reinforced in *Securing better health for children and young people through world class commissioning*³⁰ and under the Apprenticeships, Skills, Children and Learning Act 2009 in relation to Children's Trusts.

2.2 Children Act 2004

Under section 10 of the Children Act 2004, PCTs are under a duty to co-operate with local authorities and other key partners in making arrangements to improve the well-being of children in their population, and must have regard to guidance

²⁵ DH (2000) *Framework for the Assessment of Children in Need and their Families*. London: The Stationery Office.

²⁶ DfES and DH (2003) *Together from the Start – Practical guidance for professionals working with disabled children (birth to third birthday) and their families*. London: DfES and DH.

²⁷ Carlin, J (2005) *Including Me: Managing complex health needs in schools and early years settings*. London: Council for Disabled Children and DfES.

²⁸ DH (2004) *National Service Framework for Children, Young People and Maternity Services*. London: DH.

²⁹ HM Government (2006) *Joint Planning and Commissioning Framework for Children, Young People and Maternity Services*. London: DfES and DH.

³⁰ DH (2009) *Securing better health for children and young people through world class commissioning: A guide to support delivery of Healthy Lives, Brighter Futures: The strategy for children and young people's health*. London: DH.

given by the Secretary of State in exercising their functions in that regard. 'Well-being' is defined by reference to the five key Every Child Matters outcomes. Statutory guidance³¹ sets out examples of the arrangements that authorities could make to give effect to this duty, in terms of joint working at strategic levels as well as in frontline teams.

2.3 Children and Young People's Plan (England) Regulations 2005³²

Joint working embraces joint assessment of population need, joint planning and joint commissioning with pooled budgets, setting priorities and providing the necessary resources. The Children and Young People's Plan is an important tool in driving forward better local integration of local authorities and the development of local partnership arrangements.³³ *Healthy Lives, Brighter Futures: The strategy for children and young people's health* sets out how agencies will work together to build the quality of support for families at key stages in their children's lives.³⁴

2.4 Local Government and Public Involvement in Health Act 2007

The voices of children, young people and their families are expected to inform local design and delivery arrangements of services. This is reinforced in *Aiming High for Disabled Children* and in the Local Government and Public Involvement in Health Act 2007, which allows for the establishment of Local Involvement Networks or LINKs, which are set up to scrutinise and monitor health services and represent users' views. The *Joint Planning and Commissioning Framework for Children, Young People and Maternity Services* sets out the processes for commissioning integrated and well-designed services for children and young people. *The Commissioning Framework for Health and Well-being*³⁵ re-affirms the need for momentum in joint commissioning in children's services.

2.5 National Health Service Act 2006

PCTs have a duty in regulations made under section 244 of the National Health Service Act 2006 to consult with local authority overview and scrutiny committees at a formative stage on any proposed changes to the provision of local health services. This consultation with local authorities is required where PCTs have under consideration any proposal for a substantial development of the health service in

³¹ DfES (2008) *Children Trusts: Statutory guidance on inter-agency cooperation to improve well-being of children, young people and their families*. London: DfES.

³² SI 2005/2149. These Regulations were amended by the Children and Young People's Plan (England) (Amendment) Regulations 2007 (SI 2007/57).

³³ DfES (2009) *Guidance on the Children and Young People's Plan*. London: DfES.

³⁴ DCSF and DH (2009) *Healthy lives, brighter futures: The strategy for children and young people's health*. London: DCSF and DH.

³⁵ DH (2007) *Commissioning Framework for Health and Well-being*. London: DH.

the local authority's area, or a substantial variation in the provision of such service. Overview and scrutiny committees can refer proposals they are unhappy with to the Secretary of State for decision.

In addition, regarding health services for which they are responsible, NHS bodies have a duty under section 242 of the National Health Service Act 2006 to make arrangements to ensure that users of services are, either directly or through representatives, involved in:

- > planning of the provision of health services;
- > the development and consideration of proposals for changes in the way those services are provided, if implementation of the proposal would have an impact on the manner in which services are provided or the range of services available; and
- > decisions to be made by the NHS body affecting the operation of those services, if the decision would have an impact on the manner in which services are provided or the range of services available.

2.6 Safeguarding

Assessment of children, young people and their families for continuing care should take account of safeguarding policy and legislation. The Children Act 2004 places a duty on all agencies to safeguard and promote the welfare of children and young people; those children who are being considered for continuing care may be especially vulnerable to abuse. Further information can be found in *Working Together to Safeguard Children*³⁶ and *Safeguarding Disabled Children: Practice Guidance*,³⁷ following an assessment under the *Framework for the Assessment of Children in Need and their Families*.³⁸

2.7 Disability Discrimination Act 1995

The Disability Discrimination Act 1995 makes it unlawful to discriminate in relation to the provision of services against disabled people, including disabled children. For this purpose, a child has a disability if they have a physical or mental impairment that has a substantial long-term adverse effect on their ability to carry out normal day-to-day activities. Service providers have a duty under this Act to take reasonable steps to remove or alter physical barriers and to take reasonable steps to change practices, policies or procedures which make it impossible or unreasonably difficult for disabled people to use a service. Service providers should also take reasonable steps to provide auxiliary aids or services which enable disabled people to use a service or facilitate the use of such a service.

³⁶ DH (2010) *Working Together to Safeguard Children: New government guidance on interagency co-operation to protect and promote the welfare of children*. London: DH.

³⁷ DCSF (2009) *Safeguarding Disabled Children: Practice Guidance*. London: DCSF.

³⁸ DH (2000) *Framework for the Assessment of Children in Need and their Families*. London: The Stationery Office.

Annex D: Summary of the Haringey case

A summary of the judgment in *R (on the application of D and another) v Haringey London Borough Council*³⁹ ('the Haringey case') is presented here for reference. PCTs and local authorities should take into account this piece of case law in their processes for deciding on and putting in place packages of continuing care.

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

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

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

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

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

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

- > the purpose of the care – although this was described as respite care and therefore might be considered social care to assist the child's mother, its real purpose was to deal with the 'continuing medical consequences of an operation, which if not met will give rise to urgent or immediate medical needs', i.e. to provide medical care for the child. The advice on management of the care was provided by a hospital and the training by medically qualified persons;
- > the gravity of the consequences of a failure in care and duration of the care need meant that it was more a medical service provision than a social services provision; and
- > with the exception of the child's mother, who had received the required training, the service had been provided by nurses who themselves required training in tracheostomy care. Therefore, while it was possible for others to be trained in providing the care, it was clearly an important medical procedure in which people were trained.

Mr Justice Ouseley therefore held that HLBC did not have a duty to provide the respite care under section 17 of or Schedule 2 to the Children Act 1989 because these provisions did not extend to medical treatment of the nature envisaged. He commented that 'provisions in the Children Act are not to be regarded in general as reducing or replacing the important public obligations, with their qualifications and their target nature, set out in the NHS Act 1977 [now the NHS Act 2006]... Children Act nursing care provision is only that which properly falls outside the scope of the NHS'. He further commented that interpreting these provisions broadly to cover what are essentially medical needs would turn the social services authority into 'a substitute or additional NHS for children'.

With regard to sections 2 and 28A of the Chronically Sick and Disabled Persons Act Act 1970, he commented that, for the same reasoning that applied to the Children Act 1989, he did not consider that those sections 'should be given so wide an interpretation as would cover the day or night respite care' and that, although respite care 'can be seen as practical assistance' in the home in the context of those provisions (sections 2 and 28A of the 1970 Act), and with the broad health and social services division in mind, 'that phrase is not apt to include this nursing care'.

Annex E: Steering Group

Name	Title	Organisation
Jane Appleby	Lead for Children, Child and Adolescent Mental Health Services and Safeguarding	NHS East Midlands Strategic Health Authority (SHA)
John Ashcroft	Professional Adviser	Department of Health (DH)
Dr Ginny Bennett	Medical Adviser	Stillpoint Practice
Karen Brombley	Lead Nurse for Children with Complex Health Needs	Oxfordshire Primary Care Trust (PCT)
Jane Carter	Head of Disability, Inclusion, Sensory, Communication Service and Integrated Disability Service	Warwickshire Local Government
Angela Glew	Continuing Care Lead for Change Agent Team (CAT)	DH
Christine Lenehan	Director	Council for Disabled Children
Nyree Hulme	Research Administrator	Centre for Health-Related Research
Mary Lewis	Chief Nurse	Bath and North East Somerset PCT
Dr Rebecca Lloyd	Child Health Strategy Manager	DH
Katrina McNamara-Goodger	Head of Policy and Practice	ACT
Liz Morgan	Professional Adviser, Children and Young People – Nursing	DH
Michelle Morris	Head of Speech and Language Therapy	Salford PCT
Jacqueline Naylor	Head of Ill and Disabled Children Team	DH
Pat Nicholls	Policy Lead	DH
Prof. Jane Noyes	Chair in Nursing Research	Centre for Health-Related Research
Heather Sahman	Programme Manager, Children	East Midlands SHA

Name	Title	Organisation
Sue Sylvester	Children, Young People and Maternity Lead	South Central SHA
Dr Angela Thompson	Associate Specialist, Paediatrics	North Warwickshire PCT
Gail Trembl	Special Educational Needs Professional Adviser	DfES
David Vickers	Consultant Paediatrician	South Cambridgeshire PCT
Mark Whiting	Consultant Nurse, Children with Complex Health Needs	Hertfordshire Partnership NHS Trust
David Widdas	Consultant Nurse, Children with Complex Health Needs	Warwickshire Community Health

Glossary

Assessment

A multi-agency process whereby 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 recording the reason why a package of continuing care is being provided, its contents and its intended outcomes.

Carer

A carer spends a significant proportion of their life providing unpaid support to family or sometimes friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.

Child or young person

In relation to the National Framework for Children and Young People's Continuing Care, a child or young person is a person under the age of 18.

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.

Children and young people's Decision Support Tool

The children and young people's Decision Support Tool is part of the children and young people's continuing care assessment process. Once completed by the nominated children and young people's health assessor, it can be used by the multi-agency decision-making forum, together with the health assessor's recommendations, to make a decision as to whether a child or young person has a need for continuing care and, if so, what package of continuing care should be provided. It will be for PCTs and local authorities to decide what contribution each will make towards a package of continuing care. The children and young people's Decision Support Tool is the fourth area of the assessment phase and 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. The tool is not prescriptive, and professional judgement should be exercised in all cases to ensure that the child or young person's and their family's overall level of need is correctly assessed.

Children's Trusts

Children's Trusts bring together all services for children and young people in an area, underpinned by the duty under the Children Act 2004 to co-operate, to focus on improving outcomes for all children and young people. The terms 'Children's Trust' and 'Children's Trust arrangements' also include the concept of the totality of change needed to deliver better and more responsive integrated services.

Commissioning

The process that primary care trusts (PCTs) and local authorities use to secure the best care and best value for local citizens. It is the process of specifying and procuring services for individuals and the local population, and involves translating their aspirations and needs into services that:

- > deliver the best possible health and well-being outcomes, including promoting equality;
- > provide the best possible health and social care provisions; and
- > achieve this with the best use of available resources.

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.

Core Offer

The Aiming High for Disabled Children Core Offer sets out in one place a national statement of expectations for how disabled children and their families will be informed and involved as their needs are assessed and the necessary services are delivered.

End-of-life and palliative care

Palliative care for children and young people with life-limiting conditions is an active and holistic approach to care, embracing physical, emotional, social and spiritual elements. It focuses on the enhancement of quality of life for the child or young person and support for the family, including the management of distressing symptoms, the provision of short breaks, and care through death and bereavement.

Key worker designate

The link person in an adult service who works closely with local authority key workers and through whom adult services can be effectively accessed.

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 a key element of effective frontline delivery of integrated services. It ensures that professional involvement is rationalised, co-ordinated and communicated effectively. More importantly, it provides a better experience for children, young people and their families involved with a range of agencies.

Multi-agency decision-making forum

The multi-agency decision-making forum will comprise professionals from different disciplines, i.e. from both PCTs 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 PCT and the local authority to decide what services each will commission and fund.

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 the PCT 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

All the rights, duties, powers, responsibilities and authority that by law a parent of a child has in relation to the child and his/her property. Throughout the document, references to 'family' includes those with parental responsibility.

Personal health budget

An amount of money allocated to meet a child or young person's health and well-being 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. PCTs are able to offer personal health budgets that do not involve giving money directly to individuals. Once the pilot programme of direct payments has begun, where a pilot scheme is in force a parent, person with parental responsibility or young person may be given money to enable them to secure the healthcare services they need.

Responsible commissioner

The PCT that discharges the Secretary of State's functions under the National Health Service Act 2006 for an individual patient. Secondary care commissioning responsibilities have been delegated to PCTs by Regulation 3 of the National Health Service (Functions of Strategic Health Authorities and Primary Care Trusts and Administration Arrangements) (England) (Amendment No. 2) Regulations 2007.

Specialist services

Health services which are specialised and target specific groups. Examples are Community Children's Nursing and Child and Adolescent Mental Health Services.

Universal services

Health services that are available to the general population.



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