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Consultation Document

Children and Young People's Continuing Care Guidance

Date of issue: **20 December 2011**

Action required: Responses by **13 March 2012**

Children and Young People's Continuing Care Guidance

- Overview** This consultation invites views and comments on the Welsh Government's draft guidance on Children and Young People's Continuing Care.
- How to respond** Response forms can be sent to the following address:
Adults and Childrens Health
Medical Directorate
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

Or completed electronically and sent to:
adultsandchildrenshealth@wales.gsi.gov.uk.
- Further information and related documents** Large print, Braille and alternate language versions of this document are available on request.

The consultation documents can be accessed on the Welsh Government website at www.wales.gov.uk/consultations
- Contact details** For further information:
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Adult and Children's Health Services Branch
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Tel: 029 2082 5840

Data protection

How the views and information you give us will be used.

Any response you send us will be seen in full by Welsh Government staff dealing with the issues which this consultation is about. It may also be seen by other Welsh Government staff to help them plan future consultations.

The Welsh Government intends to publish a summary of the responses to this document. We may also publish responses in full. Normally, the name and address (or part of the address) of the person or organisation who sent the response are published with the response. This helps to show that the consultation was carried out properly. If you do not want your name or address published, please tell us this in writing when you send your response. We will then blank them out.

Names or addresses we blank out might still get published later, though we do not think this would happen very often. The Freedom of Information Act 2000 and the Environmental Information Regulations 2004 allow the public to ask to see information held by many public bodies, including the Welsh Government. This includes information which has not been published. However, the law also allows us to withhold information in some circumstances. If anyone asks to see information we have withheld, we will have to decide whether to release it or not. If someone has asked for their name and address not to be published, that is an important fact we would take into account. However, there might sometimes be important reasons why we would have to reveal someone's name and address, even though they have asked for them not to be published. We would get in touch with the person and ask their views before we finally decided to reveal the information.

What are the main issues?

The draft guidance 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 LHBs and local authority Social Services and Education departments and their partners, should work together to assess need and put in place packages of continuing care. It should be read by all those with responsibility for planning and providing continuing care to children and young people.

The document does not provide guidance on the content or funding of the actual packages of continuing care. It is not a prescriptive tool, and cannot replace the need for strong local decision making regarding the continuing care needs of individual children and young people which must be based on assessed needs. Rather, use of the Guidance will help agencies ensure that:

- Children, young people, their families and carers are actively engaged in the continuing care process.
- The continuing care process is co-ordinated and consistent between organisations.
- Health, education and social care practitioners, (including those working in the independent and third sectors), and service users, understand the continuing care process and use it effectively.

Where are we now?

An informal consultation document on Children and Young People's Continuing Care issued on 31 March 2011, under cover of a letter from the Chief Executive NHS Wales, to a range of stakeholders inviting comments by 23 May.

The letter advised responsible organisations that until definitive guidance was issued the draft guidance contained in the informal consultation document should be used.

As a result of the informal consultation further refinements have been made to the document and the Welsh Government is now seeking views from a wider audience.

The need for change

Assessing and providing the continuing care that disabled children need to live independent and fulfilled lives is a complex issue and there are inconsistencies of approach when assessing an individual's needs and a lack of clarity around the responsibilities of agencies involved in planning and providing children's continuing care services.

The Welsh Government is seeking views and comments on the draft guidance which will make the needs assessment process more effective and prompt.

Proposals

The children and young people's continuing care process should:

- Adhere to a set of core values, promoting children's rights, with consistent key principles and timetables.
- Make the child or young person and their parents and carers the focus of the continuing care process.
- 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 multiple or repeated assessment or fragmented care.
- Include measurement of outcomes and promote continuous quality improvement.
- Recognise language as a care need.

Executive summary

The Children and Young People's Continuing Care Guidance (the Guidance) is designed for use by all those planning and providing children's continuing care services in Local Health Boards (LHBs) and local authorities and their partners.

It describes the interagency process, led by LHBs, that all organisations should implement 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.

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- 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 multiple or repeated assessment or fragmented care.
- Include measurement of outcomes and promote continuous quality improvement.
- Recognise language as a care need.

This document does not give guidance on the content or funding of the actual packages of continuing care. It is not a prescriptive tool, and cannot replace the need for strong local decision making regarding the continuing care needs of individual children and young people which must be based on assessed needs. Rather, use of the Guidance will help agencies ensure that:

- Children, young people, their families and carers are actively engaged in the continuing care process.
- The continuing care process is co-ordinated and consistent between organisations.
- Health, education and social care practitioners, (including those working in the independent and third sectors), and service users, understand the continuing care process and use it effectively.

Adult Continuing NHS Healthcare

Guidance on Adult Continuing NHS Healthcare – “The National Framework for Implementation in Wales (Welsh Assembly Government Circular 015/2010 was issued in May 2010 and replaces *NHS Responsibilities for Meeting Continuing NHS Health Care Needs (2004)*, supported by the *Continuing NHS Health Care: Framework for Implementation in Wales 2004*.”

The 2010 guidance for adults makes it clear that guidance on the assessment and provision for care for children and young people will be addressed separately as there are different requirements.

Children and Young People with Additional Learning Needs

Professionals should be aware that there is continuing development work reforming the processes associated with Additional Learning Needs (ALN) and that the Continuing Care Guidance is consistent with this. The general direction of change of the ALN process is of assuring the rights of the child, including their health, well-being and participation are taken into consideration and that all children and young people should have the opportunity to benefit from inclusive and personalised learning in whatever setting they are educated. The challenge is to improve the capacity of the system to enable all children and young people to achieve their potential.

The development of a web based Individual Development Plan, which is being trialled, would ensure that a multi-disciplinary approach is taken in relation to meeting the additional needs of children and young people, some of whom have severe and complex needs. This model will be robustly trialled as the intention is better outcomes should be gained in meeting the needs of the child or young person, their families/carers, the organisations involved ie education, health, social services, other partners and the community.

The pilot work will be fully evaluated prior to any legislative change required but officials and Ministers are looking for opportunities to implement changes which can be effected quickly, such as improved multi-agency management of provision for this group of young people. This will need a collaborative approach and officials from within Health, Education and Social Services Departments of the Welsh Government are working closely to ensure those connections are made.

On a general point, and with regard to requests for Further Education placement funding for young people aged 16 and over, health and social care must make all reasonable efforts to assess and meet the health needs of this vulnerable group of young people, even if they are assessed as not having continuing care needs. The aim is to ensure that a consistent package of support is provided during the years before and after transition to adulthood.

Rights of Children and Young Person's (Wales) Measure

The 'Rights of Children and Young Person's (Wales) Measure', received unanimous cross party support at the National Assembly for Wales on the 18 of January 2011. It then received 'Royal Approval' on 16 March, and came into force in May 2011.

This is a landmark achievement in Wales to embed the principles of the United Nations Convention on the Rights of the Child (UNCRC) in Welsh law. This builds upon the previous commitment to using the UNCRC as the basis of the Welsh Government's work with children and young people made in January 2004, by placing a duty on Welsh Ministers to have due regard to the substantive rights and obligations within the UNCRC and its optional protocols:

- a) When making any decision relating to developing policy and legislation between 1st May 2012 – 30th April 2014, and then;
- b) When exercising their functions from 1st May 2014.

The Children's Continuing Care Guidance has been written with due regard to these principles.

1. Introduction

1. This Guidance 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 LHBs and local authority Social Services and Education departments, should work together to assess need and put in place packages of continuing care. It should be read by all those with responsibility for planning and providing continuing care to children and young people.

2. In some areas, strong local co-ordination of the continuing care process may already be happening. This Guidance is designed to build on existing good practice where it exists 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 parents, is at Annex B.

4. The Guidance comprises 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 transition 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 assist local decision making about the care that is needed.
- A continuing care pathway to help plan, design, deliver and evaluate services.
- Details of the legal framework for children and young people's continuing care.

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 illness that cannot be met by existing universal or specialist services alone. Children and young people with care needs that may be met appropriately through existing universal or specialist services should have their needs addressed using a case management approach.

6. Continuing care is organised differently for children and young people compared with 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 by the NHS 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.

7. 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 or up to the age of 19 if a child has a SEN statement) 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 carers, and professionals, is a particularly important aspect.

8. 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 services or care: predominantly health, social care and education. It is likely that a continuing care package will include a range of services planned and delivered by LHBs, local authority children's services and sometimes others.

9. Many parents and carers are trained by professionals to undertake tasks/procedures that would in the case of adults be undertaken by or under the supervision of professionals. It cannot be assumed, however, that all parents or carers will be able to undertake these tasks/procedures, and the continuing care assessment will need to take account of parents' and carers' capacity to assume responsibility for these, including consideration of training, updating and public liability insurance.

10. In determining the level of care/support required it must not be assumed that the tasks undertaken by parents can be transferred to untrained carers. This is particularly relevant when considering the provision of respite care or short breaks for children with continuing care needs. Lack of training and support for relevant skills may severely limit the uptake of respite care services.

1.2 The leadership role of the Local Health Board

11. Primary legislation governing the health service does not use the expression 'continuing care'. However, section 1 of the National Health Service (Wales) Act 2006 requires Welsh Ministers to continue the promotion in Wales of a comprehensive health service, designed to secure improvement in:

- The physical and mental health of the people of Wales.
- The prevention, diagnosis and treatment of illness.

12. Furthermore, Welsh Ministers are 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 Wales, to the extent they consider necessary to meet all reasonable requirements.

13. All agencies, Health, Education and Social Care have a clear role in providing services for these children. However for the purposes of the continuing care process LHBs are responsible for leading the interagency process set out in this guidance, mindful that a child or young person with continuing care needs may require services planned and delivered by the LHB, Social Services, Education and Housing departments and a range of other partners. Where a child or young person requires services delivered by multiple organisations, the LHB is responsible for leading the planning and delivery of the care process, involving other partners as appropriate. The continuing care assessment will be informed by a core assessment undertaken by children's social care services in line with the requirements of the Assessment Framework as well as the statement of educational needs where one exists.

14. LHBs 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.
- Promoting awareness of the Guidance.
- Ensuring flexibility to shape strategic planning 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.

15. 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, education or care setting.

16. 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. Whatever model is used, there must be robust arrangements to ensure timely decision making about funding. It is unacceptable for care to be delayed due to interagency disputes about share of funding.

17. 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 and carers, takes place in a consistent and open manner.

Vulnerable Children and Young Persons placed Out of Area

18. If a vulnerable child is to be placed away from home the responsible Local Health Board must make arrangements compliant with the regulations and guidance set out in "Towards a Stable Life and a Brighter Future" (Placement of Children (Wales) Regulations 2007 and Local Health Boards (Functions) (Wales) (Amendment) Regulations 2007) - co operating in the best interest of the child with Welsh Health Specialised Services Committee (WHSSC) where appropriate. Arrangements must be in place to meet the healthcare needs of the child - including primary, secondary or tertiary needs. There must be in place processes that consider future arrangements for transition to adult services.

19. LHBs retain responsibility for certain categories of young persons placed out of area up to the age of 21, providing they were in one of the categories below immediately before reaching the age of 18:

- Children looked after by a local authority.
- Care Leavers.
- Children subject to a Special Guardianship Order – or who were looked after by a local authority after the age of 16 years.
- Children resident at a school named in their SEN statement.
- Children with on-going health needs on longer term placements.

20. All care packages will need to ensure that there are appropriate safeguards in place to protect the child, according to local policies and procedures.

21. If a child is placed away from the area where they are ordinarily resident the placing responsible authority will need to notify the local authority of the receiving area, the child's general practitioner and also any general practitioner who the child will be registered with following the placement. In respect of "looked after" children these arrangements will be made in conjunction with the local authority that has parental responsibility.

22. If the NHS has arranged a care package which requires the child to be accommodated for three months or more in a hospital or specialist residential placement, the NHS has a duty under section 85 of the Children Act 1989 to notify

the relevant local authority (Visits to Children in Long Term Residential Care Regulations 2011).

The Belonging Regulations (Education)

23. Whenever a package is being developed for a child or young person where the provision of education is included, consideration needs to be given to the “Education (Areas to Which Pupils and Students Belong) Regulations 1996”, as amended by the “Education (Areas to Which Pupils and Students Belong) (Amendment) (Wales) Regulations 2009”. These are commonly known as the ‘Belonging Regulations (Education)’, but will be referred to in this section as ‘The Regulations’.

24. The Belonging Regulations were introduced to help Education Authorities to estimate the number of pupils resident in their area, in order to plan their budgets effectively. They were also brought in to make clear where financial responsibilities lie in cases of pupils requiring specialist education that have been placed out of area, so that costs can be recouped.

25. These Regulations set out the general principle that for the purposes of education provision, a child is treated as belonging to the area in which he is ordinarily resident. Where the child has no ordinary residence, he assumes the ‘ordinary residence’ and becomes the responsibility of the area of the authority in which he currently resides. The exception to this principle is where a child is ‘Looked After’ by a Local Authority under the auspices of a Care Order, and has been placed with a Foster Carer (who is not a relative). In this situation, Regulation 105(6) of the Children Act 1989 comes into force and stops the child from assuming the ordinary residence status of his foster carer. This means that until the Care Order is discharged, Reg 7 of the Belonging Regulations applies.

26. Recoupment of costs for education provision may be voluntary or mandatory. Voluntary recoupment will occur where agreements have been arrived at between authorities. Mandatory recoupment will occur in situations where the costs of provision of education to a pupil are unusually high as may frequently be the case for specialist education. Pupils who fall into the mandatory category include those that:

- Attend special schools.
- Have a statement of Special Educational Need.
- Receive education in hospital.

27. In all cases, the authority providing the education is entitled to recoup the cost from the authority to which the pupil belongs. Where there is a need for specialist provision, Regs 4 to 7 set out where financial responsibility lies. This is determined based on the circumstances of the provision and where the person responsible for the pupil is “ordinarily resident”. Where there is no person responsible for the pupil, depending on the circumstances of the provision, the pupil will belong to the area in which either:

- The person who has care of the pupil is ordinarily resident.

- The hospital that they are a patient is situated.
- The Education Authority that is maintaining their SEN Statement falls.

However, in cases of Looked After Children who fall into the categories mentioned in para 26, the child will **always** belong to the area of the Local Authority which is looking after them.

28. The term 'Ordinarily Resident' is defined in Reg 2(2) and states that it is the area in which a person habitually and normally resides (barring temporary or occasional absences), with the exception of pupils studying at boarding schools, who would retain the ordinary residence of the area in which the person responsible for them resides. The reference to the person responsible for a pupil is also defined in Reg 2(3).

2. The continuing care process

This section gives an overview of the principles by which service planners and providers should design and deliver a continuing care pathway for a child or young person and describes in detail each phase of the process.

2.1 Overview

29. The continuing care process is a three-phase activity which LHBs, 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.

30. The first stage is assessment and is led by a nominated children and young people's health assessor. Of the four areas considered in the assessment evidence is first gathered in three areas regarding:

- The preferences of the child or young person and their family/carer.
- Holistic assessment taking account of the Carer's assessment undertaken by Social Services as part of the Core assessment process of the child or young person and their family/carer.
- Reports and risk assessments from the multidisciplinary team.

The information is then collated in the fourth area:

- The children and young people's Decision Support Tool (see Annex A).

31. The outcome of the assessment 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 planning and funding arrangements.

32. The next step is decision-making and usually involves a multidisciplinary, multi-agency forum to decide whether or not the child or young person has a continuing care need. They decide on the nominated health assessor's recommendations and costed options. Planners will then use this information to decide how the continuing care will be provided, what resource is required to deliver it and what needs to be specially planned.

33. After a decision has been taken regarding a package of continuing care, the LHB, local authority and partners will undertake planning and delivery to put it in place. They will also need arrangements for regular review to ensure that the child's evolving needs are met.

2.2 Principles

34. This section sets out the core values and key principles which LHBs, 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 Guidance 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.

35. The children and young people's continuing care process should include:

- Clinical effectiveness.
- Patient safety.
- The experience of the child or young person and their parents.

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 parents of their support needs, and their preferences in having those needs met, should be at the heart of the continuing care process. The rights of the child, and the wishes and expectations of the parents and carers of how and where 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.

36. The child or young person and their parents/carers 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.

37. 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.
- Ensure that quality of life is maintained for the family as a whole.

38. Where the views of the child or young person are different from those of their parents, the possibility of advocacy should be discussed.

39. The continuing care process should be:

- Fair.
- Consistent.
- Transparent.

- Culturally sensitive, and
- Non-discriminatory.

40. 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.

41. 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.

42. 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, FE or specialist FE 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.

43. 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.
- Appropriate referrals to or input from specialist assessments, such as those by Child and Adolescent Mental Health Services, are made.

44. LHBs should identify a named first point of contact for the planning and delivery 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.

45. 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.

46. Where a child or young person is found not to have a need for continuing care, a clear explanation of the rationale for this should be provided to the child or young person and parents/carers. In this instance, their needs should be addressed through existing universal and specialist services using a case management approach.

47. 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 parent's preferred option for either delivery or content, a clear explanation of the rationale for the package should be provided. If the child or young person and their parents do not agree with the decision and explanation provided, they should follow their LHB's local complaints procedure.

48. 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 plan and deliver care is not indefinite as needs may change; this should be clear to the child or young person and their parents.

49. 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 requirements 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 Timelines

50. A clear timeline is important because it is in the best interest of the child or young person and their parents 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, 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.

51. Provision of a package of continuing care should occur as soon as possible following a multi-agency decision-making panel and the child or young person and family being informed.

52. 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.

53. Diagram 2 in Annex B outlines the indicative timescales for each phase of the children and young people's continuing care pathway.

2.4 Assessment phase

54. 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.

55. 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. Children with continuing care needs will often have had a range of other individual assessments, including a core assessment undertaken by Social Services special assessments and an assessment of children's specialist educational needs. The results of these should inform both the assessment and decision-making processes of the child or young person's continuing care assessment.

56. The nominated children and young people's health assessor should lead the assessment phase of the continuing care process on behalf of the providers. 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 Guidance, 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/carers.
- Working with children and young people and their families/carers.

The assessor should also have highly developed listening skills and an understanding of planning and delivery of service.

57. 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.

58. There are four areas of the assessment phase, which LHBs, 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 parents/carers.
- Holistic assessment of the child or young person and their parents/carers.
- 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 A).

59. 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 parents/carers**

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 providers 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**

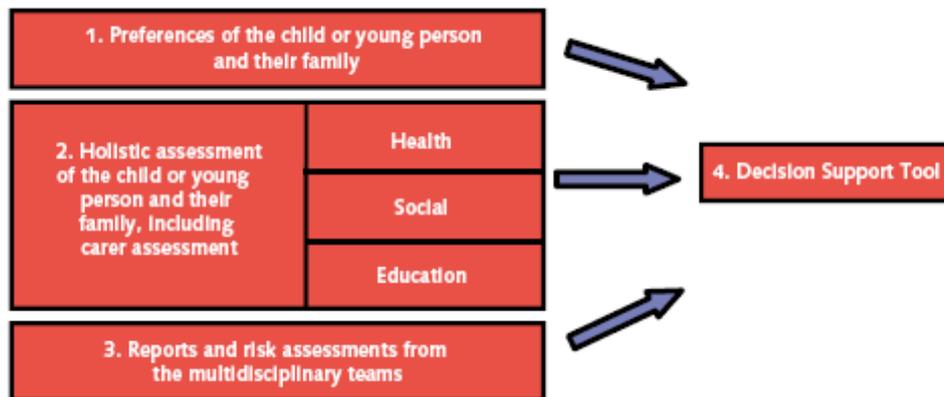
In the third area, the nominated children and young people's health assessor is responsible for undertaking any necessary healthcare risk assessments that have not already been undertaken and collating the relevant risk assessments and reports (health, social and education).

- **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.

60. **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



61. 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.

62. 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 parents 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.

63. The input of the third sector should be considered in the assessment phase, as appropriate.

64. 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.

65. 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.

66. 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.

67. Exceptionally, information may be withheld from a child or young person or someone with parental responsibility for him/her if the LHB 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.

68. 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.

69. 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.

2.5 Decision-making phase

70. Decisions about the planning and delivery 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.

71. 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 planning and funding 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 LHBs 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.

72. 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.

73. 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.

2.6 Arrangement of provision phase

74. After a decision has been taken and communicated, LHBs 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. 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 family being informed.

2.7 Review & Dispute Resolution

75. 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.

76. 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 planners 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. Given the particular needs of children it is advisable that LHBs and local authorities work together on a regional or sub-regional basis on the establishment and management of the review process.

77. 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 parents 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.

78. Any such review should be transparent, involve the child or young person and their parents/carers 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.

79. 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 parents should be supported throughout this transition.

2.8 Complaints

80. Specific guidance has yet to be issued to the NHS regarding the management of complaints by children, although some work has been carried out on this for the LHBs in North Wales by Children in Wales. In any event the NHS complaints procedure is applicable for children as it is for adults. In addition the complaints procedures of other agencies are also applicable. Children who wish to make a complaint should have information on advocacy services and access to an advocate if they wish.

2.9 Dispute Resolution

81. LHBs and Local Authorities will need to develop procedures for dealing with disputes that arise out of a lack of agreement on funding responsibility. These disputes are usually between the NHS and local authorities but they might in some circumstances be between different NHS bodies i.e. LHBs, WHSSC. Resolving commissioning arrangement disputes removes the potential barriers to effective care for vulnerable categories of children who have complex needs and require secondary/specialist health intervention. A dispute resolution protocol is set out in Towards a Stable Life and a Brighter Future.

82. Every effort should be made to resolve these as quickly as possible. The framework for adults has provided an example of a dispute procedure between funding agencies. In any event the interests of the child must be paramount and no child should be denied access or have access to appropriate health care delayed as a result of a dispute.

83. In instances where the complaint relates specifically to local authority children's and young people's services, the LHB will act as the designated first point of contact for children or young people and their families and co-ordinate as appropriate.

84. There should be no gaps in responsibility – no treatment should be refused or delayed due to uncertainty or ambiguity as to which LHB is responsible for funding an individual's healthcare provision.

2.10 Transition from child to adult services

85. Transition is an area that can cause great distress for children their parents and carers. When some children move from children services to adult services they experience uncertainty about future care provision and support and also the loss of income due to changes in benefits.

86. The National Service Framework (NSF) for Children, Young People and Maternity Services has identified a standard for interagency collaboration in the development of systems for identifying children in the year before their 14th birthday, who may require services as adults.

87. Specific actions in the NSF require the identification by agencies of a key transition worker, the provision of information to the young person to help them make

decisions about their future and the development of a joint organisations transition plan that is reviewed 6 monthly. Both children and adult services should be involved in the transition planning process. Information from transition plans should inform the development of individual adult care plans. Aggregated information should be collated in such a way that Health Social Care and Well-Being Plans for adults may anticipate future needs.

88. All LHBs should ensure that they are actively involved, with their partners, in the strategic development and oversight of their local transition planning processes, and that their representation includes those who understand and can speak on behalf of Adult Continuing Healthcare (CHC). LHBs should also ensure that adult CHC is appropriately represented at all transition planning meetings to do with individual young people whose needs suggest that there may be potential adult CHC eligibility. Local authorities and LHBs should have systems in place to ensure that appropriate referrals are made whenever either organisation is supporting a young person who, on reaching adulthood, may have a need for services from the other organisation.

89. It is best practice that future entitlement to adult CHC should be clarified as early as possible in the transition planning process, especially if the young person's needs are likely to remain at a similar level into adulthood.

90. At the age of 17, eligibility for adult CHC should be determined in principle by the relevant LHB, so that, wherever applicable, effective packages of care can be planned in time for the individual's 18th birthday (or later, if it is agreed that it is more appropriate for responsibility to be transferred then). If needs could change, it may be appropriate to make a provisional decision, and then to recheck it by repeating the process as adulthood approaches.

91. Entitlement to adult CHC should initially be established using the decision-making process set out in the 2010 Framework, including the use of the Adult Decision Support Tool. The decision on eligibility should be made using the relevant LHB's usual CHC decision-making processes. The health plans and other assessments and plans developed as part of the transition process will provide key evidence to be considered in the decision-making process. Any entitlement that is identified by means of these processes before a young person reaches adulthood will come into effect on their 18th birthday, subject to any change in their needs.

92. Young people who require continuing services, such as those who are disabled or chronically ill, young people with persistent mental illness or disorders, vulnerable young people and their families and carers, and care leavers, are offered a range of co-ordinated multi-agency services, according to assessed need, in order to make effective transitions from childhood to adulthood.

93. Even if a young person is not entitled to adult CHC, they may have certain health needs that are the responsibility of the NHS. In such circumstances, LHBs should continue to play a full role in transition planning for the young person, and should ensure that appropriate arrangements are in place for services that meet these needs to be planned or provided. The focus should always be on the individual's desired outcomes and the support needed to achieve these.

94. A key aim is to ensure that a consistent package of support is provided during the years before and after the transition to adulthood. The nature of the package may change because the young person's needs or circumstances change. However, it should not change simply because of the move from children's to adult services or because of a switch in the organisation with planning 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 of the need for adult health and social care services, including the funding responsibilities.

95. Transitional arrangements with key milestones should be identified in care plans and LHBs must work with their partner and with the young person and their family/carer to agree a process for transition from children's services into adult services.

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 assessors to guide their work in this phase, and by planners 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 child or young person's needs.

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. LHBs 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 LHBs and specialist children's hospitals/units 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 (including challenging behaviour)** - 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 standards, particularly the following:

- Chapter 2 – Child and Family Centred Services Standard - Children, young people and their families receive services that meet their particular needs. They are treated with respect by service providers and are provided with information and support appropriate to their needs and ability that assists them in making decisions about the care that they receive.
- Chapter 5 – Access to Services Standard - All disabled children and their families receive accessible information about, and equitable and prompt access to, high quality co-ordinated services appropriate to their assessed needs
- Chapter 5 – Transitions Standard. Young people who require continuing services, such as those who are disabled or chronically ill, young people with persistent mental illness or disorders, vulnerable young people and their families and carers, and care leavers, are offered a range of co-ordinated multi-agency services, according to assessed need, in order to make effective transitions from childhood to adulthood.

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

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. 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.

6. 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.

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

7. 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 consulting and using existing assessments by local authority children and young people's services on behalf of the planners, 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.

8. 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 Guidance.

Area 3: Reports and risk assessments from the multidisciplinary team

9. 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.

10. 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.

11. 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.

12. Reports may be obtained from the following to assist multidisciplinary:

- Hospital consultants/specialists
- Specialist nurses assessments
- Therapists/general practitioners
- Community children's nurses
- Learning disability teams
- Psychologists
- Child and adolescent mental health services (CAMHS) reports
- Schools either maintained or special
- FE placement including FE specialist placement
- Transition key worker
- Careers Wales.

13. Multi-agency reports which should be accessed are as follows:

- The core assessment report including the carer's assessment.
- Educational statement of special educational needs, and annual reviews.
- LAC assessments.

14. Records:

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

15. Independent reports may be available from:

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

Risk assessment

16. Risk assessment should be undertaken during the assessment phase and should be used for appraising options for delivery of care. When conducting a risk assessment around the care of a child with continuing care needs, it is important to assess that child within their environment and for the assessment to include risk factors faced by the whole family. Risk assessments should incorporate the views of the children whose needs are being addressed, and their families. What they want, why they want it, what their abilities are and whether there are extraneous risk factors all need to be taken into account, otherwise the service user may not feel committed to or 'own' the resulting intervention.

17. There are many risk assessment models available, and most models of risk assessment look at the risk factors in a child's environment, which could result in loss of quality of life, or in potential significant harm. Any risk assessment or risk management framework used should be shared with and explained to children and their families. The risks identified may lessen depending on the strengths present, thus it is essential to explore both. Although conducting a risk assessment using a tool, can be a useful summary in planning services, it should flow from a comprehensive needs assessment, and it does not replace professional judgement when assessing overall risk. A good risk assessment tool will look at the following areas as a minimum:

- The background and current risk factors for the child and each family member.
- The strengths in each case.
- List any environmental hazards.
- Actions taken to reduce the risks identified.

Area 4: Children and Young People's Decision Support Tool

18. The Decision Support Tool has been developed to bring assessment information together and present it in a concise, consistent way. It is not a stand-alone tool and should be used to pull together the three key areas of assessment:

- The preferences of the child or young person and their family/carer.
- Holistic assessment of the child or young person and their family, including carer assessment.
- Reports and risk assessments from multidisciplinary team.

19. Wherever possible, the person co-ordinating the assessment process will liaise with the multi-disciplinary team members to complete the Decision Support

Tool, matching as far as possible the individual's level of need with the description that most closely relates to their specific needs.

20. The tool provides practitioners with a framework to bring together and record the various needs in eleven care domains. The domains are sub-divided into statements of need representing low, moderate, high, severe or priority levels of need, depending on the domain.

21. The care domains are:

- Behaviour
- Cognition
- Psychological and emotional needs
- Communication
- Mobility
- Nutrition, food and drink
- Continence
- Skin and tissue viability
- Breathing
- Drug therapies
- Altered states of consciousness' (ASC).

22. The result of completing the tool should be an overall picture of the child's needs which captures their nature and their complexity, intensity and/or unpredictability and thus the quality and quantity of care required to meet their individual needs.

23. There may be circumstances, on a case-by-case basis, where an individual may have particular needs which are not easily categorised by the care domains described here. In this situation, it is the multi disciplinary team who know the individual who make the decision of need.

24. 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.

25. 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.

26. 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.

Care Domains

Challenging behaviour

i.e. behaviour of such intensity, frequency, or duration that the physical safety of the person or others is likely to be placed in 'serious jeopardy' and behaviour which is likely to impair a child's personal growth, development, family life and which represents a challenge to services, families and to the children themselves, however caused.

Description	Level of Need
No evidence of challenging behaviour	No additional needs
Some incidents of challenging behaviour that are manageable and do not pose a significant risk or barrier to intervention. The person is usually compliant with care.	Low
Challenging behaviour that follows a predictable pattern and can be managed by a skilled carer or care worker* who is able to maintain a level of behaviour that does not pose a risk to self or others	Moderate
Challenging behaviour (severity or frequency) that requires specialist clinical assessment, advice and review	High
Challenging behaviour (severity or frequency) that poses a significant risk to self and/or others and that requires special skill from daily carers and prompt responses to manage the number of levels of incidents or risks. NB the behaviour may be evidenced on a frequent basis, or it may be that the withdrawal of skilled support would result in those behaviours reoccurring a program of intervention could support child and family locally	Severe
Behaviour that poses an immediate risk to self and others (severity or frequency) requiring urgent specialist intervention to reduce or manage risk and needs a highly specialist multi-agency program of intervention that cannot be provided locally	Priority

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

Cognition

Children and Young People with a learning disability will inevitably have cognition difficulties. Therefore, although this domain applies to all children and young people, for those with a learning disability or developmental disorder there must be a summary of their known cognitive functioning compared with that expected for a child of the same age and evidence of a significant deficit in the child or young person's cognitive functioning compared with usual ability at that age, to support increased healthcare needs in this domain.

Description	Level of Need
No evidence of developmental delay, confusion or disorientation.	No needs
Cognitive impairment which requires some supervision, prompting or assistance with more complex activities of daily living appropriate to age, but awareness of basic risks that affect their safety is evident.	Low
Cognitive impairment (which may include comprehension or memory issues) that requires some supervision, prompting and/or assistance with basic care needs and daily living activities. Some awareness of needs and basic risks is evident. The child or young person is usually able to make choices appropriate to needs with assistance. However, child or young person has limited ability even with supervision, prompting or assistance to make decisions about some aspects of their lives, which consequently puts them at some risk of harm, neglect or health deterioration.	Moderate
<p>Cognitive impairment that may include marked comprehension or memory issues and maybe lack of understanding of time and place.</p> <p>The child or young person has awareness of only a limited range of needs and basic risks.</p> <p>The child or young person finds it difficult even with supervision, prompting or assistance to make decisions about key aspects of their lives, which consequently puts them at high risk of harm, neglect or health deterioration.</p>	High
Although they may be able to indicate some wishes on a limited range of issues they are unable to make choices appropriate to need on most issues, even with supervision, prompting or assistance.	Severe

Psychological and Emotional Needs

Description	Level of Need
No additional psychological or emotional needs apparent for age and development stage.	No additional needs
<p>Mild depressive or anxiety symptoms, periods of distress which respond to prompts and reassurance.</p> <p>OR</p> <p>Requires prompts to motivate self towards activity and to engage in care plan and/or daily activities.</p>	Low
<p>Depression, anxiety or anger which results in periods of distress which do not readily respond to prompts and reassurance.</p> <p>OR</p> <p>Withdraws form social situations. Demonstrates difficulty in engaging in care plan and/or daily activities.</p>	Moderate
<p>Rapidly fluctuating moods of depression, anxiety or anger necessitating specialist support and intervention.</p> <p>OR</p> <p>Unmotivated, requiring continuous support and intervention to engage in care plan and/or daily activities.</p>	High

Communication

This section relates to difficulties with receptive and expressive language, both verbal and non-verbal that is not commensurate with age and developmental milestones. It does not include those children where English is not their first language but are able to communicate.

Description	Level of Need
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	No additional needs
Needs prompting to communicate their needs. The child or young person's ability to understand and communicate is appropriate for age and recognised developmental milestones. Special effort may be needed to ensure accurate interpretation of needs or may need additional support visually, either through touch or with hearing. Carers may be able to anticipate needs through non-verbal signs due to familiarity with the individual. Expressive or receptive language.	Low
Communication about basic needs is difficult to understand or interpret, even when prompted, unless with familiar people and requires regular support.	Moderate
Requires frequent or significant support from carers and professional to enable the child to either understand or communicate basic needs, requirements or ideas, even with familiar people.	High

Mobility

Description	Level of Need
Independently mobile as appropriate for age and development 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 extra curricular activities.	Low
Completely unable to stand but able to assist or co-operate with transfer and/or repositioning by one carer or care worker to a level appropriate for developmental age.	Moderate
<p>Unable to move in a developmentally appropriate way. Cared for in one position (bed or chair) and due to risk of physical harm, loss of muscle tone, tissue viability or pain on movement needs careful positioning, and is unable to assist or needs more than one carer to reposition or transfer.</p> <p>OR</p> <p>At a high risk of injuries, requiring a structured management plan to minimise risk, appropriate to the stage of development.</p> <p>OR</p> <p>Involuntary contractures placing themselves and carers at risk.</p>	High
<p>Completely immobile and unstable clinical condition such that on movement or transfer there is a high risk of serious physical harm.</p> <p>OR</p> <p>Where the positioning is critical to physiological functioning or life.</p>	Severe

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 normal for their development age,</p> <p>OR</p> <p>Needs supervision, prompting, encouraging with food and drinks above normal requirement for development age.</p> <p>OR</p> <p>Parent, carer child or young person needs support and advice about diet because of underlying condition which may create a greater chance of non-compliance, including limited understanding of consequences of food or drink intake.</p> <p>OR</p> <p>Needs feeding when this is not normal developmentally, 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 any food and drink by mouth. All nutritional requirements taken by artificial means e.g. via a non-problematic tube feeding device, naso-gastric tube included.</p>	Moderate
<p>Dysphagia requiring management plans with additional skilled intervention to ensure adequate nutrition or hydration and minimize the risk of choking and aspiration and maintain airway e.g. suction</p> <p>OR</p> <p>problems with intake of food and drink, requiring skilled intervention to manage nutritional status. Unintended weight loss placing the individual at risk and needing skilled intervention</p> <p>OR</p> <p>Problems relating to a feeding device that require skilled assessment and review</p>	High
All fluids and nutritional requirements taken by intravenous means	Severe

Continence and Elimination

Description	Level of Need
Continent of urine and faeces (appropriate to age and development).	No additional needs
<p>Continence care is routine on a day-to-day basis and age appropriate:</p> <p>Incontinence of urine managed through e.g. medication, regular toileting, pads use of penile sheath etc.</p> <p>AND</p> <p>Is able to maintain full control over bowel movements or has a stable stoma and may have occasional faecal incontinence.</p>	Low
<p>Continence care is routine but requires monitoring to minimise risks, e.g. those associated with urinary catheters, frequent double incontinence and/or the management of severe or recurrent constipation or urinary infection or self catheterisation</p>	Moderate
<p>Continence care is problematic and requires timely intervention by a skilled practitioner or trained carer</p> <p>OR</p> <p>Intermittent catheterization</p> <p>OR</p> <p>Is regularly incontinent of faeces several times a day or has a stoma that needs attention several times a day</p>	High
requires peritoneal /haemodialysis to sustain life	Priority

Skin and Tissue Viability

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

Breathing

Description	Level of Need
Normal breathing (age appropriate rate) no issues with shortness of breath routine use of inhalers, nebulisers etc.	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 a low level of oxygen therapy each night or room continuous oxygen is required 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>	Moderate
<p>Is able to breath independently through a tracheotomy that they can mange themselves or with the support of carers/parents. Has patent but sub-optimal airway without tracheotomy tube</p> <p>OR</p> <p>Is able to breath unaided during the day but needs to go on a ventilator for supportive ventilation - the ventilation can be discontinued for up to 48hours without clinical harm</p> <p>OR</p> <p>Is on Continuous Positive Airways Pressure (CPAP)</p>	High
<p>Has frequent hard to predict apnoeas</p> <p>AND/OR</p> <p>Severe life threatening breathing difficulties</p> <p>Extreme difficulty in breathing (or a tracheotomy), which requires aspiration to maintain airway, by a fully trained carer or a tracheotomy that requires frequent suction and is essential for breathing</p> <p>AND/OR</p> <p>Requires ventilation at night for very poor respiratory function has respiratory drive and would survive accidental disconnection but would not be well and require hospital support</p>	Severe
<p>Unable to breathe independently, requires permanent mechanical ventilation</p> <p>OR</p> <p>Has no respiratory drive when asleep or unconscious and requires ventilation and 1:1 support whilst asleep, as disconnection would be fatal</p> <p>OR</p> <p>A highly unstable tracheotomy, frequent occlusions, difficult to change tubes</p>	Priority

Drug Therapies and Medicines

Description	Level of Need
Parent, informal carer or self-ministered medicine as age appropriate.	No additional needs
<p>Requires a suitably trained member or formal carer, teaching assistant or nurse to administer medicine due to:</p> <ul style="list-style-type: none"> • Age • Non compliance • Type of medicine • Route of medicine • Place where medication is to be given 	Low
<p>Requires administration of medicine regime by a registered nurse or care worker specifically trained for this task</p> <p>AND</p> <p>monitoring because of potential fluctuation of the medical condition that can be non-problematic.</p>	Moderate
<p>Has a drug regime that requires management by a registered nurse (within prescription) due to a fluctuating and/or unstable condition or symptom management.</p>	High
<p>Has a medicine regime that requires daily management by a registered nurse and reference to a medical practitioner to ensure effective symptom management associated with a rapidly changing/deteriorating condition.</p>	Severe
<p>Has a medicine regime that requires daily management by a registered nurse and reference to a medical practitioner to ensure effective symptom and pain management associated with a rapidly changing/deteriorating condition, where 1:1 monitoring of symptoms and their management is required.</p>	Priority

Seizures or Altered States of Consciousness (ASC)

Description	Level of Need
No evidence of seizures.	No additional needs
History of seizures or ASC but none in the past 3 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.	Moderate
ASC or 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.	High
Severe uncontrolled seizures daily or more resulting in unconsciousness that does not respond to treatment and results in a high probability of risk to self or others.	Severe
Requires daily intervention by a registered nurse. Where clinical judgement is required to select and implement appropriate interventions to manage related risks.	Priority

Other significant care needs to be taken into consideration:

There may be circumstances, on a case-by-case basis, where an individual may have particular needs which do not fall into the care domains described above. It is the responsibility of the assessor to determine and record the extent and type of these needs. The severity of the need and its impact on the individual need to be weighted, using the professional judgement of the assessor, in a similar way to the other domains. This weighting also needs to be used in the final decision.

Information to consider:

- Do the changes reported reflect any changes in the support services received?
- Describe the actual needs of the individual.
- Identify how this can be changed and what can be managed- specify what health interventions are *currently* in place to meet health needs and what *additional* interventions could be implemented to help achieve this outcome.
- Provide the evidence that informs the decision about which level is appropriate, such as the times and situations when intervention is likely to be performed across a range of typical daily routines and the frequency and duration of the intervention.
- Include the frequency and intensity of need, unpredictability, deterioration and any instability.
- Are the person's support needs episodic (for example, requiring additional inputs for time limited periods) or long term?
- Note any overlap with other domains.

Annex B: Continuing Care Pathway for Children and Young People

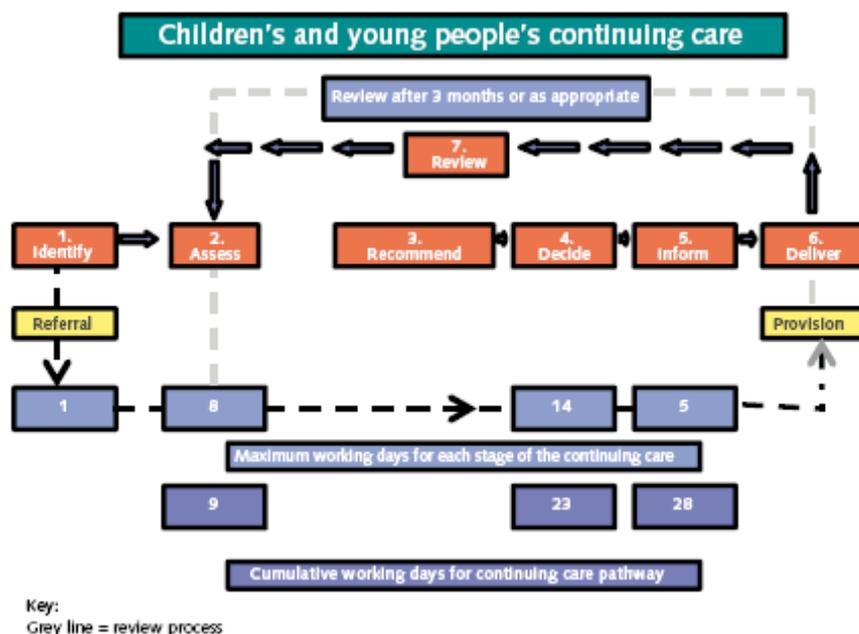
Introduction

1. 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.

2. Care pathways have been developed to ensure that services are more user-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 aims to link children, young people and their families/carers with community services, hospital-based services, local authority children's and young people's services and the third sector to ensure a properly integrated approach to meeting the continuing care needs of children and young people.

3. 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 continuing care package. The seven stages of this pathway go from initial identification 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/carers involved in the continuing care pathway understand what should be happening 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.

Diagram 2: Overview of the pathway, including timescales



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 guidance.

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 assess or complete four areas of assessment.		
Decision-making phase	3) Recommend	Nominated children's and young people's health assess or 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/carers in the process.
- Information should be available for families, and age-appropriate information should be available for children or young people and their families/carers to clarify the process of referral.
- Families and carers 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 planners. 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/carers 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/carers 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/carers are kept informed throughout the process, and know the outcome of and reasons behind the assessment.
- Children, young people and their families/carers 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 (see Annex C: Relevant Legislation, Guidance and Documents).

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 the NSF for Children, Young People and Maternity Services in Wales & the Children Act 2004.

- 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.

Best practice principle: Involvement in decision-making

Children or young people and their families/carers 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 LHB and local authority professionals, including planners 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 LHB and the local authority should use planning 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.
- 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 planning 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 Section 2.8).

ANNEX C: Relevant Legislation, Guidance and Documents

Children Act 1989

Children Act 2004

Chronically Sick and Disabled Persons Act 1970

Disability Discrimination Act 1995

Education Act 1996 and the Special Education Needs Code of Practice for Wales 2002

Education (Areas to which Pupils and Students Belong Regulations (Wales) (Amendment) 2009

Framework for Children in Need and Their Families, Welsh Assembly Government

Human Rights Act 1998

National Health Service (Wales) Act 2006

National Service Framework for Children, Young People and Maternity Services (WAG 2005)

Placement of Children (Wales) Regulations 2007 and Local Health Boards (Functions) (Wales) (Amendment) Regulations 2007

Rights of Children and Young Persons (Wales) Measure 2011

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

Safeguarding Children - Working Together under the Children Act 2004, April 2007 [W]

Shared Planning for Better Outcomes (WAG 31/2007) Guidance on statutory Children and Young People's Plans.

Stronger Partnerships for Better Outcomes (WAG 37/2006) Guidance on Children and Young People's Partnerships and local duties to cooperate.

Towards a Stable Life and Brighter Future, Welsh Assembly Government regulations and guidance (July 2007)

Visits to Children in Long Term Residential Care Regulations 2011

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 (usually using the decision support tool – see below).

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 this guidance, 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 LHBs 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.

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.

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.

Multi-agency decision-making forum

The multi-agency decision-making forum will comprise professionals from different funding agencies involved, including LHBs 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 all the agencies involved to reach a timely decision on what services each will deliver or 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 LHB and the local authority to decide what services each will plan, deliver 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.

Planning

The process that Local Health Boards (LHBs) and local authorities use to secure the best care and best value for local citizens. It is the process of measuring need /planning to meet that need, 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.
- Achieve this with the best use of available resources.

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 and education services that are available to the general population.