



Llywodraeth Cymru  
Welsh Government

# The Children and Young People's Continuing Care Guidance

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# SECTION 1

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## INTRODUCTION

- 1.1. This guidance assists Local Health Boards (LHBs), Local Authorities (LAs) and their partners (for example Children's Hospice, Action for Children, Barnardo's, specialist educational provision) to plan and support children and young people's continuing care needs.
- 1.2. It supports understanding of the range of potential health needs - physical and learning disabilities, mental health needs, neurodevelopmental disorder and behaviours considered to be challenging - and how meeting those needs with a package of continuing care may fit with other types of support. It can assist LHB's in understanding their responsibilities towards children and young people with complex needs and in reaching an agreement with their local authority partners.
- 1.3. It provides advice based on existing practice across the country on undertaking a holistic assessment of the child or young person's needs. The guidance supports agencies, such as health, education and social care in meeting their statutory duties under the National Health Service (Wales) Act 2006 (NHS Act 2006) and the Social Services and Well-being (Wales) Act 2014 (SSWBA). LHBs have autonomy on how they fulfil this function and what process they adopt but adherence to the principles of this framework should ensure consistency and fairness.
- 1.4. The children and young people's continuing care process should:
  - Ensure that leaders and staff are aware of and adhere to the principles of children's rights and wellbeing in line with [The United Nations Convention on the Rights of the Child](#);
  - Make the child or young person and their parents and carers the focus of the continuing care process using person-centred practice and a "what matters" approach, in line with the Social Services and Well-being (Wales) Act 2014;
  - Recognise that children and young people's continuing care is part of a graduated response to meeting the needs of children and young people. Joint assessment processes must be supported to reduce the possibility of multiple or repeated assessment or fragmented care;
  - All children and young people who are deemed eligible for continuing care will have outcomes recorded in a plan of care, for example, a care and support plan, care and treatment plan or an individual development plan (IDP). These will be reviewed and measured in line with statutory responsibilities set out in the SSWBA, the Mental Health

(Wales) Measure 2010 and the Additional Learning Needs and Educational Tribunal Wales Act 2018;

- Follow local pathways agreed and jointly owned by LHBs, LAs and their partners,
- In line with the Welsh Language (Wales) Measure 2011, Welsh language services should be built into planning and delivery and Welsh language services should be offered to Welsh speakers without them having to request it.

1.5. The guidance comprises of the following:

- A definition of children and young people's continuing care and its place within support for children with complex needs.
- Legislation and policy for LHBs and LAs to include statutory responsibilities.
- The principles, timelines and the phases involved in assessing and arranging provision of continuing care. It also considers the transition from child to adult services.
- A range of assessment tools to aid identification of continuing care needs in children and young people. This includes a nursing assessment and an eligibility support tool which explores needs using a person-centred approach.
- A governance framework for the continuing care pathway from assessment to delivery and evaluation of care.
- The roles and responsibilities of the LHB, health assessor and other professionals involved in a child or young person's care.

### **Asylum seeking/refused asylum children and young people**

- 1.6. Whether a child is an asylum seeker going through the asylum process or a refused (failed) asylum seeker whose appeal rights are exhausted, they are still a child. Welsh Government takes a rights-based approach to children and is signatory to the UNCRC via the Rights of Children and Young Persons (Wales) Measure 2011.
- 1.7. The National Health Service (Charges to Overseas Visitors) (Amendment) (Wales) Regulations 2009 provide for any asylum seeker whose application for asylum has failed will not be charged for services forming part of the health service.

## SECTION 2

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### OVERVIEW OF CHILDREN AND YOUNG PEOPLE'S CONTINUING CARE

#### What is Continuing Care?

- 2.1. A small number of children and young people may have very complex health needs. These may be the result of congenital conditions, long-term or life-limiting or life-threatening conditions, disability, or the after-effects of serious illness or injury. They may have technology-dependence requiring nursing input. Some children and young people will have complex mental health or a learning disability requiring specialist therapeutic input or placement provision.
- 2.2. Most needs can be met by the care which is routinely provided by LHBs, or in some cases, Welsh Health Specialised Services (WHSSC) - an example would be Specialist Tier 4 services for Mental Health. However, for a small number of children, their needs are such that they cannot be met by these existing universal or specialist services by a case management approach. An additional package of support may be needed. This package of additional support has come to be known as continuing care. This framework supports LHBs in determining if a child's needs are such that they require a package of continuing care.

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*A continuing care package may be required when a child or a young person has long-term health needs arising from e.g. physical and learning disabilities, mental health needs, neurodevelopmental disorder and behaviours which may be considered challenging and cannot be met by existing universal or specialist services alone.*

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- 2.3. Continuing care is **additional** to care which is provided either as a universal service, or a specialised service. **It is not an alternative.** It is needed because universal or specialised services do not fully meet a child or young person's needs, due to their complexity. An assessment of needs should be undertaken on the basis that it is believed that these existing services are insufficient to meet a child or young persons' needs. An assessment for continuing care and agreement of eligibility should not be undertaken to remove an effective existing package of support or shift commissioning responsibility between health and social care.
- 2.4. This guidance builds on existing good practice where it exists and provides clear guidance for areas where processes and partnerships are less well developed.
- 2.5. The child or young person with continuing care needs should have a structured care pathway, which should form part of the continuum of care which starts with universal services and into specialist services. This is clearly outlined in guidance for regional

partnership boards for the integrated commissioning of services for families, children and young people with complex needs 2018<sup>1</sup>.

- 2.6. Where there are consistent or recurring identified gaps in universal and specialist services, LHBs may consider commissioning services to meet an identified population need rather than using an individual approach through continuing care.

### **Differences between children and young person's continuing care (CYP CC) and NHS Continuing Healthcare (CHC)**

- 2.7. It is important to recognise, and reflect in practice, that children and young people's continuing care covers young people up to their eighteenth birthday. Thereafter, young people with very complex needs *may* be eligible for NHS Continuing Healthcare and NHS-funded Nursing Care, for which there is a National Framework for Adult Continuing Healthcare and supporting guidance and tools. <http://www.cciss.org.uk/home>
- 2.8. The convention of referring to children's 'continuing care' has developed over time to reflect the broad similarities of the two approaches. However, there are fundamental differences.
- 2.9. In particular, NHS Continuing Healthcare (CHC) is a complete package of ongoing care arranged and funded solely by the NHS through Local Health Boards (LHBs), where an individual's primary need has been assessed as health-based. The NHS is consequently responsible for providing for all of the individual's assessed health and associated social care needs, including accommodation, if that is part of the overall need.
- 2.10. If a child or young person is found to be eligible for children and young people's continuing care (CYP CC) agencies such as health, education and social care must work together to ensure that there are no gaps in meeting those assessed needs. A LHB and a LA may therefore jointly fund care to meet a child or young person's needs as part of a joint health and social care package. The NHS Continuing Healthcare framework should not be used with children and young people (except when anticipating the needs of a young person approaching their eighteenth birthday, see Section 4 below).
- 2.11. Although a child or young person may receive a package of continuing care, they may not be eligible for NHS Continuing Healthcare or NHS-funded Nursing Care once they turn eighteen.

### **The children and young people's continuing care process**

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<sup>1</sup> Welsh Local Government Association (WLGA) 2018 Guidance for Regional Partnership Boards - Integrated Commissioning of Services for Families, Children and Young People with Complex Needs

- 2.12. The continuing care process comprises of five phases. Identify, assessment, decision-making, the arrangement of provision and review. Each phase is discussed in detail in Section 3.
- 2.13. Examples of screening and assessment tools are to be found in Annex A.

### **Identify**

- 2.14. Referrals may be made by a variety of professionals including professionals in primary, secondary and tertiary care, Child Adolescent Mental Health Services (CAMHS), Community children's nursing teams, learning disability teams as well as social services, education and voluntary sector providers.
- 2.15. There should be a clear process for referral into children and young people's continuing care available for professionals to include how they will submit assessments or reports.

### **Assessment**

- 2.16. The assessment is led by a children and young people's health assessor nominated by the LHB, who will draw on the advice of other professionals and may undertake a pre-assessment to determine whether a full assessment is necessary. The assessor considers all relevant evidence to make a holistic assessment of the child's needs, including:
- The preferences of the child or young person and their family/carers and advocate where appropriate. This should be following the fundamental principle of the Social Services and Well-being (Wales) Act 2014 of voice and control – putting the individual and their needs at the centre of their care and giving them a voice in, and control of the outcomes that help them achieve well-being;
  - Holistic assessment taking account of the range of appropriate assessments, based on the requirements of the individual, such as a nursing assessment and the care and wellbeing assessment;
  - Reports and risk assessments from the multi-disciplinary team.
- 2.17. Best practice supports that a multi-disciplinary team meeting is convened and the information above is collated and used to determine the unmet needs using a person-centred approach. The multi-disciplinary team should consist of professionals who know the child (for example Learning Disability Nurse, Community Children's Nurse, Occupational Therapist, Speech and Language Therapist, Occupational Therapist, Social Worker, Support Worker and Teacher) and can actively contribute to the plan of care. This team will include representation from both the LHB and the LA.
- 2.18. The nominated children and young people's health assessor makes a recommendation, following the consensus of the multi-disciplinary team meeting, as to whether the child or young person has continuing care needs that cannot be met by existing universal or specialist services and will require a package of care involving bespoke planning and



funding arrangements.

- 2.19. The recommendation of continuing care eligibility and a summary of the care package required with costed options should be produced in preparation for the decision making phase of the process. Best practice supports robust quality assurance is built into the continuing care pathway in line with LHB's governance framework. Further advice on different agencies responsibilities for the provision of care is included in this guidance.

### **Decision making**

- 2.20. The second phase involves a multi-agency decision-making panel considering the evidence and the assessor's recommendation, to decide if the child or young person has a continuing care need.
- 2.21. The decision-making panel agrees on what care will be provided, what resources are required to deliver it and what needs to be commissioned, again taking into account the recommendation of the assessor.

### **Arrangement of care package**

- 2.22. This is followed by the development of a package of care. Once a decision has been made and communicated, LHBs and LAs as appropriate, will need to make the necessary logistical, funding and contractual arrangements to initiate the delivery of provision of the package of care.
- 2.23. Provision of a package of care should begin as soon as possible following a decision being made and the child or young person and their family being informed. **Under no circumstances should care be withheld whilst funding agreements are being made.**
- 2.24. On occasion, a child or young person will need to commence a package of care pending a decision on continuing care eligibility. An example of this may be where a specialist placement is required and a child commences this placement before continuing care eligibility being agreed at the multi-agency decision panel. In this circumstance, the LA may recoup the health costs incurred over the interim period to the date of the panel decision.

### **Review**

- 2.25. 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 the provision phase. A lead professional should be nominated to case manage and coordinate the care package.
- 2.26. 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.

### Timeline for children and young people's continuing care process

Phase	Step	Summary of key actions	Time-scale
Identification and assessment phase	Identify & Assess	<p>Child or young person with possible continuing care needs is referred to the LHB.</p> <p>Screen referral if necessary.</p> <p>Fast track if necessary.</p> <p>Nominated children and young people's health assessor collates multiagency assessments, reports, risk assessments.</p>	1-3 weeks
Decision making phase	Recommend	<p>Multiagency meeting held and recommendation made for eligibility and package of care outlined.</p> <p>Assessment, recommendations and costed options are quality assured within LHB governance framework.</p>	3-5 Weeks
	Decide	<p>A multi-agency decision making forum considers the recommendations and costed options and decides on the package of care for the child or young person where continuing care is identified.</p>	6 weeks
Arrangement	Inform	<p>Child or young person and family informed of the decision.</p>	5 days

of provision phase	Deliver	Providers for package of care identified and commissioned.  Training and monitoring arrangements for carers outlined.	Routine – up to 3 months  Fast track (end of life) 3 days
	Review	Care package reviewed at 3 months following initial assessment, then annually	3 months

## SECTION 3

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### CHILDREN AND YOUNG PEOPLE'S CONTINUING CARE PATHWAY

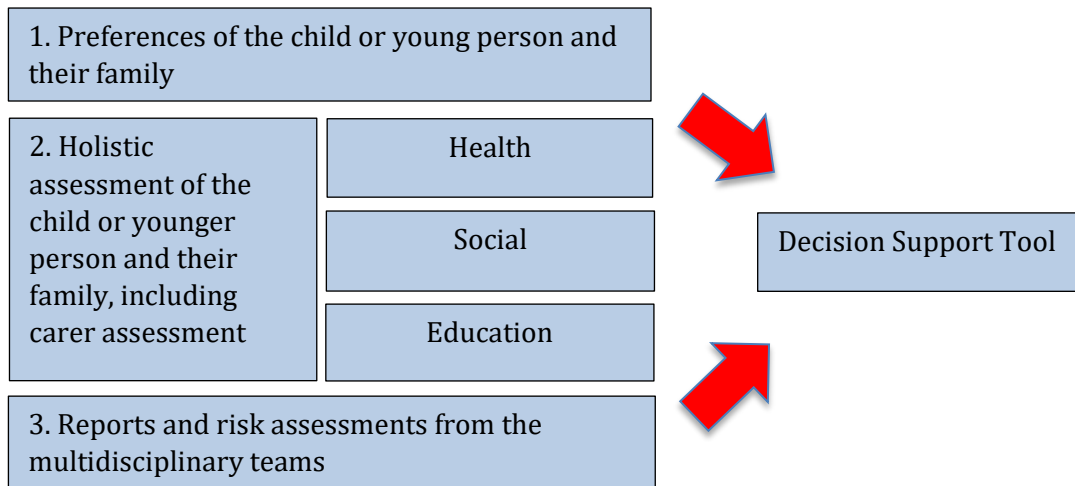
#### Step 1: Identify

- 3.1. Referrals may be made by a variety of professionals including professionals in primary, secondary and tertiary care, Child Adolescent Mental Health Services (CAMHS), Community children's nursing teams, learning disability teams as well as social services, education and voluntary sector providers. Professionals in all relevant settings should be able to provide evidence on a child's needs and the current input from universal and specialist services.
- 3.2. Consent of the child, young person or parent must be sought. It should be made explicit to the individual that this consent includes the sharing of information; the organisations' privacy notice must be made available in line with General Data Protection Regulation (GDPR).
- 3.3. The competency and rights of young people older than 16 years in respect to consent need to be taken into account and, where appropriate, a mental capacity assessment and best interest decision undertaken.  
  
<https://pathways.nice.org.uk/pathways/decision-making-and-mental-capacity>
- 3.4. Information should be available for families with age-appropriate information available for children and young people; this should include information on referral and the process.
- 3.5. There should be clear local process for referral into children and young people's continuing care available for professionals to include how they will submit assessments or reports. This may be through multi-agency referral panels or health panel. Where the continuing care need has been emerging over some time and the child or young person is known to a range of agencies and professionals, the care and support plan should be attached to the referral. Ideally, with the increasing move to integrated IT systems (WCCIS) these plans will be shared across agencies.
- 3.6. A checklist may be used to consider referrals pre-assessment and a suggested template is included in Annex A. Where there is clear evidence of unmet need this will not be necessary and there should be no delay in the assessment process.
- 3.7. For children and 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.
- 3.8. Children and young people who are at end of life should not have barriers to receiving care and any applications for a package of care should be fast-tracked.

Equally, there should be no barriers for looked after children being placed within the specialist provision.

## Step 2: Assessment

- 3.9. The children and young people's health assessor is the health professional allocated to lead the assessment process on behalf of the LHB.
- 3.10. The children and young people's health assessor should be a health practitioner with the relevant skills and competencies to undertake assessments **within the scope of their practice**. This role may be a dedicated role within a continuing care team or a practitioner within a community children's nursing team, learning disability team or CAMHS team. LHB's will need to ensure that the health assessor role is properly resourced and supported to make a recommendation.
- 3.11. The skills required by the assessor should include as a minimum:
- Sound knowledge of children and young people's continuing care;
  - Knowledge of the principles of children's rights and wellbeing in line with [The United Nations Convention on the Rights of the Child](#);
  - An understanding of child and young people's development;
  - Experience of working with children young people and their families;
  - Experience of assessing children and young people and their families within the scope of their practice;
  - Well-developed leadership qualities;
  - Listening skills;
  - An understanding of local universal and specialist services and commissioning processes for continuing care and specialist provision where this applies (e.g. mental health);
  - knowledge of planning and delivery of services;
  - Mental capacity and best interest decision making.
- 3.12. The nominated children and young people's assessor is responsible for undertaking an assessment using **three broad areas of assessment** which will combine to provide a holistic multi-agency assessment of need. Each is important to determine if there is a need for continuing care.



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

- 3.13. The child, young person and their family should be supported to be partners in the assessment process and assessed using a person-centred approach. Care is often highly invasive of the family home and the needs and preferences of all the family members should be sought as far as possible.
- 3.14. The health assessor is responsible for identifying and capturing the child or young person's and their families' preferences. This may require the child having access to advocacy services and should link to the child or young person's care and well-being assessment.
- 3.15. Consideration must be given to the child, young person or the family's first language, and if necessary, an interpreter arranged. Parents with learning disabilities or communication difficulties require appropriate support from adult services.
- 3.16. The carer's assessment should consider the family capacity for resilience; this relates to a families ability to 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 be considered.
- 3.17. Equally, there needs to be an open and honest conversation about parenting responsibilities and the family's expectations of what a package of care may look like, acknowledging equitable and fair use of resources.
- 3.18. Where a child or young person may require support to give a view or opinion, or their views are different from those of their parents, the possibility of advocacy services should be discussed.

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

- 3.19. The children and young person's assessor undertakes a health assessment and/or collates existing assessments from the professionals in the child's multi-disciplinary team. The health assessor may need to get additional expert advice and there may be a need to commission specialist healthcare assessments.
- 3.20. In instances where social and education assessments have not already been undertaken the assessor should liaise with the appropriate professionals to instigate an assessment in these areas but be mindful that assessments should be appropriate and proportional as outlined in the SSWBA.

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

- 3.21. The assessor is responsible for collating the reports and risk assessments in preparation for the multi-agency team meeting.
- 3.22. The input of the third sector should be considered in the assessment phase, as appropriate.
- 3.23. 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.

### **Step 3: Decision making**

- 3.24. It is recommended that all the assessments are brought together within a multiagency meeting and a person-centred and needs-based approach used to outline the assessed needs. This may be with the use of a tool which identifies the child or young person's needs, which of these may be met through universal and specialist services and those which may require a package of care. An example of a Decision Support Tool is included in Annex B
- 3.25. The child or young person and their family, along with an advocate if required, are invited to attend the multi-agency meeting; ideally this meeting can be part of a statutory care planning meeting, for example, a school review or care and support meeting or a looked after child (LAC) review. Before the multi-agency team meeting, best practice would support that children, young people and their families have written information on the Multi-Disciplinary Team (MDT) and decision-making process (Annex B).
- 3.26. The multi-agency team meeting will be facilitated by the children and young people's health assessor or a continuing care or team manager. All key agencies should have input and/or representation at the meeting. A recommendation for eligibility will be made by the multiagency team. The recommendation for eligibility

must be made first before moving on to the details around the care package.

- 3.27. The package of care should be needs-led and the proposed package should meet the identified health needs. This may involve innovative ways of working across agencies and should build on existing universal and specialist services.
- 3.28. Children, young people and their families should have clear advice on what a package of care may look like with realistic expectations about a sustainable long term package of care.
- 3.29. No discussions about funding responsibilities should be had at the multi-agency team meeting.
- 3.30. Following the multi-agency team meeting, the children and young person's assessor will summarise the following recommendations:
  - Whether the MDT supported eligibility for children and young people's continuing care;
  - The care package options with costings;
  - Any other issue which may be relevant to the provision of a holistic package of care e.g. any training requirements, home adaptation etc.

### **Quality Assurance of Assessments**

- 3.31. The completed assessment with recommendations and costed options should be quality assured in line with LHB governance arrangements. This may be with a dedicated professional within a LHB or a using a multi-agency team approach. Key points for consideration are as follows:
  - Evidence that the assessment process has been followed in line with the locally agreed multi-agency continuing care pathway;
  - A record kept of timelines from referral to decision making;
  - A record of the quality of the assessment;
  - The sustainability of each care option has been considered;
  - An outline of the governance arrangements for ensuring quality and contingency plans in the event of the breakdown of care;
  - Best practice for quality assurance should include completion of a checklist to ensure the locally agreed process has been followed. This will include recording timelines, quality and quantity of evidence which is current. Options for care may be outlined with associated governance to ensure quality maintained.

### **Multi-agency Decision Making Forum**

- 3.32. The completed assessment and recommendations are presented to a multi-agency decision-making forum. The multi-agency decision-making forum should be independent of those involved in the assessment and is made up of key decision making health and LA professionals including education.



- 3.33. The multi-agency decision-making forum will decide to support the recommendation or may seek further information. A decision should be made within six weeks of the commencement of the assessment.
- 3.34. If the assessment is of insufficient quality or lacks evidence to make a decision, further assessment may be requested. If a decision is made subsequently that the child or young person meets continuing care eligibility and requires a health component within the package of care, the LHB should reimburse the other parties back to the date of the multi-agency decision-making forum meeting.
- 3.35. In some instances, for example, end of life, where time is critical there may be a need for a nominated senior professional with this dedicated function, to decide to proceed with putting in place a package of continuing care, pending endorsement of the decision by the panel.
- 3.36. Following the panel's decision, the child or young person and their family/ carer should be notified verbally within 5 working days to be followed by a clear written explanation for the decision within 7 working days.

### **Funding responsibilities and joint working**

- 3.37. Services provided as part of the package for children and young people with continuing care needs will be arranged by the LHB, LAs and their partners as appropriate, enabling the child or young person to function optimally within their family, community, education or care setting.
- 3.38. All partners are responsible for funding their contributions to the continuing care package in line with their statutory functions. Ideally, this should happen through pooled or shared funding as described under the SSWBA and subsequent partnership arrangements regulations. Current arrangements under the Social Services and Well-being Act require Local Authorities and Health Boards to establish regional pooled funds for care homes for older people. However this is a minimum requirement and the statutory code of practice does set out the clear expectation that RPBs will consider pooling funds in other areas where appropriate and to consider pooled funds when doing things jointly in response to population assessments and to establish pooled funds in relation to joint commissioning.
- 3.39. Pooled funds are a key mechanism to support the integration of health and social services and will support the more effective allocation of resources. They are not a solution in themselves. What must underpin this approach is a real and genuine understanding of the needs of the child or young person and an absolute commitment to delivering services through integrated approaches.
- 3.40. 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 inter-agency disputes about funding responsibilities.

- 3.41. All LHBs should have joint arrangements in place with their relevant LAs as part of the joint commissioning process which could provide a route for ensuring referrals can easily be made, and information shared, to support continuing care and social care assessments. The pathway for assessing a child or young person's needs must be understood and agreed with all partners. For transparency, the process should be available in a document which allows all those involved to be familiar with the process.
- 3.42. For children and young people with the very complex needs which result in a continuing care need, the aim should be to ensure that the health care, and social care which the child or young person needs, are part of a single package of care, and the LHB and LA should endeavour to facilitate this.
- 3.43. However, there is often uncertainty as to the boundaries of health care and social care; this is not just an issue for continuing care, but it is a consistent challenge facing commissioners of care for children and young people with very complex needs, as the support provided will usually be in the home, and support is not only to ensure health and wellbeing but to mitigate the impact of disability on daily living.
- 3.44. The Haringey judgement (see Annex C) indicated that there are limits to what care should be funded by the LA, which should not be a substitute for additional NHS care for children. In this case, the High Court determined that the duty under section 17 of the Children Act 1989 did not extend to meeting essential medical needs. Social care should not be a substitute for health commissioned care to meet that need.
- 3.45. In his judgement, Mr Justice Ouseley was willing to apply the 'Coughlan criteria' – which relate to NHS Continuing Healthcare – to determine whether a LA or the health commissioner should provide services to a child in need of continuing care. These indicate that there is no precise legal line between care which can and cannot be provided by the LA. The distinction will depend on the facts of the individual case, and taking into account the nature and quality of the services required, and the quantity and continuing of the services. The Coughlan judgement also confirmed that a LA can commission nursing services, provided they are properly classified as part of social care and provided the NHS has not agreed to provide them (for example, if the care is very much incidental or ancillary to the provision of accommodation).
- 3.46. Section 47 of the Social Services and Well-being (Wales) Act 2014 (SSWBA) incorporates the first limb of the 'Coughlan criteria' and provides that a LA may not meet a person's needs for care and support which is required to be provided under a health enactment, unless doing so would be incidental or ancillary to doing something else to meet those needs.
- 3.47. The list below gives some examples of how different elements of a care package might fall to the relevant commissioner. It is not an exhaustive list and reflects where services which are more likely to require joint commissioning. It does not include the full range of services which might feature in an Individual Development Plan.

**Figure 3. Elements of a care package across health, social care and education**

**Example: a child with complex needs who is immobile, incontinent and has a gastrostomy and is dependent on ventilator support overnight**

Health	Local Authority	
	Social Care	Education
Community children’s nursing support for family Nursing assessment	Care and well-being assessment Care and support plan Carers assessment	ALN - Statutory assessment Individual development plan
Training and assessment of competency of carers	Administration of medication and gastrostomy feeds	Support assistant undertakes gastrostomy feeds
Supply of all consumables (gastrostomy and feeding equipment, pads)	Home adaptations including hoists Support to apply for grants	Adaptations required in school environment
Nursing package of care overnight due to assessed risk for airway management at night e.g. 5 nights	Short breaks e.g. two evenings a week	
Transport to hospital appointments	Assistant to apply for mobility grant	Transport to school or residential respite
<b>Team around the Child</b>		
<b>One care plan – regular review</b>		
Occupational Therapist Physiotherapist Speech and language therapist Dietitian Community Paediatrician Community children’s nurse	Social worker Support worker	Support worker ALNCo

### Complaints and Dispute Resolution

- 3.48. Where a child or young person is found not to need continuing care, a clear written rationale for any decision should be provided to the child or young person and family following a verbal conversation. Ideally, the process of engagement before

this point should have informed the expectations of the family.

- 3.49. The child or young person and their family should be informed of their rights and the complaints procedure in the event of a decision which does not meet their preferences and or expectations.
- 3.50. The NHS complaints procedure “Putting Things Right–raising a concern” about health services from April 2011 described at [www.puttingthingsright.wales.nhs.uk](http://www.puttingthingsright.wales.nhs.uk) is as applicable for children as it is for adults. Also, 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.
- 3.51. LHBs and LAs must-have dispute resolution built into their agreed continuing care pathway.
- 3.52. Best practice supports that disputes are resolved as quickly as possible. The interests of the child are paramount and no child should be denied access or have access to the appropriate health care delayed as a result of a dispute.
- 3.53. The initial aim is always to encourage joint conversations within the multi-disciplinary team to support local resolution and escalation when required back to the multi-agency decision-making forum for advice and support.

#### **Step 4: Arrangement of provision**

- 3.54. Once a decision has been made to provide a package of care, LHB’s and or LA’s, 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 care. There should be no delay in the provision of care and the development of the package of care will need to consider the following:
  - Place of care;
  - Sustainability and long term outcomes;
  - The skill mix of staff (the complement of nurses, health care assistants or carers within the package) ;
  - Staff competency and training of parents, carers;
  - Equipment;
  - Care plans and risk assessment;
  - Contingency plans and ability to flex the package of care up and down to meet any temporary increase in need;
  - Ongoing case management of the care package, identification of the lead professional.

#### **Step 5: Review**

- 3.55. The child or young person’s continuing care package should be reviewed three months after commencing the care and annually thereafter, or when circumstances

- have changed. If there has been a significant change, a full assessment is necessary. The child, young person and their family should be able to request a review at any time.
- 3.56. Best practice supports that where the child is subject to statutory review there should be a synchronised approach to review meetings so that a single review covers the holistic needs of the child or young person.
  - 3.57. All reviews should be transparent, involve the child or young person and their family and adhere to the principles of children's rights and wellbeing set out within [The United Nations Convention on the Rights of the Child](#). Reviews are an opportunity to update the multi-agency care plan and this should be shared with the child or young person and their family as appropriate.
  - 3.58. Reviews of a child or young person's continuing care needs are 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 the child or young person's continuing care needs are being met and are not financially motivated.
  - 3.59. However, reviews should be responsive to changes in a child or young person's fundamental need as there will be cases where successful management of a condition has permanently reduced or removed an ongoing need. The responsibility to commission care is not indefinite as needs may change and this should be made clear to the child or young person and their family/carers and advocate where appropriate.. As always, transparency of process and involvement of the child or young person and their family is essential to maintain fairness and consistency of the review.
  - 3.60. In instances where the successful management of a continuing care need has permanently reduced or removed an ongoing need, this will have a bearing on the child or young person's need for continuing care. However, the continuing care process should not marginalise a need just because it is being successfully managed but where the underlying need continues unreduced.
  - 3.61. In instances where transition back into universal or specialist health services is appropriate, the child or young person and their family should be supported throughout this transition, ideally from within their existing care team. Early engagement with other services is essential for proactive planning and ensuring a smooth transition.

## SECTION 4

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### TRANSITION TO ADULT SERVICES

- 4.1. All LHBs must work with their partners to ensure that there are robust transition pathways in place for all young people with complex needs. There should be active engagement of all agencies in the strategic development and oversight of their local transition processes, and that their representation includes those who understand and can speak on behalf of adult NHS Continuing Healthcare. LHBs should ensure that adult NHS continuing health care is appropriately represented at all transition meetings to do with individual young people whose needs suggest that they may be eligible for NHS Continuing Healthcare (CHC).
- 4.2. 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 an uncertainty about future care provision and support and also the loss of income due to changes in benefits.
- 4.3. The assessment of a child or young person's continuing care needs must consider the outcomes necessary to enable them to get the best from life. The outcomes should be specific, deliverable and linked directly to their wishes. They should include where appropriate, outcomes for transition, through key changes in a child or young person's life, such as changing schools, moving from children's to adult health services, or moving on from further education to adulthood.
- 4.4. Once a young person reaches the age of eighteen, they are no longer eligible for continuing care for children. The National Framework for the Continuing NHS Healthcare and the supporting guidance and tools are used to determine whether the adult has a "primary health need" and is, therefore, eligible for NHS Continuing Healthcare or, if not eligible for NHS Continuing Healthcare, whether they are eligible for NHS-funded Nursing Care.
- 4.5. Young people approaching adulthood and their families must be aware that eligibility for children's continuing care does not pre-suppose eligibility for NHS Continuing Healthcare.
- 4.6. Every child or young person with a package of continuing care approaching adulthood should have a plan for the transition to adult or universal health services or a more appropriate specialised or NHS Continuing Healthcare.
- 4.7. Key principles for the transition from children's to adult services for young people using health or social services are outlined in [NICE guidance \(2016\)](#) which equally applies to young people with continuing care needs.
- 4.8. Children's services should identify those children with potential eligibility for NHS Continuing Healthcare and should notify the appropriate adult complex care teams.

Ideally, this should occur when the child reaches the age of 14 years, especially if the young person's needs are likely to remain at a similar level into adulthood. There must be a recognition that there may be a cohort of young people whose needs are being met through universal and specialist services and therefore are not in receipt of children and young people's continuing care but who may meet eligibility for adult NHS Continuing Healthcare.

- 4.9. Once the young person reaches 16 years of age there should be a formal referral for screening to the appropriate adult NHS Continuing Healthcare team.
- 4.10. At 17 years of age the screening tool should be used to determine potential eligibility for adult NHS Continuing Healthcare, followed by a full assessment for adult NHS Continuing Healthcare to determine a primary health need wherever applicable, so that an effective package of care can be commissioned in time for the individual turning 18 years of age. If needs are likely to change, it may be appropriate to make a provisional decision and then to re-check it by repeating the process as adulthood approaches.
- 4.11. Children's services will need to work jointly with Adult services to ensure that assessment and care planning reflects the needs of the young person and to ensure a smooth transition to adult services and at 18 years of age, transition to adult NHS Continuing Healthcare, including the funding responsibilities, or to universal or specialist services should have been made. As above, a re-check of the assessment process is undertaken if necessary.
- 4.12. 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.
- 4.13. Where the 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.

## SECTION 5

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### LEGISLATION AND POLICY CONCERNING STATUTORY RESPONSIBILITIES

- 5.1. Whilst LHB's and LA's should have due regard to statutory and legal frameworks, this must not hinder collaborative thinking and joint working practices. The child or young person must remain at the heart of any care planning.

#### NHS (Wales) Act 2006

- 5.2. Children and young people's continuing care is an approach to fulfilling the statutory duty on a local health board under the [NHS \(Wales\) Act 2006](#) (as amended by the Health and Social Care Act 2012), to provide, to the extent they consider necessary to meet all reasonable requirements:
- medical and nursing services;
  - such other services or facilities for the prevention of illness, the care of persons suffering from illness and the after-care of persons who have suffered from illness, and;
  - such other services or facilities as are required for the diagnosis and treatment of illness.
- 5.3. The provision of continuing care may support LHB's in meeting other statutory duties.

#### Mental Health Act 1983 After-care Section 117

- 5.4. Chapter 33 of the Code of Practice for Wales to the Mental Health Act, 2016 sets out guidance concerning After- Care Section 117.

- 5.5. Paragraph 33.2 of the Code of Practice explains that:

*“Section 117 of the Act requires local health boards and local authorities, in co-operation with other relevant non-statutory agencies, to provide, or arrange for the provision of, after-care to patients detained in hospital for treatment under section 3, 37, 45A, 47 or 48 who cease to be detained and leave hospital. This includes patients granted leave of absence under section 17 and patients subject to community treatment orders (CTOs). It applies to people of all ages, including children”.*

- 5.6. A young person discharged from inpatient care may have a continuing care need, due to their psychological and emotional needs, or behaviours which challenge.



- 5.7. Continuing care assessments must consider all areas of a child or young person's health needs. It is not simply an assessment for complex *physical* needs or learning disability.
- 5.8. In relation to children and young people with mental health needs, there will already be mechanisms for referral to local CAMHS, or Tier 1 or 2 mental health providers. No assessment of continuing care should be made on the grounds of mental health needs without a prior referral and appropriate assessment by universal or specialised mental health services. Any consideration of whether or not a child needs additional support for a mental health need cannot be given without evidence from mental health professionals, resulting from targeted support. Similarly, where mental health needs are being met through an existing intervention or interventions, these should not be terminated to allow a service to be commissioned as continuing care.
- 5.9. The principle of continuing care, as the care needed to meet additional needs, which cannot be met by universal or specialised services, must be respected. It must not be used as an alternative to appropriate commissioned interventions. **Continuing care cannot be a catch-all to compensate for long waits or pressures in other areas of health provision, or for children and young people who have not experienced necessary specialised support.**

### **Behaviours that challenge**

- 5.10. LHBs have an important role concerning children and young people with learning disability and autism, and behaviours which challenge. The [NICE guidelines on challenging behaviour and learning disabilities](#), call for health and local authority commissioners (and professionals in education, health and social care), to work together to develop care pathways for people with a learning disability and behaviours which challenge.

The national commissioning board guidance on the Commissioning of Services for people with a Learning Disability: Good Practice Guidance (2017) gives commissioning advice for commissioners to support people with a learning disability to lead ordinary lives and may be a useful tool for planning continuing care for children and young people with behaviours that challenge.

<https://www.wlga.wales/commissioning-guidance-for-people-with-learning-disabilities>

- 5.11. As outlined in the previous section, the continuing care process should seek parity between the approach to physical and mental health. Continuing care may be needed where existing services are not sufficient to deliver the best outcomes for a child or young person, and bespoke care is needed. Children and young people should, wherever possible, receive the support and services they need to continue to live with their family, in their own home or as close to home as possible. LHBs should recognise the potential role of continuing care in making a crucial difference to a child at risk of admission.

- 5.12. Behaviours which challenge a care domain used within the assessment process, reflecting that LHB's may have a commissioning role concerning support for a child or young person with these needs. LHBs should not assume that such needs are a blanket responsibility of the LA; equally, they should not be tasked with providing health funding to support social and emotional needs, or educational or social care provision. As mentioned above, commissioners would need to consider – through a multidisciplinary team meeting, or Team Around the Child meeting - what specialist services are currently providing to support the needs of a child with behaviour which challenges – before seeking to assess for continuing care.
- 5.13. Multi-agency care plans, which explore options before a potential admission (or shortly afterwards, where an urgent admission was unavoidable), should indicate likely needs for health support and can inform an assessment for continuing care. Obviously, following discharge, a child or young person's support however commissioned, should be part of a broader care and support pathway, including health, social care, education, and access to family life.
- 5.14. Joint arrangements for commissioning for ALN provide another opportunity for ensuring commissioners collaborate on supporting children and young people with challenging behaviour. The support needed by children and young people with a learning disability, autism or both, with behaviour that challenges, may be provided under an IDP, with health, social care and educational input.

### **Additional Learning Needs and Educational Tribunal (Wales) Act 2018**

- 5.15. The Additional Learning Needs and Educational Tribunal (Wales) Act 2018 (ALNET Act) makes provision for a new statutory framework for supporting children and young people with additional learning needs (ALN). This replaces existing legislation surrounding special educational needs (SEN) and the assessment of children and young people with learning difficulties and/or disabilities (LDD) in post-16 education and training. The ALNET Act also continues the existence of the Special Educational Needs Tribunal for Wales, which provides for children, their parents and young people to appeal against decisions made by the LA concerning their or their child's ALN, but renames it the Education Tribunal for Wales.
- 5.16. The ALNET Act creates:
  - a) a unified legislative framework to support all children of compulsory school age or below with ALN, and young people with ALN in school or further education (FE);
  - b) an integrated, collaborative process of assessment, planning and monitoring which facilitates early, timely and effective interventions; and
  - c) a fair and transparent system for providing information and advice, and for resolving concerns and appeals.

- 5.17. The ALNET Act supports a single statutory plan (the individual development plan (IDP)) and increased collaborative working with children, young people and their families, including education, health and social services who will need to work together to deliver efficient, effective, child-centred support for learners with ALN. Whilst most children with ALN will not require any specific health involvement because their ALN will not be health-related, where it is relevant and appropriate, advice and assistance may be sought from health professionals. In particular, LHBs or NHS Trusts will be under a duty to consider whether there is a treatment or service that is likely to be of benefit to addressing the learner's ALN and if so, secure the provision of that treatment or service. That treatment or service will need to be included in the learner's IDP.
- 5.18. The Act will be supported by a new statutory ALN Code. The Code will facilitate national consistency by ensuring that the new ALN system has a set of clear, legally enforceable parameters within which local authorities and those other organisations responsible for the delivery of services for children and young people with ALN, must act. It will, therefore, be a type of subordinate legislation, and confer duties and rights on those subject to it. The Code will also set out practical guidance on how the statutory duties will be carried out, which will be supported by best practice illustrations.
- 5.19. Further information may be accessed via the link below

<https://beta.gov.wales/additional-learning-needs-transformation-programme-frequently-asked-questions>

### **Social Services and Well-being (Wales) Act 2014**

- 5.20. The Social Services and Well-being (Wales) Act ("SSWBA") came into force on 6 April 2016.
- 5.21. The SSWBA provides the legal framework for improving the well-being of people who need care and support, and carers who need support, and for transforming social services in Wales. It transforms the way social services are delivered, promoting people's independence to give them stronger voice and control.
- 5.22. The fundamental principles of the SSWBA are:
- Voice and control – putting the individual and their needs, at the centre of their care, and giving them a voice, and control over the outcomes that help them achieve well-being.
  - Prevention and early intervention – increasing preventative services within the community to minimise the escalation of critical need.
  - Well-being – supporting people to achieve their own well-being and measuring the success of care and support.
  - Co-production – encouraging individuals to become more involved in the design and delivery of services.

- 5.23. Children and Young People: The legal framework builds on the National Assembly's unique approach to children's rights and secures their voice and their participation in decisions about their care and support. The SSWBA and the secondary legislation bring a new focus to meeting the needs of children and young people.
- 5.24. LHBs and LAs must ensure they take account of their duties and obligations under the SSWBA when delivering Continuing Health Care for Children and Young People.
- 5.25. The SSWBA supports person-centred approaches to assessing continuing care need and planning care which should include the following:
- The child or young person's circumstances (presenting need);
  - The child or young person's outcomes (Goals);
  - Barriers (what is preventing the child or young person achieving their outcomes);
  - Risks;
  - Strengths and capabilities (the skills, capacity, support and materials available to the child or family from within themselves, their wider family and their community).

### **Children's Social Care**

- 5.26. Continuing care is intended as the provision of essential health support needed by a child or young person's complex needs. It is not intended to be a social care provision or any other form of non-clinical support. Where a carer is providing support in the home as part of a package of continuing care, they should not be providing social care support, or acting as a childminder, unless such a role is explicitly part of a joint package agreed with the LA, or alternatively, the support constitutes Health-funded respite (on which see below).
- 5.27. Families must not rely on continuing care support to fulfil their primary caring responsibilities for a child or young person (e.g. to allow them to go out or to go to work). Equally, social care support should not be providing what is primary health care (see Annex C for more detail on the Haringey judgement on this point). A continuing-care package is only intended to provide support for an individual child or young person with complex needs, and should not support siblings.

### **The Care and Support (Direct Payments) (Wales) Regulations 2015**

- 5.28. Local authorities can fund individuals for them to purchase their care. Direct Payments give people greater choice and control of their lives. They can choose what, how and when support is provided, and who provides it. Direct payments can be used as an alternative to, or alongside services commissioned by the local authority. The payments are used to support social care, however, may be used to meet health care needs which are incidental and ancillary to the provision of the care being provided by the local authority and as described in R v Haringey 2005.

## Children with Continuing Care in Hospital and School

- 5.29. A child or young person in receipt of a package of continuing care may be admitted to hospital (for example, to a paediatric intensive care unit). In such cases, depending on the child or young person's needs, it may be appropriate to suspend the package of care, if appropriate day-to-day care meeting the child's needs are provided by the hospital. A LHB should avoid a situation in which it is effectively paying for care twice in the same setting.
- 5.30. Where admission is for routine care such as an operation, unrelated to a child's continuing care need and the hospital may not be providing the support needed to meet the child's continuing care needs, and the package should continue, with adaptation as necessary for the new setting. As always, the change in the setting would not change the responsibility of the primary carer.
- 5.31. As part of the governance of children's complex needs in general, the LHB should ensure there are clear expectations on tertiary settings to share information with the continuing care team where a child with continuing care or complex needs is admitted.
- 5.32. Continuing care may be provided whilst a child or young person is in an educational setting, and it is important to ensure that when continuing care is provided, consideration is given to the educational needs of a child or young person. Ensuring a child with complex needs receives essential health support to attend school or college may be delivered through existing community health services, such as community nursing, special school nursing, or palliative care. If an IDP is not necessary, a care and support plan should be in place covering the health care needed, how it is to be delivered, and all essential information for school and community services in support.
- 5.33. The LHB mustn't be tasked with providing continuing care simply as an alternative means of ensuring the child or young person can access education in a particular setting. LA's have a statutory role in relation to support children to access school or education elsewhere: under section 19 of the [Education Act 1996](#)<sup>i</sup> a LA must make arrangements for the provision of education at school or otherwise, for children who by reason of illness would not receive a suitable education unless such arrangements were made. Joint working between the LHB and the LA – if not already established for delivering an IDP - is usually essential to ensure the needs of a child or young person with very complex needs allows them to remain in school, and continuing care may be part of the support required.
- 5.34. WG guidance on supporting learners with medical needs is outlined in the guidance below: <https://gov.wales/additional-learning-needs-special-educational-needs>

## **Short Breaks and Respite**

- 5.35. LAs have a statutory duty to provide breaks from caring, known as short breaks, to the carers of disabled children to allow the carers to undertake education, training or any regular leisure activity, meet the need of other children in the family more effectively, or carry out day to day tasks which they must perform in order to run their household.
- 5.36. LHBs may commission similar respite care for children with complex needs or disabilities. Respite care can be an important part of the health local offer. Indeed, packages of continuing care are often by their nature, providing respite – for example, when overnight care is provided to allow parents to sleep.
- 5.37. LHBs need to ensure that when considering what support a child or young person needs as part of a package of continuing care, they consider also the respite care which might benefit the family or carer.
- 5.38. The assessment of the level of need must recognise that where a child or young person requires constant supervision or care which is largely provided by family members, there will be a need for professional support to allow the family time off from their caring responsibilities, and this may require a social care assessment, and agreement, between the LHB and the local authority of their respective contribution.

# GLOSSARY

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## **Assessment**

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

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

## **Behaviour which challenges**

The NICE quality standard QS101 *Learning disabilities: challenging behaviour* states that: '*Some people with a learning disability display behaviour that challenges. 'Behaviour that challenges' is not a diagnosis and is used in this quality standard to indicate that although such behaviour is a challenge to services, family members and carers, it may serve a purpose for the person with a learning disability (for example, by producing sensory stimulation, attracting attention, avoiding demands and communicating with other people). This behaviour often results from the interaction between personal and environmental factors and can include aggression, self-injury, stereotypic behaviour, withdrawal and disruptive or destructive behaviour.*'

NICE use the following definition of behaviour which challenges, taken from Eric Emerson, *Challenging behaviour: analysis and intervention in people with learning disabilities* (Cambridge University Press, Cambridge, 1995).

'Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.'

<https://www.nice.org.uk/guidance/qs101>

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

A package of care needed over an extended period for children or young people because of disability, accident or illness, which cannot be met by universal or specialist services alone. Children and young people's continuing care is likely to require services from health and local authority children and young people's services. The term continuing care is used to highlight the similarities to NHS Continuing Healthcare.

## **Children and young people's health assessor**

A health practitioner experienced in children and young people's health and skilled in the health assessment of children who leads on the assessment phase of the continuing care process.

Following the completion of the assessment phase, the children and young people's health assessor will produce recommendations for presentation to a multi-agency decision-making forum for them to decide 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 LA to decide what services each will deliver and fund or commission.

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

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

### **Complexity**

This is concerned with how the needs present and interact to increase the skill needed to monitor the symptoms, treat the condition(s) and /or manage the care. This can arise with a single condition or can also include the presence of multiple conditions or the interactions between two or more conditions

### **Consent**

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

Where there are concerns that an individual may have significant ongoing needs, and that the level of appropriate support could be affected by their decision not to give consent, the LHB should discuss with the local authority the implications, as in any other case where consent for treatment is withheld. If the young person is 16 or over, the Mental Capacity Act may apply.

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

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

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



There will be some young people whose needs are such that they will inhibit their ability to engage with the assessment process or to give consent. In such cases, parental responsibility should be sought. For young people 16 and over, the **Mental Capacity Act** (see below) may apply and clinicians should make a best interest assessment.

### **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.

### **Intensity**

This relates to both the extent ("quality") and severity (degree) of the needs and the support required to meet them, including the need for ongoing care.

### **Mental Capacity Act**

The Mental Capacity Act (MCA) is designed to protect and empower individuals who may lack the mental capacity to make their own decisions about their care and treatment. It is a law that applies to individuals aged 16 and over. [The Mental Capacity Act Code of Practice](#) provides detailed guidance on how to undertake assessments of what is in a person's best interests. There is also an NHS factsheet <http://www.nhs.uk/conditions/social-care-and-support-guide/pages/mental-capacity.aspx>.

The NICE guideline covers decision-making in people 16 years and over who may lack capacity now or in the future. It aims to help health and social care practitioners support people to make their own decisions where they have the capacity to do so. It also helps practitioners to keep people who lack capacity at the centre of the decision-making process.

<https://www.nice.org.uk/guidance/NG108>

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

The multi-agency decision-making forum will comprise professionals from different funding agencies involved, including LHBs and LA's. The forum will take into consideration the recommendations and proposed options for packages of continuing care. If a continuing care need is identified, it is for the agencies involved to decide what services each will commission and fund.

### **Nature**

This describes the particular characteristics of a child or young person's needs (which can include physical, mental health, or psychological needs), and the type of those needs. This also describes

the overall effect of those needs on the child or young person, including the type (“quality”) of interventions required to manage them.

### **NHS Continuing Healthcare**

A package of ongoing care that is arranged and funded solely by the NHS where the individual has been found to have a ‘primary health need’ as set out in the statutory guidance (as opposed to a need for local authority care). Such care is provided to an individual aged 18 or over, to meet needs that have arisen as a result of disability, accident or illness. Where an individual has a primary health need and is therefore eligible for NHS continuing healthcare, the NHS is responsible for providing all of that individual’s assessed health and social care needs – including accommodation, if that is part of the overall need

### **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, powers, responsibilities and authority that by law a parent of a child has concerning the child and his/her property. Throughout the document references to “family” include those with parental responsibility. As defined by the Children Act 1989 (see <http://www.legislation.gov.uk/ukpga/1989/41>) a person with parental responsibility for a child could be:

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

### **Specialised services**

Health services which are specialised and target specific groups. Specialised services usually address a range of factors e.g. diagnosis of a rare or serious condition; severity; other underlying conditions; complications and developmental age. Examples include Tier 4 Child & Adolescent Mental Health Services and specialist neuroscience services for children and young people, including neurosurgery. Note that a specialised service, although usually needed for a small number of people, is not a bespoke service; unlike continuing care, it is not commissioned for an individual.

## **Universal and specialist services**

Universal Services are services which are available to all children and young people no matter what their circumstances and include provision by health, education and voluntary services. Examples include:

Health visiting;

GP services;

Nursery;

Primary and Secondary School;

Cub Scouts;

Play schemes.

Specialist services are specific services which generally have referral criteria and require both referral and regular review. Children and young people may move in and out of these services dependent on need. Examples include:

Occupational Therapy

Learning Disability Team

Community Paediatrician

Community Children's Nursing

School Action

School Action Plus

Team around the Family (TAF)

Integrated Disability Team

Children with Disability team

## **Unpredictability**

This describes the degree to which needs fluctuate, creating challenges in managing them. It also relates to the level of risk to the persons health if adequate and timely care is not provided. Someone with unpredictable healthcare need is likely to have either a fluctuating, or unstable or rapidly deteriorating condition.

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