



Welsh Government
Consultation Document

Children and Young People's Continuing Care

Date of issue: 17 May 2019

Action required: Responses by 09 August 2019

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.
This document is also available in Welsh.

Overview This consultation seeks your views on the updated guidance document for Children and Young People's Continuing Care.

How to respond This consultation will close on 09 August 2019. You may respond online, by email or by post.

Online

Please complete the online questionnaire on the consultation pages of the Welsh Government website:

Email

Please complete the consultation response form and send it to: ChildrensHealth@gov.wales

Post

Please complete the consultation response form and send it to:

Women and Children's Health
Welsh Government
Cathays Park
CF10 3NQ

Further information and related documents **Large print, Braille and alternative language versions of this document are available on request.**

Contact details For further information:

Women and Children's Health
Welsh Government
Cathays Park
CF10 3NQ

email: ChildrensHealth@gov.wales

telephone: 03000 251534

General Data Protection Regulation (GDPR)

The Welsh Government will be data controller for any personal data you provide as part of your response to the consultation. Welsh Ministers have statutory powers they will rely on to process this personal data which will enable them to make informed decisions about how they exercise their public functions. Any response you send us will be seen in full by Welsh Government staff dealing with the issues which this consultation is about or planning future consultations. Where the Welsh Government undertakes further analysis of consultation responses then this work may be commissioned to be carried out by an accredited third party (e.g. a research organisation or a consultancy company). Any such work will only be undertaken under contract. Welsh Government's standard terms and conditions for such contracts set out strict requirements for the processing and safekeeping of personal data.

In order to show that the consultation was carried out properly, 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. If you do not want your name or address published, please tell us this in writing when you send your response. We will then redact them before publishing.

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Data Protection Officer:
Welsh Government
Cathays Park
CARDIFF
CF10 3NQ

e-mail:

Data.ProtectionOfficer@gov.wales

The contact details for the Information Commissioner's Office are:

Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Tel: 01625 545 745 or
0303 123 1113

Website: <https://ico.org.uk/>

Introduction

This consultation seeks your views on the updated guidance document *Children and Young People's Continuing Care*.

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. A number of children and young people will have complex mental health or a learning disability requiring specialist therapeutic input or placement provision.

Most needs can be met by the care which is routinely provided by LHB's, or in some cases, Welsh Health Specialised Services. 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 LHB's in determining if a child's needs are such that they require such a package of continuing care.

Continuing Care is defined as care provided over an extended period of time to a person to meet physical or mental health needs which have arisen as a result of illness (any disorder or disability of the mind and any injury or disability requiring medical or dental treatment or nursing). 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.

Background

The current Children and Young People's Continuing Care Guidance (the 2012 guidance) dates from 2012 and is designed for use by all those planning and providing children's continuing care services in health boards, local authorities and their partners.

The legislative landscape has changed significantly since 2012 as several important pieces of legislation have been introduced that have direct relevance to continuing care. These include the Social Services and Well-being (Wales) Act 2016 and the Additional Learning Needs and Education Tribunal (Wales) Act 2018. There is therefore a need to produce revised guidance that takes full account of this legislation.

Welsh Government became increasingly aware that practitioners in health boards and local authorities were finding the 2012 guidance unhelpful and felt there was a focus on process at the expense of actual outcomes. We concluded there was a need to review the 2012 guidance and produce a revised version that clearly put the child at the heart of the process.

To support the development of the revised guidance and also to seek views from practitioners on the issues they had been encountering, Welsh Government held a workshop event in the SWALEC Stadium on 4 October 2018. The event was very

successful, with approximately 80 attendees from a range of health and social services settings across Wales. The outputs from the day confirmed that the 2012 guidance was considered outdated and that there was a real need for revised guidance to be introduced.

To ensure the views of people who were involved in the day to day operation of the continuing care system in Wales were fully reflected, officials established a small task and finish group consisting of practitioners from health and social services teams across Wales to draft the revised guidance.

The draft updated Children and Young People's Continuing Care Guidance is attached to this consultation. We would welcome your feedback and views and have included some specific questions which we would ask that you answer.

Consultation questions

Q1.	Is the guidance clear as to who Children and Young People's Continuing Care is for and are the criteria for eligibility clear?
Q2.	Does the check list at Annex B clearly identify those children and young people eligible for Continuing Care?
Q3.	Is the guidance and the tools sufficiently clear for the identification of need to be looked at in a multi-agency way?
Q4.	Is the process from identification of need, through to assessment clear within the guidance?
Q5.	Does the guidance allow you to understand what information should be used when conducting assessments?
Q6.	Does the guidance provide clarity on how to involve the correct stakeholders to develop a suitable programme of work in support of a child or young person who needs Continuing Care?
Q7.	Is the role of the Multi-agency Panels clear?
Q8.	The nominated children and young people's health assessor makes a recommendation, following 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.

	<p>i. Do you support that the MDT should both:</p> <p>a- Make the recommendation of eligibility?</p> <p>b- Recommend the care package based on assessed need?</p>
<p>Q9.</p>	<p>The timelines have been increased from the guidance in the 2012 document to reflect current working practice.</p> <p>i. Are the revised timelines realistic bearing in mind the plans to roll out the Welsh community care information system (WCCIS)?</p>
<p>Q10.</p>	<p>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 own 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.</p> <p>i. Do you agree with this view that assessments must be led by practitioners who have the necessary skills and competency to assess within the scope of their practice?</p>
<p>Q11.</p>	<p>The completed assessment with recommendations and costed options should be quality assured in line with health board governance arrangements.</p> <p>i. Do you support that governance arrangements should be set out within the guidance?</p> <p>ii. Do the key points cover all aspects of quality assurance?</p>
<p>Q12.</p>	<p>Best practice supports that disputes are resolved as quickly as possible. The interests of the child is paramount and no child should be denied access or have access to the appropriate health care delayed as a result of a dispute. LHB’s and LA’s must have dispute resolution built into their agreed continuing care pathway</p> <p>i. Should the guidance outline a dispute resolution pathway?</p> <p>ii. Should there be formal agreement across health boards for peer review and independent assessment?</p>
<p>Q13.</p>	<p>Does the guidance provide a clear legal position on Direct Payments and in what circumstances their use might be appropriate?</p>

Q14.	Is the guidance clear enough that the use of pooled budgets should be considered as a mechanism for ensuring timely provision of care?
Q15.	We would like to know your views on the effects that the draft Children and Young People Continuing Care Guidance would have on the Welsh language, specifically on opportunities for people to use Welsh and on treating the Welsh language no less favourably than English.
Q16.	Please also explain how you believe the draft Children and Young People Continuing Care Guidance could be formulated or changed so as to have positive effects or increased positive effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language, and no adverse effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language.
Q17.	We have asked a number of specific questions. If you have any related issues which we have not specifically addressed, please use this space to report them.

Responses to consultations are likely to be made public, on the internet or in a report. If you would prefer your response to remain anonymous, please tick here:

DRAFT

The Children and Young People's Continuing Care Guidance

May 2019

Section 1

The Children and Young People's Continuing Care Guidance – An introduction

This guidance is intended to assist Local Health Boards (LHB's), Local Authorities (LA's) 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.

It is intended to support understanding of the range of potential need - physical and learning disabilities, mental health needs, autism or behaviour which may be considered 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 agreement with their local authority partners.

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 is intended to support 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 Wellbeing (Wales) Act 2014 (SSWBA). LHB's have autonomy as to how they fulfil this function, and what process they adopt but adherence to the principles of this framework should ensure consistency and fairness.

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 which are agreed and jointly owned by LHB's, LA's 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.

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 LHB's and LA's to include statutory responsibilities.
- The principles, timelines and the phases involved in assessing and arranging provision of continuing care. It also considers 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.

Section 2

Children and Young People's Continuing Care – An overview

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

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. A number of children and young people will have complex mental health or a learning disability requiring specialist therapeutic input or placement provision.

Most needs can be met by the care which is routinely provided by LHB's, 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 LHB's in determining if a child's needs are such that they require such a package of continuing care.

An important principle of continuing care is that it 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.

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.

The child or young person with continuing care needs should have a clearly structured care pathway, 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^{1*}.

*

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

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

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

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 2014 and supporting guidance and tools. <http://www.cciss.org.uk/home>

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.

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.

If a child or young person is found to be eligible for children and young people's continuing care (CYP CC,) **the LHB is not the responsible body for funding any social care which may be needed - this remains a LA responsibility.** 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. Additionally, the NHS Continuing Healthcare framework should not be used in relation to children and young people (except when anticipating the needs of a young person approaching their eighteenth birthday, see Section 4 below).

Although a child or young person may be in receipt of a package of continuing care, they may not be eligible for NHS Continuing Healthcare or NHS-funded Nursing Care once they turn eighteen.

2.2 The children and young people's continuing care process

The continuing care process comprises of four phases. Assessment, decision-making, arrangement of provision and review.

Examples of screening and assessment tools are to be found in Annex B.

Assessment

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 or not 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 in accordance with the fundamental principle of the Social Services and Wellbeing (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 over reaching the outcomes that help them achieve well-being;
- Holistic assessment taking account of assessments such as a nursing assessment and the care and wellbeing assessment;
- Reports and risk assessments from the multi-disciplinary team.

Best practice supports that a multidisciplinary 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.

The nominated children and young people's health assessor makes a recommendation, following 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.

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 provision of care is included in this guidance.

Decision making

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.

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

This is followed by the **development of a package of care**. Once a decision has been made and communicated, LHB's and LA's as appropriate, will need to make the necessary logistical, funding and contractual arrangements to initiate the delivery of provision of the package of care.

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. 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 prior to 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

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

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.

2.3 Timeline for children and young people’s continuing care process

Phase	Step	Summary of key actions	Time-scale
Assessment phase	Identify	Child or young person with possible continuing care needs is referred to the LHB Screen referral if necessary Fast track if necessary	0-1 week
	Assess	Nominated children and young peoples health assessor collates multiagency assessments, reports, risk assessments	1-3 weeks
Decision making phase	Recommend	Multiagency meeting held and recommendation made for eligibility and package of care outlined Assessment, recommendations and costed options are quality assured within LHB governance framework	3-5 Weeks
	Decide	A multi-agency decision	6 weeks

		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.	
Arrangement of provision phase	Inform	Child or young person and family informed of the decision	5 days
	Deliver	Providers for package of care identified and commissioned Carers training and monitoring arrangements outlined	This will be dependent on complexity commissioning disabled grant funding
	Review	Care package reviewed at 3 months following initial assessment, then annually	3 months

Section 3

Children and Young People's Continuing Care Pathway

An example of a LHB pathway is included in Annex A

3.1 Step 1: Identify

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.

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).

The competency and rights of young people older than 16 years in respect to consent needs to be taken into account and, where appropriate, a mental capacity assessment and best interest decision undertaken.

<https://gov.wales/docs/dhss/publications/130417consenten.pdf>

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. An example is included in Annex B.

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. This may be through multi-agency referral panels or health panel. Where the continuing care need has been emerging over a period of 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.

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. The decision on whether or not to proceed to a formal assessment should be made within 2 weeks of the referral being received and be fully documented. In cases of any doubt a full assessment is necessary.

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.

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 specialist provision.

3.2 Step 2: Assessment

The children and young people's health assessor is the health professional allocated to lead the assessment process on behalf of the LHB.

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 own 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.

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 own 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.

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.

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

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.

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.

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.

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.

Equally, there needs to be open and honest conversation about parenting responsibilities and the families expectations of what a package of care may look like, acknowledging equitable and fair use of resource.

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.

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

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.

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.

3. Reports and risk assessments from the multidisciplinary team

The assessor is responsible for collating the reports and risk assessments in preparation for the multi-agency team meeting.

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

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.

3.3 Step 3: Decision making

It is recommended that the above assessments are brought together within a multi-agency 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 tool is included in Annex B

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 . Prior to 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)

The multi-agency 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.

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.

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.

No discussions about funding responsibilities should be had at the multi agency team meeting.

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.

3.1.1 Quality Assurance of Assessments

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;
- 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 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.

3.1.2 Multi-agency Decision Making Forum

The completed assessment and recommendations is presented to a multiagency decision making forum. The multi-agency decision making forum should be independent from those involved in assessment and is made up of key decision making health and LA professionals including education. A single panel (forum) could consider LA resource requests alongside continuing care provided the members have the right knowledge and experience.

The multi-agency decision making forum will make a decision to support the recommendation or may seek further information. A decision should be made within six weeks of the commencement of the assessment.

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 team meeting.

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.

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 clear written explanation for the decision within 7 working days.

3.1.3 Funding responsibilities and joint working

Services provided as part of the package for children and young people with continuing care needs will be arranged by the LHB, LA's and their partners as appropriate, enabling the child or young person to function optimally within their family, community, education or care setting.

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 in accordance with the SSWBA and subsequent partnership arrangements regulations. 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 funding responsibilities.

All LHB's should have joint arrangements in place with their relevant LA's 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.

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.

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.

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.

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).

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 persons 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.

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
Team around the Child		
One care plan – regular review		
Occupational Therapist Physiotherapist Speech and language therapist Dietitian Community Paediatrician Community children's nurse	Social worker Support worker	Support worker ALN-Co

3.1.4 Complaints and Dispute Resolution

Where a child or young person is found not to have a need for 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.

The child or young person and their family should be informed of their rights and of the complaints procedure in the event of a decision which does not meet their preferences and or expectations.

The NHS complaints procedure "putting things right—raising a concern" about health services from April 2011 described at www.puttingthingsright.wales.nhs.uk is as 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.

LHB's and LA's must have dispute resolution built into their agreed continuing care pathway.

Best practice supports that disputes are resolved as quickly as possible. The interests of the child is paramount and no child should be denied access or have access to the appropriate health care delayed as a result of a dispute.

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.

3.4 Step 4: Arrangement of provision

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.

3.5 Step 5: Review

The child or young person's continuing care package should be reviewed at 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.

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.

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.

Reviews of a child or young persons 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 persons continuing care needs are being met and are not financially motivated.

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, young person and their family. 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.

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.

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

Transition to adult services

All LHB's 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. LHB's 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).

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.

The assessment of a child's continuing care needs must consider the outcomes necessary to enable the child or young person to get the best from life. The outcomes should be specific, deliverable and linked directly to the child's wishes. They should include where appropriate, outcomes for transition, through key changes in a child or young person's life, such as changing schools, moving from children's to adult and/or from paediatric services to adult health, or moving on from further education to adulthood.

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.

It is important that young people approaching adulthood and their families are aware that eligibility for children's continuing care does not pre-suppose eligibility for NHS Continuing Healthcare.

Every child or young person with a package of continuing care approaching adulthood should have a plan for transition to adult or universal health services or to a more appropriate specialised or NHS Continuing Healthcare.

Key principles for transition from children's to adult's services for young people using health or social services are outlined in [NICE guidance \(2016\)](#) and support best practice which equally applies to young people with continuing care needs.

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 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.

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.

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.

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.

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.

Section 5

Legislation and policy in relation to statutory responsibilities

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.

5.1 NHS (Wales) Act 2006

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.

The provision of continuing care may support LHB's in meeting other statutory duties.

5.2 Mental Health Act 1983 After-care Section 117

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

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”.

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

It is essential that continuing care assessments 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.

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. Clearly, 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.

The principle of continuing care, as 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 which have not experienced necessary specialised support.**

5.3 Behaviours that challenge

LHB's have an important role in relation to 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>

As outlined in the previous section, the continuing care process should seek for 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. LHB's should recognise the potential role of continuing care in making a crucial difference to a child at risk of admission.

Behaviours which challenge a care domain used within the assessment process, reflecting that LHB's may have a commissioning role in relation to support for a child or young person with these needs. LHB's 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.

Multi-agency care plans, which explore options prior to 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.

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.

5.4 Additional Learning Needs and Educational Tribunal (Wales) Act 2018

The Additional Learning Needs and Education 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 in relation to their or their child's ALN, but renames it the Education Tribunal for Wales.

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.

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, LHB's 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.

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. Further information may be accessed via the link below

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

5.5 Social services and Wellbeing (Wales) Act 2014

The Social Services and Well-being (Wales) Act came into force on 6 April 2016.

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.

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 reaching 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.

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.

LHB's and LA's must ensure they take account of their duties and obligations under the SSWBA when delivering Continuing Health Care for Children and Young People.

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 personal 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).

5.6 Children's Social Care

Continuing care is intended as provision of essential health support needed by a child or young person's complex needs. It is not intended to be 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).

It is essential that families do 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 a primarily 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.

5.7 The Care and Support (Direct Payments) (Wales) Regulations 2015

Local authorities can fund individuals in order for them to purchase their own 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 provision of the care being provided by the local authority and as described in R v Haringey 2005.

5.8 Children with Continuing Care in Hospital and School

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 is provided by the hospital. A LHB should avoid a situation in which it is effectively paying for care twice in the same setting.

Obviously, 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 setting would not change the responsibility of the primary carer.

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.

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.

It is important that the LHB is not tasked with providing continuing care simply as an alternative means of ensuring the child or young person is able to 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](#)ⁱ 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.

WG guidance on supporting learners with medical needs is outlined in guidance below: <http://learning.gov.wales/docs/learningwales/publications/170330-healthcare-needs-en.pdf>

5.9 Short Breaks and Respite

LA's 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.

LHB's 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.

LHB's 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.

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

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/chapter/Introduction>

Children and young people's continuing care

A package of care needed over an extended period of time 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, and to indicate the long-term nature of the support needed, as it is unlikely that the needs will lessen over time.

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 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 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 in relation to 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.

ANNEX A

Children and Young People Continuing Care Pathway (example)

Referral criteria identified

- Emerging need recognised at child or young persons review
- Discharge planning identifies increased health need which may require a bespoke package of care



Referral form completed and sent to continuing care coordinator / central triage point. Referral logged. Co-ordinator sends letter of receipt to referrer.



Referral discussed in referral/triage meeting. This meeting includes representation from health, social services and education. Referrer and family receive decision in writing. If referral declined the rationale for this is explained.

Once the referral is accepted a health assessor is identified. This is the professional who has the necessary skills and experience to assess the child/ young person's specific needs.



Health assessor collates assessments and reports. Undertakes health assessment. Maintains contact with the child, young person and family.



Multi-disciplinary Team (MDT) Meeting held. Recommendation made on eligibility for children and young peoples continuing care. Package of care discussed and recommendation made.



The completed assessment and recommendations from the MDT are quality assured to ensure that the evidence submitted supports the recommendation made by the MDT. The package of care is outlined with costed options. Liaison with other agencies at this time to discuss feasibility and sustainability of the package of care – for looked after children and specialist placements this may be via the local complex needs panels.



The assessment is presented to the multi-agency decision making panel for multi-agency sign-off. Letter written to child/ young person/ family to confirm decision. *****

Information leaflet

Information for families about referral for children and young people's continuing care

What is continuing care?

Continuing Care is generally defined as a package of care provided to children or young people to meet physical or mental health needs that cannot be met by existing services alone. The package of care will be health focused but may have input from education, social services and sometimes others.

What are the eligibility criteria?

The child must be under the age of 18 years and usually resident in the Local Health Board area.

Why has my child been referred for continuing care?

Professionals (for example a community children's nurse or Learning Disability Nurse) working with your child may have identified increased health needs which require extra support.

This may have been discussed with you at a review or discharge planning meeting

Who can make a referral?

Anyone can make a referral for consideration of eligibility for Continuing Care. This is often a health professional or social worker.

The young person and/or family will need to consent to the process.

The referrer will receive written acknowledgement of the referral.

What happens to the referral?

A health assessor will be assigned to your child; often this is a health professional known to you, for example the community children's nurse or a therapist.

How will I know if the referral is appropriate?

The health assessor will present the referral to a multi-agency meeting who will make a decision on this. Sometimes further information is required before the referral is accepted.

A decision will be sent to the referrer in writing. They will let you know the outcome

My child's referral has not been accepted, Can I appeal against the decision?

If you are not happy about the decision please discuss this with the referring professional who should be able to explain the reason to you.

My child's referral has been accepted, what happens now?

A health assessor will be in contact with you to arrange a more in-depth assessment, often this is a health professional known to you. You and your child's views and opinions will be part of this assessment.

What is the process?

Assessments from health and other professionals involved in your child's care will be collected by the health assessor. Your child may have had numerous assessments and as long as these are still current there would be no need to ask other professionals to reassess. The health assessor will meet with your child to ensure all health information is identified. A meeting, called a multi disciplinary team (MDT) meeting, is then held to discuss the findings and summarise all identified needs. You will be invited to this meeting.

Health needs which are unmet and require specific management will be considered for continuing care. The MDT meeting will make a recommendation on whether your child is eligible for children and young peoples continuing care. The type of care package that may be needed is also recommended by the MDT.

The assessments and recommendations made by the MDT are presented to a multi agency decision making forum. This forum is made up of senior representation from the local health board and the local authority. This forum examine the evidence submitted and make a decision in regard to eligibility.

If a continuing care need is identified, it is for the LHB and the LA to decide what services each will plan, deliver and fund.

How long does the process take?

The process from referral to decision making will take up to 6 weeks. In some instances the decision will be “fast tracked” to ensure a child receives the care needed at the time.

A decision in writing will be sent to you following presentation of your child’s case at the forum.

Preparing the package of care

Once the decision is made the package of care will need to be arranged and the time this takes will depend on the type of care needed. Sometimes a team of carers need to be employed and have specific training to meet your child’s health care needs; this can take a number of months. Your health team will keep you informed of the progress of this.

Can you appeal against the decision of the Panel?

Yes, if you feel that the assessment was not an accurate reflection of your child’s needs please contact and discuss this with your health assessor in the first instance.

In some instances you may be offered an independent review of the collated assessments.

Should you feel that the matter cannot be resolved locally please use the NHS complaints procedure “Putting Things Right – Raising a Concern about Health Services from April 2011” described at:

www.puttingthingsright.wales.nhs.uk

Or ask your health assessor for a leaflet detailing contact numbers.

ANNEX B

Checklist for consideration of Children and Young People's Continuing Care eligibility

The Children and Young People's continuing Care guidance applies to children and young people whose health needs cause them to require a bespoke multi agency package of continuing care **that cannot be met by existing universal or specialist services alone**. Although the main reason for such a package will derive from the child or young person's health needs, they are likely to require multi agency service provision involving input from education, social services and sometimes others.

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.

This checklist is not a substitute for the continuing care process and the outcome does not necessarily indicate eligibility for continuing care, however it will support practitioners to consider when a full holistic assessment is required and there may be indication for children and young people's continuing care.

This checklist must be used in conjunction with a nursing assessment or working knowledge of the child / young person.

On completion of the checklist the health assessor will inform the referrer and child / young person and their family /carer of the decision.

Personal Details

Date of Completion	
Patients Name	
Date of Birth	
NHS Number	
Gender	
Permanent Address	
Telephone Number	
Current Residence (if not permanent address)	
Name of representative (Parent/carer)	
Name of referrer	

Date of referral	
-------------------------	--

Summary of the referral with child or young person’s situation, relevant history and current needs, including clinical summary and identified significant risks.

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Please list the multi-agency universal and specialist services which input into the child’s / young person’s care. Examples of universal services: GP, Dentist, Health Visitor, School nurse, Education. Specialist services: CCN Service, Enteral Feeding Team, Specialist Nurses, OT, Physio, Salt, Dietitian, Community consultant, Specialist consultant, Social services.

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**Care Domains
Behaviours which challenge**

Description (appropriate to age)	Score =	How is this need currently being met?
No evidence of challenging behaviour or Some incidents of challenging behaviour that are manageable and do not pose a significant risk or barrier to intervention. The child or young person is usually compliant with care. Or 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.	C	
Challenging behaviour (severity or frequency) that requires specialist clinical assessment, advice and review. Or 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. NBV the behaviour may be evidenced on a frequency basis, or it may be that the withdrawal of skilled support would result in those behaviours reoccurring.	B	
Behaviour (severity or frequency) that poses an		

immediate risk to self and others requiring urgent specialist intervention to reduce or manage risk and needs a highly specialist multi-agency program of intervention.	A	
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Cognition

Description (appropriate to age)	Score=	How is this need currently being met?
No evidence of developmental or learning problems, confusion or disorientation. or 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.	C	
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, the 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.	B	
Cognitive impairment that may include marked comprehensive or memory issues and maybe lack of understanding of time and place. The child or young person has awareness of only a limited range of needs and basic risks. 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. Or 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.	A	

Psychological and Emotional Needs

Description (appropriate to age)	Score=	How is this need currently being met?
<p>No additional psychological or emotional needs apparent for age and development stage. Or Mild depressive or anxiety symptoms, periods of distress which respond to prompts and reassurance. OR Requires prompts to motivate self towards activity and to engage in care plan and/or daily activities.</p>	C	
<p>Depression, anxiety or anger which results in periods of distress which do not readily respond to prompts and reassurance. OR Withdraws from social situations. Demonstrates difficulty in engaging in care plan and/or daily activities.</p>	B	
<p>Rapidly fluctuating moods of depression, necessitating specialist support and intervention, which have a severe impact on the child or young person's health and well being to such an extent that they cannot engage with daily activities such as eating, drinking, sleeping or which place the child or young person at risk: OR Acute and/or prolonged presentation of emotional/psychological deregulation, poor impulse control placing child, your person or others at serious risk, and/or symptoms of serious mental illness that places the young person at risk to his/her self and others; this will include high-risk, intentional self-harming behaviour.</p>	A	

Communication

Description (appropriate to age)	Score=	How is this need currently being met?
<p>Communicates clearly, verbally or non verbally appropriate to development. Has a good understanding of their primary language. May require translation if English not their first language or the ability to communicate through the medium of Welsh if that is their preferred language. Able to understand or communicate clearly, verbally or non verbally within their primary language appropriate to their development level. Or</p>	C	

Requires 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 child or young person. Expressive or receptive language.		
Communication about basic needs is difficult to understand or interpret, even when prompted, unless with familiar people and requires regular support.	B	
Requires frequent or significant support from carers and professionals to enable the child to either understand or communicate basic needs, requirements or ideas, even with familiar people.	A	

Mobility

Description (appropriate to age)	Score	How is this need currently being met?
Independently mobile as appropriate for age and development stage (with or without aids). Or Able to stand as appropriate for developmental age, but needs some assistance and, requires support to access curricular or extra-curricular activities. Or 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.	C	
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. OR At high risk of injuries, requiring a structured management plan to minimise risk, appropriate to the stage of development. OR Involuntary spasms placing themselves and carers at risk.	B	
Completely immobile and unstable clinical condition such that on movement or transfer there is a high risk of serious physical harm. OR	A	

Where the positioning is critical to physiological functioning or life		
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Nutrition, Food and Drink

Description (appropriate to age)	Score=	How is this need currently being met?
<p>Able to take adequate food and drink by mouth to meet all nutritional requirements. Appropriate to developmental age.</p> <p>or</p> <p>Some assistance required above normal for their age.</p> <p>OR</p> <p>Needs supervision, prompting, encouraging with food and drinks above normal requirement for age. 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 undertaking of consequences of food or drink intake. OR</p> <p>Needs feeding when this is not normal developmentally, but is not time consuming.</p>	C	
<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. OR</p> <p>Unable to take adequate food and drink by mouth, most nutritional requirements taken by artificial means e.g. via a non-problematic tube feeding device, nasogastric tube included.</p>	B	
<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 OR</p> <p>Problems with intake of food and drink, requiring intervention to manage nutritional status. Unintended weight loss placing the child or young person at risk and needing skilled intervention OR</p> <p>Problems relating to a feeding device that requires skilled assessment and review.</p> <p>or</p> <p>All fluids and nutritional requirements taken by intravenous means</p>	A	

Continence and Elimination

Description (appropriate to age)	Score=	How is this need currently being met?
Continent of urine and faeces (appropriate to age) Or Continenence care is routine on a day-to-day basis and age appropriate: Incontinence of urine managed through e.g medication, regular toileting, pads use of penile sheath etc. AND Is able to maintain full control over bowel movements or has a stable stoma and may have occasional faecal incontinence.	C	
Continenence 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.	B	
Continenence care is problematic and requires timely intervention by a skilled practitioner or trained carer OR Intermittent catheterization OR Is regularly incontinent of faeces several times a day or has a stoma that needs attention several times a day Or Requires peritoneal/haemodialysis to sustain life	A	

Skin and Tissue Viability

Description (appropriate to age)	Score=	How is this need currently being met?
No evidence of pressure damage or skin condition Or Evidence of pressure damage and pressure or a minor wound requiring treatment or Skin condition that requires clinical re-assessment less than weekly.	C	
Open wound(s), responding to treatment OR Active skin condition requiring a minimum of weekly re-assessment and which is responding to treatment OR High risk of skin breakdown, which requires preventative intervention from skilled carer or care worker several times each day without which skin	B	

<p>integrity would break down Or Open wound(s), not responding to treatment and require a minimum of daily monitoring/re-assessment OR Active skin condition, which requires a minimum of daily monitoring or re-assessment</p>		
<p>OR Specialist dressing regime, several times weekly in place, which is responding to treatment. Requiring regular supervision by a Consultant Or Life threatening skin conditions or burns requiring complex distressing routines over a prolonged period.</p>	A	

Breathing

Description	Score=	How is this need currently being met?
<p>Normal breathing (age appropriate rate) no issues with shortness of breath Routine use of inhalers, nebulisers, etc</p>	C	
<p>Episodes of acute breathlessness, which do not respond to self-management and need specialist recommended input Requires the use of a low level oxygen therapy each night or oxygen via a facial or nasal mask or other therapeutic appliances to maintain airflow to prevent secondary health issues OR Has profoundly reduces mobility leading to increased susceptibility to chest infection OR Requires daily physiotherapy to maintain optimal respiratory function</p>	B	
<p>Is able to breathe independently through a tracheotomy that they can manage themselves or with the support of carers/parents. Has patent but sub-optimal airway without tracheotomy tube OR Is able to breathe unaided during the day but needs to go on a ventilator for supportive ventilation – the ventilation can be discontinued for up to 48 hours without clinical harm OR Is on Continuous Positive Airways Pressure (CPAP) Has frequent hard to predict apnoeas AND/OR Severe life threatening breathing difficulties Extreme difficulties 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 AND/OR Requires ventilation at night for very poor respiratory function has respiratory drive and would survive</p>	A	

accidental disconnection but would not be well and require hospital support or Unable to breathe independently, requires permanent mechanical ventilation Has no respiratory drive when asleep or unconscious and requires ventilation and 1:1 support whilst asleep, as disconnection would be fatal A highly unstable tracheotomy, frequent occlusions, difficult to change tubes		
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Drugs Therapies and Medicines

Description	Score=	How is this need currently being met?
Parent, informal carer or self-administered medication	C	
Requires a suitably trained member of formal carer, teaching assistant or nurse to administer medicine due to:- <ul style="list-style-type: none"> • Age • Non compliance • Type of medicine • Route of medicine • Place where medication is to be given Or Requires administration of medicine regime by a registered nurse or care worker specifically trained for this task AND Monitoring because of potential fluctuation of the medical condition that can be non-problematic	B	
Has a drug regime that requires management by a registered nurse (within prescription) due to a fluctuating and/or unstable condition or symptom management or 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 rapidly changing/deteriorating condition or Has a medicine regime that requires daily management by 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	A	

Seizures or Altered States of Consciousness (ASC) Description	Score	How is this need currently being met?
No evidence of seizures or ASC. Or History of seizures or ASC but none in the past 3 months. Medication (if any) is stable.	C	
Occasional seizures or periods of unconsciousness that have occurred within the last three months which require the supervision of a carer or care worker to minimise the risk of self-harm.	B	
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. Or 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. Requires daily intervention by a registered nurse who will use clinical judgement to select and implement from a range of appropriate interventions to manage seizures and treat any related risks	A	

Other significant care needs to be taken into consideration:

There may be circumstances, on a case-by-case basis, where a child or young person 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 child or young person 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.

Outcome

Care Domain	C	B	A
Challenging Behaviour			
Cognition			
Psychological and Emotional Needs			
Communication			
Mobility			
Nutrition, food and Drink			

Continence			
Skin & Tissue Viability			
Breathing Drug Therapies			
Drug Therapies			
Altered States of Consciousness			
Other significant care needs			

A score of mainly C's would indicate that care needs are low and /or routine and could be met through core services. A score of mainly B's may indicate the need for continuing care depending on level of input required and skills. May require full assessment for consideration for children and young people's continuing care. Mainly A's would indicate nursing needs and consideration for children and young people's continuing care.

Recommendation	Please tick as appropriate	Rationale
The identified health needs can be met through existing universal and / or specialist services		
The identified health need cannot be met through existing universal and / or specialist services and a full assessment for children and young people's continuing care is required		

Signature of health assessor:

Date:

The referrer and the child / young person and / or family/carers must be informed of the outcome and decision to proceed or not proceed with continuing care process. A rationale must be given.

Assessment Tool – from NWIS (awaiting sign off)

National – Community Nursing - Childrens Assessment

CCIS ID		NHS No		Referral No	
First Name		Middle Name		Last Name	
Date of Birth:		Age		Age if Estimated	
Gender			Nationality		
Religion			Ethnicity		
Primary Address					
Post Code		Email Address			
Home Phone		Mobile Phone		Work Phone	
Preferred Language		Preferred Contact Method		Interpreter Required	

Assessment Date

DD	MM	YYYY
----	----	------

Date(s) Child/young person and family members seen/interviewed

Date	Name	Was the child/young person seen at interview
		Yes <input type="checkbox"/> No <input type="checkbox"/>

Medical History

Medical History

Current Medication

Client Allergies

Allergy Type	Allergen - What Substance Caused the Reaction	Reaction	Start Date and Time	Level
--------------	---	----------	---------------------	-------

Medical History

Medical History

Current Medication

Client Allergies

Allergy Type	Allergen - What Substance Caused the Reaction	Reaction	Start Date and Time	Level
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WHAT MATTERS

What matters to me (the child/young person)

What is stopping you from achieving the things that matter to you?

Views of Others Who Know Me

What Outcomes am I trying to achieve

--

I think that (my) parent(s)/corporate parent/family member/carer/advocate/other could provide support in the following ways

--

What additional support does the child/young person require?

--

MAKING EVERY CONTACT COUNT (MECC)

The making every contact count (MECC) lifestyle information resource is available at the MECC Public Health Wales website

Available here <http://www.wales.nhs.uk/sitesplus/888/page/65550>



MECC Public Health Network

Mental Health/Emotional Well Being

Have you recently been feeling of low mood/depressed?	Comments
Do you ever feel anxious?	Comments
Do you ever feel lonely?	Comments

--	--

Exercise

Are you physically active?	Comments
----------------------------	----------

Nutrition

Do you require any healthy eating advice and support?	Comments
Do you drink alcohol?	If yes, how much?
Does the patient require any support with reducing their alcohol consumption? If yes, please consider drug and alcohol services	Comments

Smoking

Are you a smoker or vape user?	If yes, do you require support to reduce or quit smoking?
--------------------------------	---

	https://www.helpmequit.wales/
--	---

Medication

MECC - Medication

Are you up to date with your immunisations?	Comments
---	----------

Mental Health/Emotional Well Being

Have you recently been feeling of low mood/depressed?	Comments
Do you ever feel anxious?	Comments
Do you ever feel lonely?	Comments

Exercise

Are you physically active?	Comments
----------------------------	----------

Nutrition

Do you require any healthy eating advice and support?	Comments
Do you drink alcohol?	If yes, how much?
Does the patient require any support with reducing their alcohol consumption? If yes, please consider drug and alcohol services	Comments

Smoking

Are you a smoker or vape user?	If yes, do you require support to reduce or quit smoking? https://www.helpmequit.wales/
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Medication

MECC - Medication

Are you up to date with your immunisations?	Comments
---	----------

COMMUNICATION DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

COGNITIVE/NEUROLOGICAL DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

Is there an Epilepsy care plan?

Title	Type	Sub Type	Owner	Status
Epilepsy Care Plan	Health	Health - Incoming Correspondence	David Hopkins	Active

LAC Legal Status

Start Date (item 6)	Reason (item 7)	Legal Status (item 8)	End Date (item 11)
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MENTAL CAPACITY

Tool Tip:

For children under 16 consider Fraser Guidelines and Gillick Competency. For young people aged 16 and over consider Mental Capacity.

Is the patient aged 16 or over?

Do you have any concerns about the patients capacity to engage in this assessment or cognitive ability?

Is it temporary or permanent

Does the individual lack the understanding of the consequences of making or not making the decision?

Is the individual unable to understand the information being provided?

SPIRITUAL DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

Is there a Paediatric Advance Care Plan

SLEEP DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

PAIN DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

Has a pain assessment been completed?

NUTRITION DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

Is there a concern about the child's height and weight?

How is the child/young person fed?

Is there a dietetic feeding regime?

MENTAL CAPACITY

Tool Tip:

For children under 16 consider Fraser Guidelines and Gillick Competency. For young people aged 16 and over consider Mental Capacity.

Is the patient aged 16 or over?

Do you have any concerns about the patients capacity to engage in this assessment or cognitive ability?

Is it temporary or permanent

Does the individual lack the understanding of the consequences of making or not making the decision?

Is the individual unable to understand the information being provided?

PERSONAL CARE DOMAIN

Patient Concerns are

Nurse's Comments/Observations

Has puberty commenced?

Are there any issues around sexual health?

ORAL HEALTH

Child/young person/carer concerns are

Nurse's Comments/Observations

Has an oral assessment been undertaken?

Are there oral health issues?

If yes please complete ORAL ASSESSMENT TOOL

SKIN DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

--

Pressure Sore Predictor Score (PSPS)

RISK ASSESSMENT SCORING TOOL

BUILD AND WEIGHT FOR HEIGHT	MOBILITY
APPETITE	ELIMINATION
SKIN CONDITION	DRUGS

Total Risk Score

Low Risk (0-5) Medium Risk (6-10) High Risk (11 or more)

--

Pressure Sore Predictor Score (PSPS)

RISK ASSESSMENT SCORING TOOL

BUILD AND WEIGHT FOR HEIGHT	MOBILITY
APPETITE	ELIMINATION
SKIN CONDITION	DRUGS

Total Risk Score

Low Risk (0-5) Medium Risk (6-10) High Risk (11 or more)

--

BLADDER AND BOWEL DOMAIN

Child/young person/carer concerns are

--

Nurse's Comments/Observations

If products are supplied, please give details

MOBILITY DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

BREATHING DOMAIN

Child/young person/carer concerns are

Nurse's Comments/Observations

DRUG THERAPIES AND MEDICATION DOMAIN

Child/young person/carer concerns are

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Nurse's Comments/Observations

--

OBSERVATIONS

Client Height & Weight

Date/Time Taken	Weight Kilograms	Height Metres	Head Circumference	Length Centimetres	Date/Time Of Next Screening	BMI Score	Owner

Physical Observation

Date & Time Taken	Temperature (Celsius)	BP (Systolic)	Blood Pressure Reading Type	BP (Diastolic)	Seco nd BP Systolic	Seco nd BP Reading Type	Seco nd BP Diastolic	Pulse	Respiration	O2 Saturation	Pe ak Flow	Blood Sugar Levels (mmols/Litres)

24 Hour Care Regime as indicated by child/young person/ parent/ carer

Time	Activity	By Whom
01:00		
02:00		

03:00		
04:00		
05:00		
06:00		
07:00		
08:00		
09:00		
10:00		
11:00		
12:00		
13:00		

14:00		
15:00		
16:00		
17:00		
18:00		
19:00		
20:00		
21:00		
22:00		
23:00		
24:00		

Specialist Equipment

Item	Manufacture	Amount	Purchased by	Service Due Date

CCIS ID		NHS No		Referral No	
First Name		Middle Name		Last Name	
Date of		Age		Age if	

Consumables Equipment Required

Item	Size	Amount per month	Supplied by

SOAP

SOAP / Case Note

Summary of Need Tool

National - Community Children's Nursing - Decision Support Tool

Birth:				Estimated	
Gender			Nationality		
Religion			Ethnicity		
Primary Address					
Post Code		Email Address			
Home Phone		Mobile Phone		Work Phone	
Preferred Language		Preferred Contact Method		Interpreter Required	

Was the child or young person involved in the completion of the DST **YES/NO**

Does the child / young person have an independent advocate or parent representative?
(From 14 years all CYP should be referred for independent advocacy) **YES/NO**

If yes, did the representative attend the completion of the DST **YES/NO**

Has a mental capacity assessment been undertaken?
(this will apply to YP from 16 years who are unable to make some or all decisions) **YES/NO**

Contact details of the representative (name, address and telephone number)

Name	Details

Personal Details

Summary pen portrait of the child or young person's situation, relevant history and current needs, including clinical summary and identified significant risks, drawn from the multidisciplinary assessment.

Summary of **child or young person's** view of their care needs and whether they consider that the multidisciplinary assessment accurately reflects these:

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Summary of **carer's** view of care needs and support they need as carer and whether they consider that the multidisciplinary assessment accurately reflects these.

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Personal Details

Note below whether and how the child, young person, parent/carer (or their representative) contributed to the assessment of their needs. If they were not involved, record whether they were not invited or whether they declined to participate.

List the assessments and other key evidence that were taken into account in completing the DST, including the dates of the assessments:

Evidence	Date

MDT member's and Health Assessor's name and contact details

Name	Profession/Designation	Contact Details	Signature

Primary Health Needs Approach

When examining domains of care it is recommended to use the four headings as outlined below in order to capture the service, staff and skill resource which may be required to meet the child’s needs. This also allows for discussion on parental resilience and capacity for care. The aim is to identify the needs which remain unmet after consideration of universal and specialist services

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.

Intensity: This relates to both the extent (‘quantity’) and severity (degree) of the needs and the support required to meet them, this would also including the need for short break support where care is constant and demanding.

Complexity: This is concerned with how the needs present and interact to increase the skill needs 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. There should be discussion on those tasks which may be delegated and the training needs and governance arrangements which may need to be put in place. Where a task cannot be delegated health may need to consider a bespoke package of care.

Unpredictability: This describes the degree to which needs fluctuate, creating challenges in managing them. It also relates to the level of risk to the person’s health is adequate and timely care is not provided. Someone with an unpredictable healthcare need is likely to have either a fluctuating, or unstable or rapidly deteriorating condition. This may help form the type of care package required and the level of expertise needed by a trained carer.

Role of Health Care Assessor: 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 health assessor is responsible for ensuring that the child/young person and their family are informed about the process from assessment to the decision by the multi-agency decision making panel. Consent must be obtained from the child/YP and/or their family and should include consent to share information with other professionals and partner agencies.

Care Domains

This document aims to bring assessment information together in a format which puts the child / young person at the centre of care planning. Where possible this summary of need should be used within a multi - disciplinary meeting and outcomes embedded into the child/ young person’s care plan.

The 10 domains should build a picture of the child/ young person’s overall needs and how these are currently being met or how they may be met through existing services. When a need remains unmet after examination of available universal and specialist services there may be a need for a bespoke package of care.

1. Behaviours that Challenge

Behaviour, compared with children of the same age, 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.

1. Describe the actual needs of the child/young person (this may be referenced to the supporting evidence).
2. How is this need currently being met?
3. What is working?
4. What further interventions or referrals are required for unmet need?

<p>Nature <i>What is happening now? What are the risks? What is required to reduce risk?</i></p>	<p>Complexity <i>What is the level of skill needed to manage the behaviours? What training can be put in place to ensure carers have skills needed to support child/young person?</i></p>
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<p>Unpredictability <i>Is the behaviour pattern predictable? Can a care worker follow a prescribed plan of care?</i></p>	<p>Intensity <i>Are behaviours frequent with high risk of injury to self / others? What would be the result of withdrawal of intensity of support?</i></p>

2. Psychological and Emotional Needs

Beyond what is normally expected at this age use this domain to record the child or young person's psychological and emotional needs and how they contribute to the overall care needs, noting the underlying causes. There should be evidence of whether or not the child or young person has already got a diagnosed psychiatric disorder, and whether there have been recent changes in psychological needs and their impact on the child or young person's health and well being. To avoid double weighting, difficulties with behaviour that are not clearly related to underlying mental health difficulties should be considered under the **'Challenging Behaviour Domain' and not this domain.** Where the child or young person is unable to express their psychological/ emotional needs (even with appropriate support) due to the nature of their overall needs, this should be recorded and a professional judgement made based on the overall evidence and knowledge of the child or young person.

1. Describe the actual needs of the child or young person (this may be referenced to the supporting evidence).
2. How is this need currently being met?
3. What is working?
4. What further interventions or referrals are required for unmet need?

<p>Nature <i>Is there a diagnosis or symptoms of a serious mental illness? What would the consequences be if current support was withdrawn?</i></p>	<p>Complexity <i>Is specialist support/ referral required? What level of skill is required to help the child/young person engage in care or daily activities?</i></p>
Unpredictability	Intensity

<p><i>What are the risks to this child/young person? Is there history of self-injurious behaviours?</i></p>	<p><i>What is the level of monitoring required to support this child/young person?</i></p>
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3. Communication

Some children and young people will have long term communication difficulties which can be anticipated and managed through familiarity with the child or young person. This domain should clearly identify how the child or young person usually communicates and any changes in communication. If children or young people have communication needs these should be reflected in the MDT assessment. This section relates to difficulties with expression and understanding, not with the interpretation of language.

For some children and young people their first language is Welsh. To ensure that they can express themselves and that information is communicated effectively it is important that they are able to use their own language in accordance with the Welsh Language (Wales) Measure 2011. This would equally apply to children and young people who are unable to communicate through the spoken word.

From 14 years advocacy should be offered to young people as part of their transition to adult services.

1. Describe the actual needs of the child or young person, this may be referenced to the supporting evidence.
2. How is this need currently being met?
3. What is working?
4. What further interventions or referrals are required for unmet need?

<p>Nature <i>What is the level of disability for this child/young person? What are the risks to the child if unable to communicate even basic needs?</i></p>	<p>Complexity <i>What support is required to ensure the child/young person's basic needs are understood?</i></p>
<p>Unpredictability <i>Do carers need to anticipate all care needs?</i></p>	<p>Intensity <i>Does the child/young person require high levels of support over a 24hr period?</i></p>

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4. Mobility

This section considers children and young people with impaired mobility. Where mobility problems are indicated, an up-to-date Moving and Handling and Falls Risk Assessment should exist or have been undertaken as part of the current assessment process and the impact and likelihood of any risk factors considered.

1. Describe the actual needs of the child or young person, this may be referenced to the supporting evidence.
2. How is this need currently being met?
3. What is working?
4. What further interventions or referrals are required for unmet need?

<p>Nature <i>Is there a history of fracture due to immobility?</i></p>	<p>Complexity <i>What are the skills and training required for moving and handling? Is positioning critical to physiological functioning or life?</i></p>
<p>Unpredictability <i>Is moving and handling unpredictable due to involuntary spasms?</i></p>	<p>Intensity <i>How often does the child/young person require change of position?</i></p>

5. Nutrition, Food and Drink

Where Children and Young People are at risk of malnutrition, dehydration and/or aspiration they should either have an existing assessment of these needs or have had one carried out as part of the assessment process with any management and risk factors supported by a management plan. Such assessments must be evidence based and used in conjunction

with clinical judgement.

Well established enteral feeding via gastrostomy is a safe method of feeding and children/ young people would no longer be considered at risk

1. Describe the actual needs of the child or young person, this may be referenced to the supporting evidence.
2. How is this need currently being met?
3. What is working?
4. What further interventions or referrals are required for unmet need?

<p>Nature <i>What are the risks associated with the current feeding needs? Is there potential for reduction of risk?</i></p>	<p>Complexity <i>What are the skills and training required to undertake this task? Can this task be delegated to a carer with training and assessment of competency?</i></p>
<p>Unpredictability <i>Is there a history of choking and aspiration? How is this risk managed?</i></p>	<p>Intensity <i>Is the feed plan intense? How many feeds a day? How many flushes including access for medication?</i></p>

6. Continence and Elimination

Where continence problems are identified, a full evidence based continence assessment exists or has been undertaken as part of the assessment process, any underlying conditions identified, and the impact and likelihood of any risk factors evaluated.

1. Describe the actual needs of the child or young person, this may be referenced to the supporting evidence.
2. How is this need currently being met?
3. What is working?
4. What further interventions or referrals are required for unmet need?

<p>Nature <i>What are the long term implications for the child/young person?</i></p>	<p>Complexity <i>Are there identified tasks associated with continence which require specialist skills? Can these skills be delegated to a support worker?</i></p>
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Unpredictability	Intensity <i>Is there evidence of the child /young person requiring frequent interventions in regard to continence care?</i>
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7. Skin and Tissue Viability

Evidence of wounds should derive from an evidence based wound assessment or tissue viability assessment completed by an appropriate professional. Here, a skin condition is taken to mean any condition which affects or has the potential to affect the integrity of the skin. Wound management should be supported by a care plan identifying the wound with a regular evaluation of the treatment given, documented on a wound assessment chart. This chart should clearly state the wound dimensions and appearance. A rationale for the type of dressing should also be provided. This domain should consider the relationship with other domains including mobility and nutrition.

1. Describe the actual needs of the child or young person, this may be referenced to the supporting evidence.
2. How is this need currently being met?
3. What is working?
4. What further interventions or referrals are required for unmet need?

Nature <i>Is there a diagnosis which requires regular supervision by a consultant or specialist nurse?</i>	Complexity <i>Is there a complex dressing routine to manage a chronic skin condition?</i>
Unpredictability <i>Is there evidence that management of skin is unpredictable?</i>	Intensity <i>Is there high risk of skin breakdown which requires preventative intervention from a skilled carer?</i>

8. Breathing

Evidence of breathing difficulties should derive from a clinical assessment by the appropriate professional e.g Respiratory nurse. Here a breathing condition is taken to mean any condition which affects respiratory and the impact that this may have on a child or young person's ability to independently undertake activities of daily living. In determining the level of need, it is the knowledge and skill required to manage the clinical need that is the determining factor.

1. Describe the actual needs of the child or young person, this may be referenced to the supporting evidence.
2. How is this need currently being met?
3. What is working?
4. What further interventions or referrals are required for unmet need?

<p>Nature <i>Is the child/young person ventilated / dependent on tracheostomy / oxygen?</i></p>	<p>Complexity <i>What is the level of skill and training required to support this care need? Can the task be safely delegated?</i></p>
<p>Unpredictability <i>Is there a history of apnoea? Does the child/young person have an unstable airway? What are the risks?</i></p>	<p>Intensity <i>How often are the interventions carried out in relation to airway management? Is there a requirement for 24hr support?</i></p>

9. Drugs Therapies and Medicines

There is an expectation that parents / guardians will retain responsibility for the management and administration of prescribed medications. Where medication regimes are complicated by changing dosages, large numbers of medications and varying routes of administration. In some situations, a child or young person or their carer will be managing their own medication and this can require a high level of skill.

1. Describe the actual needs of the child or young person, this may be referenced to the supporting evidence.
2. How is this need currently being met?
3. What is working?

4. What further interventions or referrals are required for unmet need?

<p>Nature <i>Is the child/young person's condition managed primarily through medication?</i></p>	<p>Complexity <i>Does the administration of medication involve specialist skill? Is specialist training required?</i></p>
<p>Unpredictability <i>Is there frequent change to prescriptions, involving titration of medicines on a daily basis?</i></p>	<p>Intensity <i>Is there a large volume of medicines which need to be administered over a 24hr period?</i></p>

10. Seizures or Altered States of Consciousness (ASC)

ASCs can include a range of conditions that affect consciousness.

1. Describe the actual needs of the child or young person; this may be referenced to the supporting evidence.
2. How is this need currently being met?
3. What is working?
4. What further interventions or referrals are required for unmet need?

<p>Nature</p>	<p>Complexity <i>What is the skill set required to adhere to the care plan? Can training and assessment of competency meet this need? Is identified treatment plan complex?</i></p>
<p>Unpredictability <i>How well controlled are seizures? What are risks in relation to child/young person's safety?</i></p>	<p>Intensity <i>How much time is spent over 24hr period managing seizure activity?</i></p>

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Other significant care needs to be taken into consideration:

There may be circumstances, on a case-by-case basis, where a child or young person 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 child or young person 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.

Outcomes which can be met through universal and specialist services

Outcome 1:		
What needs to be done?	By whom	By when
Outcome 2:		
What needs to be done?	By whom	By when
Outcome 3:		
What needs to be done?	By whom	By when

Evidence of unmet needs and plan of action

Action 1:		
How can this be met?	By whom	By when

Recommendation in regard to eligibility for children and young people's continuing care:-

Name	Role	Signature

Annex C: Summary of the Haringey case

A summary of the judgment in R (on the application of D and another) v Haringey London Borough Council ('the Haringey case') is presented here for reference and should be taken into account when deciding on and putting in place packages of continuing care.

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

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

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

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

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