



Llywodraeth Cymru  
Welsh Government

# The Children and Young People's Continuing Care Guidance

January 2020

Annexes

## ANNEX A

### 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

|                           |  |
|---------------------------|--|
| <b>Date of Completion</b> |  |
| <b>Patients Name</b>      |  |
| <b>Date of Birth</b>      |  |
| <b>NHS Number</b>         |  |

|                                                        |  |
|--------------------------------------------------------|--|
| <b>Gender</b>                                          |  |
| <b>Permanent Address</b>                               |  |
| <b>Telephone Number</b>                                |  |
| <b>Current Residence (if not permanent address)</b>    |  |
| <b>Name of representative (Parent/carer)</b>           |  |
| <b>Name of referrer</b><br><br><b>Date of referral</b> |  |

**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? |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------|---------------------------------------|
| <p>No evidence of challenging behaviour</p> <p>or</p> <p>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.</p> <p>Or</p> <p>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.</p>                                                      | C       |                                       |
| <p>Challenging behaviour (severity or frequency) that requires specialist clinical assessment, advice and review.</p> <p>Or</p> <p>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.</p> | B       |                                       |
| <p>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.</p>                                                                                                                                                                                                                                                                                                   | A       |                                       |

## Cognition

| Description (appropriate to age)                                                                                                                                                                                      | Score= | How is this need currently being met? |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------|---------------------------------------|
| <p>No evidence of developmental or learning problems, confusion or disorientation.</p> <p>or</p> <p>Cognitive impairment which requires some supervision, prompting or assistance with more complex activities of</p> | C      |                                       |

|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |   |  |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---|--|
| daily living appropriate to age, but awareness of basic risks that affect their safety is evident.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |   |  |
| 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 |  |
| <p>Cognitive impairment that may include marked comprehensive or memory issues and maybe lack of understanding of time and place.</p> <p>The child or young person has awareness of only a limited range of needs and basic risks.</p> <p>The child or young person finds it difficult even with supervision, prompting or assistance to make decisions about key aspects of their lives, which consequently puts them at high risk of harm, neglect or health deterioration.</p> <p>Or</p> <p>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.</p> | 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.</p> <p>Or</p> <p>Mild depressive or anxiety symptoms, periods of distress which respond to prompts and reassurance.</p> <p>OR</p> | C      |                                       |

|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |   |  |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---|--|
| Requires prompts to motivate self towards activity and to engage in care plan and/or daily activities.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |   |  |
| Depression, anxiety or anger which results in periods of distress which do not readily respond to prompts and reassurance.<br><br>OR<br><br>Withdraws from social situations. Demonstrates difficulty in engaging in care plan and/or daily activities.                                                                                                                                                                                                                                                                                                                                                                                                                               | B |  |
| 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:<br><br>OR<br><br>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. | A |  |

### Communication

| Description (appropriate to age)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          | Score= | How is this need currently being met? |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------|---------------------------------------|
| 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.<br><br>Or<br><br>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 | C      |                                       |

|                                                                                                                                                                                                                         |   |  |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---|--|
| 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? |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------|---------------------------------------|
| <p>Independently mobile as appropriate for age and development stage (with or without aids).</p> <p>Or</p> <p>Able to stand as appropriate for developmental age, but needs some assistance and, requires support to access curricular or extra-curricular activities.</p> <p>Or</p> <p>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.</p>                                                                | C     |                                       |
| <p>Unable to move in a developmentally appropriate way. Cared for in one position (bed or chair) and due to risk of physical harm, loss of muscle tone, tissue viability or pain on movement needs careful positioning, and is unable to assist or needs more than one carer to reposition or transfer.</p> <p>OR</p> <p>At high risk of injuries, requiring a structured management plan to minimise risk, appropriate to the stage of development.</p> <p>OR</p> <p>Involuntary spasms placing themselves and carers at risk.</p> | B     |                                       |

|                                                                                                                                                                                                                                     |   |  |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---|--|
| <p>Completely immobile and unstable clinical condition such that on movement or transfer there is a high risk of serious physical harm.</p> <p>OR</p> <p>Where the positioning is critical to physiological functioning or life</p> | A |  |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---|--|

### 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. <b>OR</b></p> <p>Needs supervision, prompting, encouraging with food and drinks above normal requirement for age. <b>OR</b></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. <b>OR</b></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. <b>OR</b></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, naso-gastric 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</p> <p><b>OR</b></p>                                                                                                                                                                                                                                                                                                                                                                                                                                                   | A      |                                       |



|                                                                                                                                                                                                                                                                                                                                                                                        |  |  |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|--|
| <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> |  |  |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|--|

### Continence and Elimination

| Description (appropriate to age)                                                                                                                                                                                                                                                                                                                                                                           | Score= | How is this need currently being met? |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------|---------------------------------------|
| <p>Continent of urine and faeces (appropriate to age)</p> <p>Or</p> <p>Continence care is routine on a day-to-day basis and age appropriate:</p> <p>Incontinence of urine managed through e.g medication, regular toileting, pads use of penile sheath etc.</p> <p>AND</p> <p>Is able to maintain full control over bowel movements or has a stable stoma and may have occasional faecal incontinence.</p> | C      |                                       |
| <p>Continence care is routine but requires monitoring to minimise risks, e.g those associated with urinary catheters, frequent double incontinence and/or the management of severe or recurrent constipation or urinary infection or self catheterisation.</p>                                                                                                                                             | B      |                                       |
| <p>Continence care is problematic and requires timely intervention by a skilled practitioner or trained carer</p> <p>OR</p> <p>Intermittent catheterization</p> <p>OR</p> <p>Is regularly incontinent of faeces several times a day or has a stoma that needs attention several times a day</p> <p>Or</p> <p>Requires peritoneal/haemodialysis to sustain life</p>                                         | A      |                                       |

## Skin and Tissue Viability

| Description (appropriate to age)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | Score= | How is this need currently being met? |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------|---------------------------------------|
| <p>No evidence of pressure damage or skin condition</p> <p>Or</p> <p>Evidence of pressure damage and pressure or a minor wound requiring treatment</p> <p>or</p> <p>Skin condition that requires clinical re-assessment less than weekly.</p>                                                                                                                                                                                                                                                                                                                                                 | C      |                                       |
| <p>Open wound(s), responding to treatment</p> <p>OR</p> <p>Active skin condition requiring a minimum of weekly re-assessment and which is responding to treatment</p> <p>OR</p> <p>High risk of skin breakdown, which requires preventative intervention from skilled carer or care worker several times each day without which skin integrity would break down</p> <p>Or</p> <p>Open wound(s), not responding to treatment and require a minimum of daily monitoring/re-assessment</p> <p>OR</p> <p>Active skin condition, which requires a minimum of daily monitoring or re-assessment</p> | B      |                                       |
| <p>OR</p> <p>Specialist dressing regime, several times weekly in place, which is responding to treatment. Requiring regular supervision by a Consultant</p> <p>Or</p> <p>Life threatening skin conditions or burns requiring complex dressing 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</p> <p>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</p> <p>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</p> <p>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</p> <p>Is on Continuous Positive Airways Pressure (CPAP)</p> <p>Has frequent hard to predict apnoeas AND/OR</p> <p>Severe life threatening breathing difficulties</p> <p>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</p> <p>Requires ventilation at night for very poor respiratory function has respiratory drive and would survive accidental disconnection but would not be well and require hospital support or</p> <p>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</p> <p>A highly unstable tracheotomy, frequent occlusions, difficult to change tubes</p> | A      |                                       |

## Drugs Therapies and Medicines

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

## Seizures or Altered States of Consciousness (ASC)

| Description                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   | Score | How is this need currently being met? |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------|---------------------------------------|
| <p>No evidence of seizures or ASC.</p> <p>Or</p> <p>History of seizures or ASC but none in the past 3 months. Medication (if any) is stable.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | C     |                                       |
| <p>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.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                           | B     |                                       |
| <p>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.</p> <p>Or</p> <p>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.</p> <p>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</p> | 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.**

| <b>Recommendation</b>                                                                                                                                                              | <b>Please tick as appropriate</b> | <b>Rationale</b> |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------|------------------|
| 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.**

\*\*\*\*\*

Annex B

**National - Community Children's Nursing - Decision Support Tool**

|                    |  |                          |             |                      |  |
|--------------------|--|--------------------------|-------------|----------------------|--|
| 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 |  |

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)**

| <b>Name</b> | <b>Details</b> |
|-------------|----------------|
|             |                |

**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:

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 |
|----------|------|
|          |      |
|          |      |
|          |      |
|          |      |
|          |      |
|          |      |

## 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?

## 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?

## 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?

#### **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?

#### **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?

## **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?

## **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?

## **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?

## **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?

**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?

**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.

**Summary Section**

**Outcomes which can be met through universal and specialist services**

|                               |                |                |
|-------------------------------|----------------|----------------|
| <b>Outcome 1:</b>             |                |                |
| <b>What needs to be done?</b> | <b>By whom</b> | <b>By when</b> |

|                               |                |                |
|-------------------------------|----------------|----------------|
|                               |                |                |
| <b>Outcome 2:</b>             |                |                |
| <b>What needs to be done?</b> | <b>By whom</b> | <b>By when</b> |
|                               |                |                |
| <b>Outcome 3:</b>             |                |                |
| <b>What needs to be done?</b> | <b>By whom</b> | <b>By when</b> |
|                               |                |                |

**Evidence of unmet needs and plan of action**

|                             |                |                |
|-----------------------------|----------------|----------------|
| <b>Action 1:</b>            |                |                |
| <b>How can this be met?</b> | <b>By whom</b> | <b>By when</b> |
|                             |                |                |

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

| Name | Role | Signature |
|------|------|-----------|
|------|------|-----------|

## ANNEX C

### Coughlan and Haringey

#### 1. The meaning of incidental or ancillary

2. The Oxford Dictionary definition of incidental is “happening as a minor accompaniment to something else“.

3. The definition of ancillary is “in addition to something else, but not as important“. From reading the above definitions it’s easy to understand why incidental and ancillary uses would appear very similar.

#### 4. Coughlan

5. The court concluded that the Secretary of state **can** exclude some nursing services from the services provided by the NHS. Such services can then be provided as a social or care service rather than a health service.

6. It stated that nursing services which can be provided as part of the care services are limited to those which can legitimately be regarded as being provided in connection with accommodation which is being provided to the classes of person referred to in section 21 of the NAA 1948 (repealed in Wales, and replaced with section 47 SSWBA) who are in need of care and attention; in other words as part of a social services care package.

7. The fact that the nursing services are to be provided as part of social services care and will have to be paid for by the person concerned (unless that person’s resources mean that he or she will be exempt from having to pay for those services), does not prohibit the secretary of state from deciding not to provide those services.

8. The fact that some nursing services can be properly regarded as part of social services care, to be provided by the local authority, does not mean that all nursing services provided to those in the care of the local authority can be treated in this way. The scale and type of nursing required in an individual case may mean that it would not be appropriate to regard all or part of the nursing as being part of "the package of care" which can be provided by a local authority. There can be no precise legal line drawn between those nursing services which are and those which are not capable of being treated as included in such a package of care services.

9. The distinction between those services which can and cannot be provided is one of degree which in a borderline case will depend on a careful appraisal of the facts of the individual case. However, as a very general indication as to where the line is to be drawn, it can be said that if the nursing services are (i) **merely incidental or ancillary to the provision of the accommodation** which a local authority is under a duty to provide to the category of persons to whom section 21 of the 1948 Act refers and (ii) of a nature which it can be expected that an authority whose primary responsibility is to provide social

services can be expected to provide, then they can be provided under section 21.

10. It will be appreciated that the first part of the test is focusing on the overall quantity of the services and the second part on the quality of the services provided.
11. The judgment went further and said that they did not accept the original judges' conclusion that all nursing care must be the sole responsibility of the NHS and has to be provided by the health authority. Whether it can be provided by the LA has to be determined on an assessment of the circumstances of the individual concerned. The secretary of state accepted that where the primary need is a health need then the responsibility is that of the NHS, even when the individual has been placed in a home by a local authority.
12. The Court recognised that what services can be appropriately treated as responsibilities of a LA may evolve with changing standards.
13. With regards to the eligibility criteria the Court stated there needs to be at least two categories of persons. . . *“those who because of their health needs, should be regarded as wholly the responsibility of a health authority. Secondly, there are those whose nursing services in general can be regarded as being the responsibility of the LA but whose additional requirements are the responsibility of the NHS.”*
13. The judgment was clear that the LA cannot meet the costs of services which are not its responsibility because of the terms of section 21(8) NAA 1948.
14. The court was clear in its judgement that *“if a portion of nursing can still be provided as a service for which the LA is responsible, then we do not see anything improper in those services being charged for under the LA regime. Other services for which the NHS is responsible can be provided on health service terms.”*

#### **Conclusion to Coughlan:**

15. The Court concluded that the NHS **does not** have the sole responsibility for all nursing care and nursing care for a chronically sick patient may in appropriate cases be provided by a local authority as a social service and the patient may be liable to meet the cost of that care according to a patient's means. It was **not unlawful** for the health authority to decide to transfer responsibility for the general nursing care to the local authority. **“Whether it is lawful depends generally on whether the nursing services are merely incidental or ancillary to the provision of the accommodation which a local authority is under a duty to provide and of a nature which it can be expected that an authority whose primary responsibility is to provide social services can be expected to provide.”**

16. **Haringey**

17. The court accepted that there is a broad distinction to be drawn between health and social care provision. He noted that the discussion in Coughlan is helpful as to the indicators relevant to that case i.e. the provisions of the Children Act are not to be regarded in general as reducing or replacing important public obligations as set out in the NHS Act.
18. It endorsed Coughlan by reflecting the scale and type of nursing care is particularly important as is the question of 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.
19. The Court was clear that it did not want to create a form of parallel or substitute the national health service, enforceable by individuals against the local authority.

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

21. Section 47 The Social Services and Well-being (Wales) Act 2014 states that a:

*“A local authority may not meet a young person’s needs for care and support by providing or arranging for the provision of a service or facility which required to be provided under a health enactment unless doing so would be incidental or ancillary to doing something else to meet needs.”*

22. Section 47 of the SSWBA 2014 therefore incorporates the first limb of Coughlan which applies to both children and adults alike and sets out limitations on a local authority's powers to provide health services. A local authority may not meet a person’s need for care and support by providing a service which must be provided under the NHS (Wales) Act 2006 (or other specified health enactments). The starting point is that a local authority is not permitted to meet a person's needs for care and support by providing health services which are required to be provided under a health enactment except in specified circumstances .
23. This prohibition does not apply to the provision of health services which are “incidental or ancillary” to something else that the local authority is doing to meet a person's needs under sections 35 to 45 (meeting needs of adults, children and carers for care and/or support) or to the provision of other services under section 15 (preventative services). Local authorities can, in certain circumstances, allow staff with appropriate training, support and supervision to take on certain specified health related tasks whilst providing social care. An example of this is the provision of support with the administration of some medication. Even where a local authority does have the power to provide health services which are incidental or ancillary to something else which is being done, they are still prohibited from meeting needs or providing

preventative services by providing or arranging the provision of nursing care by a registered nurse.

24. This prohibition on a local authority providing nursing care does not prevent it from arranging for the provision of nursing care and accommodation in a nursing home, provided consent has been obtained from the relevant NHS body (specified in the Care and Support (Provision of Health Services) (Wales) Regulations 2015 (S.I. 2015/1919 (W. 285)), or, if the case is urgent, the arrangements made are temporary and consent is obtained as soon as feasible.
25. **Primary Health Need**
26. In the *Grogan v Bexley NHS Care Trust* 2006 case the Court considered the issue of who was responsible for paying accommodation and support in the context of health and social care. This was a High Court matter whereby the person in question argued that the decision to deny her full NHS funding was unlawful, since the eligibility criteria put in place by the health body were contrary to *Coughlan*.
27. Mr Justice Charles decided the health body did not have in place or applied criteria which properly identified the test or approach to be followed in deciding whether the claimant's primary need was a health need. In reaching his decision Charles J identified that the "limits of social care" test in statutory in origin (i.e. s.21(8) National Assistance Act 1948 – now s.47 (1) of the SSWBWA 2014).
28. The Court considered that the "primary health need" test was a policy construct developed by the Secretary of State and while the Secretary of State was entitled to put forward a policy, she could not by guidance undermine the statutory regime. Since there should be no gap in entitlement, the Court held that the only way of resolving this problem (short of statutory amendment) was for the NHS to lower the policy bar to the same height set by the Court of Appeal in *Coughlan* when defining the limits of social care support.
29. It is therefore apparent that the 'primary health need' requirement is currently only applied in respect of adults (it is not discussed as a consideration in *Haringey*) and although it is accepted that this is a policy construct by both the Welsh and UK government, it is a very influential one which has been expressly adhered to in *Coughlan* and repeated in judgements. It has previously been advised, when amending the current adult framework, that to depart from it would require formulating and consulting on alternative policy.