Bristol, North Somerset and South Gloucestershire Integrated Care Board

Reference: FOI.ICB-2223/001

Subject: Children's Continuing Care

*I can confirm that the ICB **does hold some of the information requested**; please see responses below:*

QUESTION	RESPONSE
The questions below which we would like you to answer are designed to help me understand how you commission services that provide regular overnight breaks at home to enable parents or carers of children and young people with life-limiting and life-threatening conditions to sleep. They are also designed to help me understand how you commission packages of NHS continuing care for children and young people. In order to help you meet my request, I provide definitions to the terms I use in my questions below: **Life-limiting and life-threatening conditions** "Life-limiting conditions are those for which there is no reasonable hope of cure and from which children will die. Some of these conditions cause slow deterioration over time rendering the child increasingly dependent on parents and carers. Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer." **Children and young people** Babies, children and young people aged 0-18. **Complex clinical care**	

This includes (but is not limited to) care which involves overnight ventilation, enteral feeding, oxygen therapy and/or seizure management, for example.	
1. Do you commission services that provide regular overnight breaks at home to enable parents or carers of children and young people with life-limiting and life-threatening conditions to sleep? (Yes/No) 2. If you answered yes to (1), please describe the services that you commission, including: • 2.1 the criteria that children and young people must meet in order to access them • 2.2 the criteria that parents and carers must meet in order to access them • 2.3 if these services are available at weekends and bank holidays • 2.4 how frequently parents and carers can access them (a certain number of hours or nights per week, for example). 3. If you answered yes to (1), do you specify that these services are to be provided by trained nurses and/or other carers with the skills and experience needed to provide complex clinical care to children and young people with life-limiting and life-threatening conditions (Yes/No)? 4. If you answered yes to (3), please describe out the skills and experiences that you specify.	1. The CYP (Children and Young People) team provide commissioned services to support and to meet the children and Young Person's assessed health needs. This support would take into consideration parental requests and needs which may include the ability for the parents to sleep during the agreed times. 2. Personal Health Budgets (PHBs), commissioned Lifetime service or agency provider to meet the children and Young People assessed health needs. • 2.1 The child or young person must be eligible for Children's Continuing Care • 2.2 There is no such criteria • 2.3 Services are commissioned to meet assessed needs, including over weekends and bank holidays where appropriate. • 2.4 This is variable from child to child depending on the assessed need. 3. Yes – dependent on the child's health needs for the majority of cases we would expect a trained Health Care Assistant / Personal Assistant to deliver the support package. On occasion if required we may assess the need for a trained nurse. 4. This is dependent on the child's clinical needs.

5. Please set out the criteria that children and young people in your CCG area must meet in order to access NHS children and young people's continuing care, if this is different to your answer to question 2. Please attach a copy of your criteria document or assessment document for children and young people's continuing care. 6. Please set out the number of children and young people your CCG has provided NHS children and young people's continuing care packages to each year in the years 2017/18-2021/22 inclusive. 7. Please set out the number of new NHS children and young people's continuing care packages your CCG has awarded to children and young people in each of the years 2017/18-2021/22 inclusive. 8. Please set out how much money your CCG has spent on providing NHS children and young people's continuing care each year in the years 2017/18-2021/22 inclusive.	5. NHS Children's and Young People Continuing Care Framework (2016) - https://www.gov.uk/government/publications/children-and-young-peoples-continuing-care-national-framework Please find enclosed the Children's Continuing Care DST (Decision Support Tool). 6. Questions 6, 7, and 8 are answered in the table below. Bristol North Somerset and South Gloucestershire were separate CCG's and were amalgamated into one CCG in April 2018. We don't have access to this information from before this time.

Year	Total CCC packages	Total new in year	Total spend
2018-19	47	7	£2,958,320
2019-20	30	3	£2,805,877
2020-21	57	11	£2,640,082
2021-22	57	1	£3,098,051

The information provided in this response is accurate as of 3 August 2022 and has been approved for release by Rosi Shepherd, Director of Nursing and Quality for NHS Bristol, North Somerset and South Gloucestershire ICB.

NHS
Bristol, North Somerset and South Gloucestershire
Clinical Commissioning Group

Children Continuing Care Decision Support Tool (DST)

PART ONE: TO BE COMPLETED BY NURSE ASSESSOR			
Child or Young Person's Details			
Name:			
Date of birth:		NHS Number:	
Address:			
Gender: (delete as appropriate)	**MALE**	**FEMALE**	
First language: (if not English)		Translator needed:	
		Other communication support needed:	
Mother's name:		Father's name:	
Contact no.		Contact no.	
NB. details of one parent only are acceptable, but it must be the parent with responsibility.			
If Parental Responsibility Is Not Held By Parents			
Parental responsibility held by:		Contact no.	
		E-mail:	
Basis of parental responsibility: (e.g. legal guardian, LA section 20 etc.)		Address:	
Address of GP practice:			
Name of GP: (if child or young person has a named doctor)			
Local Authority:			

Referral & Assessment Details	
Date of Referral	
Referred by	
Designation	
Tel and Email	
Date of Assessment	
Location of Assessment	
Was the child involved in the assessment?	
Who was present at the assessment?	
Assessment completed by (Health)	
Designation	

Consent		
Do you have a Completed Consent Form	Yes	No
A DST cannot go to panel without a completed consent form.		

Children's Continuing Care Summary
1. Summary of child/young person and family preferences
2. Summary of the child/young person's current conditions, diagnosis and presenting difficulties
3. Summary of Need:
4. Summary of any external factors which may influence the effectiveness of any package of care (housing, family health, family dynamics)

Team around the Child				
	Professional	**Name**	**Contact Details**	**Days/Hours**
Education	School			
	Teacher			
	LSA in school			
	SEN Co-ord			
	EHCP?			
	Other			
Clinician	Comm Paed			
	Spec Consult			
	Spec Consult			
	Psychiatry			
	Psychology			
	CAMHS			
	Other			
Nurse	School Nurse			
	Health Visitor			
	CCN Lifetime			
	CCN			
	LD Nurse			
	Clin Nurse Spec			
	Clin Nurse Spec			
	Jessie May			
	LAC Nurse			
Therapy	Physiotherapist			
	OT (Health)			
	Dietician			
	SALT			
LA	Social Worker			
	OT (LA)			
	Family Link			
	Time to Share			
	Community Care			
	Contract Carer			
Support Services	Hospice			
	Lifetime Homecare			
	Residential Respite			
	Carer (family)			
	Jessie May			
	DP/PHB Worker			
	Other			

Evidence		
	Evidence from Health, Social Care & Education	Document
Appendix 1		
Appendix 2		
Appendix 3		
Appendix 4		
Appendix 5		

PART TWO: TO BE COMPLETED BY NURSE ASSESSOR

Decision Support Tool for Children Requiring Continuing Health Care

CARE DOMAINS

1. Breathing

Describe the actual needs of the individual providing the evidence why that level has been chosen, including the frequency, complexity and intensity of need, unpredictability, deteriorations and any instability.

Verbal Report:

Evidence:

Rationale:

Description	Level of Need
Breathing typical for age and development.	No additional needs
Routine use of inhalers, nebulisers, etc.; **or** care plan or management plan in place to reduce the risk of aspiration.	Low
Episodes of acute breathlessness, which do not respond to self-management and need specialist-recommended input; **or** intermittent or continuous low-level oxygen therapy is needed to prevent secondary health issues; **or** supportive but not dependent non-invasive ventilation which may include oxygen therapy which does not cause life-threatening difficulties if disconnected; **or** child or young person has profoundly reduced mobility or other conditions which lead to increased susceptibility to chest infection (Gastroesophageal Reflux Disease and Dysphagia); **or** requires daily physiotherapy to maintain optimal respiratory function; **or** requires oral suction (at least weekly) due to the risk of aspiration and breathing difficulties; **or** has a history within the last three to six months of recurring aspiration/chest infections.	Moderate

Description	Level of Need
Requires high flow air / oxygen to maintain respiratory function overnight or for the majority of the day and night; **or** is able to breathe unaided during the day but needs to go onto a ventilator for supportive ventilation. The ventilation can be discontinued for up to 24 hours without clinical harm; **or** requires continuous high level oxygen dependency, determined by clinical need; **or** has a need for daily oral pharyngeal and/or nasopharyngeal suction with a management plan undertaken by a specialist practitioner; **or** stable tracheostomy that can be managed by the child or young person or only requires minimal and predictable suction / care from a carer.	High
Has frequent, hard-to-predict apnoea (not related to seizures); **or** severe, life-threatening breathing difficulties, which require essential oral pharyngeal and/or nasopharyngeal suction, day or night; **or** a tracheostomy tube that requires essential interventions (additional to routine care) by a fully trained carer, to maintain an airway; **or** requires ventilation at night for very poor respiratory function; has respiratory drive and would survive accidental disconnection, but would be unwell and may require hospital support.	Severe
Unable to breath independently and requires permanent mechanical ventilation; **or** has no respiratory drive when asleep or unconscious and requires ventilation, disconnection of which could be fatal; **or** a highly unstable tracheostomy, frequent occlusions and difficult to change tubes.	Priority

2. Eating and Drinking
Describe the actual needs of the individual providing the evidence why that level has been chosen, including the <u>frequency, complexity and intensity of need, unpredictability, deteriorations and any instability.</u> **Verbal Report:** **Evidence:** **Rationale:**

Description	Level of Need
Able to take adequate food and drink by mouth, to meet all nutritional requirements, typical of age.	No additional needs
Some assistance required above what is typical for their age; **or** needs supervision, prompting and encouragement with food and drinks above the typical requirement for their age; **or** needs support and advice about diet because the underlying condition gives greater chance of non-compliance, including limited understanding of the consequences of food or drink intake; **or** needs feeding when this is not typical for age, but is not time consuming or unsafe if general guidance is adhered to.	Low
Needs feeding to ensure safe and adequate intake of food; feeding (including liquidised feed) is lengthy; specialised feeding plan developed by speech and language therapist; **or** unable to take sufficient food and drink by mouth, with most nutritional requirements taken by artificial means, for example, via a non-problematic tube feeding device, including nasogastric tubes.	Moderate
Faltering growth, despite following specialised feeding plan by a speech and language therapist and/or dietician to manage nutritional status;	High

Description	Level of Need
or dysphagia, requiring a specialised management plan developed by the speech and language therapist and multi-disciplinary team, with additional skilled intervention to ensure adequate nutrition or hydration and to minimise the risk of choking, aspiration and to maintain a clear airway (for example through suction); **or** problems with intake of food and drink (which could include vomiting), requiring skilled intervention to manage nutritional status; weaning from tube feeding dependency and / recognised eating disorder, with self-imposed dietary regime or self-neglect, for example, anxiety and/or depression leading to intake problems placing the child/young person at risk and needing skilled intervention; **or** problems relating to a feeding device (e.g. nasogastric tube) which require a risk-assessment and management plan undertaken by a speech and language therapist and multidisciplinary team and requiring regular review and reassessment. Despite the plan, there remains a risk of choking and/or aspiration.	
The majority of fluids and nutritional requirements are routinely taken by intravenous means.	Severe

3. Mobility
Describe the actual needs of the individual providing the evidence why that level has been chosen, including the <u>frequency, complexity and intensity of need, unpredictability, deteriorations and any instability.</u> **Verbal Report:** **Evidence:** **Rationale:**

Description	Level of Need
Mobility typical for age and development.	No additional needs
Able to stand, bear their weight and move with some assistance, and mobility aids. **or** moves with difficulty (e.g. unsteady, ataxic); irregular gait.	Low
Difficulties in standing or moving even with aids, although some mobility with assistance. **or** sleep deprivation (as opposed to wakefulness) due to underlying medical related need (such as muscle spasms, dystonia), occurring three times a night, several nights per week; **or** unable to move in a way typical for age; cared for in single position, or a limited number of positions (e.g. bed, supportive chair) due to the risk of physical harm, loss of muscle tone, tissue viability, or pain on movement, but is able to assist.	Moderate
Unable to move in a way typical for age; cared for in single position, or a limited number of positions (e.g. bed, supportive chair) due to the 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 a high risk of fracture due to poor bone density, requiring a structured	High

Description	Level of Need
management plan to minimise risk, appropriate to stage of development; **or** involuntary spasms placing themselves and carers at risk; **or** extensive sleep deprivation due to underlying medical/mobility related needs, occurring every one to two hours (and at least four nights a week).	
Completely immobile and with an unstable clinical condition such that on movement or transfer there is a high risk of serious physical harm; **or** positioning is critical to physiological functioning or life.	Severe

4. Continence or Elimination
Describe the actual needs of the individual providing the evidence why that level has been chosen, including the <u>frequency, complexity and intensity of need, unpredictability, deteriorations and any instability.</u> **Verbal Report:** **Evidence:** **Rationale:**

Description	Level of Need
Continence care is routine and typical of age.	No additional needs
Incontinent of urine but managed by other means, for example, medication, regular toileting, pads, use of penile sheaths;	Low

Description	Level of Need
or is usually able to maintain control over bowel movements but may have occasional faecal incontinence.	
Has a stoma requiring routine attention, **or** doubly incontinent but care is routine; **or** self-catheterisation; **or** difficulties in toileting due to constipation, or irritable bowel syndrome; requires encouragement and support.	Moderate
Continence care is problematic and requires timely intervention by a skilled practitioner or trained carer; **or** intermittent catheterisation by a trained carer or care worker; **or** has a stoma that needs extensive attention every day. **or** requires haemodialysis in hospital to sustain life.	High
Requires dialysis in the home to sustain life.	Severe

5. Skin and Tissue Viability

Interpretation point: where a child or young person has a stoma, only the management of the stoma itself as an opening in the tissue should be considered here; use of the stoma should be considered under the domain ***Continence or elimination****. In the same way, a tracheostomy should only be considered here where there are issues relating to the opening; the use of the tracheostomy to aid breathing, and its management (e.g. use of suction), should be considered under* ***Breathing.***

Describe the actual needs of the individual providing the evidence why that level has been chosen, including the frequency, complexity and intensity of need, unpredictability, deteriorations and any instability.

Verbal Report:

Evidence:

Rationale:

Description	Level of Need
No evidence of pressure damage or a condition affecting the skin.	No additional needs
Evidence of pressure damage or a minor wound requiring treatment; **or** skin condition that requires clinical reassessment less than weekly; **or** well established stoma which requires routine care; **or** has a tissue viability plan which requires regular review.	Low
Open wound(s), which is (are) responding to treatment; **or** active skin condition requiring a minimum of weekly reassessment and which is responding to treatment; **or** high risk of skin breakdown that requires preventative intervention from a skilled carer several times a day, without which skin integrity would break down; **or** high risk of tissue breakdown because of a stoma (e.g. gastrostomy, tracheostomy, or colostomy stomas) which require skilled care to maintain skin integrity.	Moderate
Open wound(s), which is (are) not responding to treatment and require a minimum of daily monitoring/reassessment **or** active long-term skin condition, which requires a minimum of daily monitoring or reassessment; **or**	High

Description	Level of Need
specialist dressing regime, several times weekly, which is responding to treatment and requires regular supervision.	
Life-threatening skin conditions or burns requiring complex, painful dressing routines over a prolonged period.	Severe

6. Communication
Describe the actual needs of the individual providing the evidence why that level has been chosen, including the <u>frequency, complexity and intensity of need, unpredictability, deteriorations and any instability.</u> **Verbal Report:** **Evidence:** **Rationale:**

Description	Level of Need
Able to understand or communicate clearly, verbally or non-verbally, within their primary language, appropriate to their developmental level. The child/young person's ability to understand or communicate is appropriate for their age and developmental level within their first language.	No additional needs

Description	Level of Need
Needs prompting or assistance to communicate their needs. Special effort may be needed to ensure accurate interpretation of needs, or may need additional support visually – either through touch or with hearing. **or** Family/carers may be able to anticipate needs through non-verbal signs due to familiarity with the individual.	Low
Communication of emotions and fundamental needs is difficult to understand or interpret, even when prompted, unless with familiar people, and requires regular support. Family/carers may be able to anticipate and interpret the child/ young person's needs due to familiarity. **or** support is **always** required to facilitate communication, for example, the use of choice boards, signing and communication aids. **or** ability to communicate basic needs is variable depending on fluctuating mood; the child/young person demonstrates severe frustration about their communication, for example, through withdrawal.	Moderate
Even with frequent or significant support from family/carers and professionals, the child/young person is rarely able to communicate basic needs, requirements or ideas.	High

7. Drug Therapies and Medication

Describe the actual needs of the individual providing the evidence why that level has been chosen, including the <u>frequency, complexity and intensity of need, unpredictability, deteriorations and any instability.</u>

Verbal Report:

Evidence:

Rationale:

Description	Level of Need
Medicine administered by parent, carer, or self, as appropriate for age.	No additional needs
Requires a suitably trained family member, formal carer, teaching assistant, nurse or appropriately trained other to administer medicine due to: • age • non-compliance • type of medicine; • route of medicine; and/or • site of medication administration	Low
Requires administration of medicine regime by a registered nurse, formal employed carer, teaching assistant or family member specifically trained for this task, or appropriately trained others; **or** monitoring because of potential fluctuation of the medical condition that can be non-problematic to manage; **or** sleep deprivation due to essential medication management – occurring more than once a night (and at least twice a week).	Moderate
Drug regime requires management by a registered nurse at least weekly, due to a fluctuating and/or unstable condition; **or** sleep deprivation caused by severe distress due to pain requiring medication management – occurring four times a night (and four times a week). **or** requires monitoring and intervention for autonomic storming episodes.	High
Has a medicine regime that requires daily management by a registered nurse and reference to a medical practitioner to ensure effective symptom management associated with a rapidly changing/deteriorating condition;	Severe

Description	Level of Need
or extensive sleep deprivation caused by severe intractable pain requiring essential pain medication management – occurring every one to two hours **or** requires continuous intravenous medication, which if stopped would be life threatening e.g. epoprostenol infusion (vasodilator).	
Has a medicine regime that requires at least daily management by a registered nurse and reference to a medical practitioner to ensure effective symptom and pain management associated with a rapidly changing/deteriorating condition, where one-to-one monitoring of symptoms and their management is essential.	Priority

8. Psychological and Emotional Needs **(beyond what would typically be expected from a child or young person of their age).** *Interpretation point: a separate domain considers Challenging Behaviour, and assessors should avoid double counting the same need.*

Describe the actual needs of the individual providing the evidence why that level has been chosen, including the frequency, complexity and intensity of need, unpredictability, deteriorations and any instability.

Verbal Report:

Evidence:

Rationale:

Description	Level of Need
Psychological or emotional needs are apparent but typical of age and similar to those of peer group.	No additional needs
Periods of emotional distress (anxiety, mildly lowered mood) not dissimilar to those typical of age and peer group, which subside and are self-regulated by the child/young person, with prompts/ reassurance from peers, family members, carers and/or staff within the workforce.	Low
Requires prompts or significant support to remain within existing infrastructure; periods of variable attendance in school/college; noticeably fluctuating levels of concentration. Self-care is notably lacking (and falls outside of cultural/peer group norms and trends), which may demand prolonged intervention from additional key staff; self-harm, but not generally high risk; **Or** Evidence of low moods, depression, anxiety or periods of distress; reduced social functioning and increasingly solitary, with a marked withdrawal from social situations; limited response to prompts to remain within existing infrastructure (marked deterioration in attendance/attainment / deterioration in self-care outside of cultural/peer group norms and trends).	Moderate
Rapidly fluctuating moods of depression, necessitating specialist support and intervention, which have a severe impact on the child/young person's health and well-being to such an extent that the individual cannot engage with daily activities such as eating, drinking, sleeping or which place the individual or others at risk; **or** acute and/or prolonged presentation of emotional/psychological deregulation, poor impulse control placing the young person or others at serious risk, and/or symptoms of serious mental illness that places the individual or others at risk; this will include high-risk, self-harm.	High

9. Seizures
Describe the actual needs of the individual providing the evidence why that level has been chosen, including the <u>frequency, complexity and intensity of need, unpredictability, deteriorations and any instability.</u> **Verbal Report:** **Evidence:** **Rationale:**

Description	Level of need
No evidence of seizures.	No additional needs
History of seizures but none in the last three months; medication (if any) is stable; **Or** occasional absent seizures and there is a low risk of harm.	Low
Occasional seizures including absences that have occurred with the last three months which require the supervision of a carer to minimise the risk of harm; **or** up to three tonic-clonic seizures every night requiring regular supervision.	Moderate
Tonic-clonic seizures requiring rescue medication on a weekly basis; or 4 or more tonic-clonic seizures at night.	High
Severe uncontrolled seizures, occurring at least daily. Seizures often do not respond to rescue medication and the child or young person needs hospital treatment on a regular basis. This results in a high probability of risk to his/her self.	Severe

10. Challenging Behaviour

"*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" (Eric Emerson)*

A specialist assessment of an individual with serious behavioural issues will usually be required which includes an overall assessment of the risk(s) which are likely to impair a child's personal growth, development and family life.

Describe the actual needs of the individual providing the evidence why that level has been chosen, including the frequency, complexity and intensity of need, unpredictability, deteriorations and any instability.

Verbal Report:

Evidence:

Rationale:

Description	Level of Need
No incidents of behaviour which challenge parents/carers/staff.	No Additional Needs
Some incidents of behaviour which challenge parents/carers/staff but which do not exceed expected behaviours for age or stage of development and which can be managed within mainstream services (e.g. early years support, health visiting, school).	Low
Occasional challenging behaviours which are more frequent, more intense or more unusual than those expected for age or stage of development, which are having a negative impact on the child and their family / everyday life.	Moderate
Regular challenging behaviours such as aggression (e.g. hitting, kicking, biting, hair-pulling), destruction (e.g. ripping clothes, breaking windows, throwing objects), self-injury (e.g. head banging, self-biting, skin picking), or other behaviours (e.g.	High

Description	Level of Need
running away, eating inedible objects), despite specialist health intervention and which have a negative impact on the child and their family / everyday life.	
Frequent, intense behaviours such as aggression, destruction, self-injury, despite intense multi-agency support, which have a profoundly negative impact on quality of life for the child and their family, and risk exclusion from the home or school.	Severe
Challenging behaviours of high frequency and intensity, despite intense multi-agency support, which threaten the immediate safety of the child or those around them and restrict every day activities (e.g. exclusion from school or home environment).	Priority

PART THREE: SUMMARY – TO BE COMPLETED BY NURSE ASSESSOR

Summary of Assessed Levels of Need

	Care Domain	P	S	H	M	L	N
1	Breathing						
2	Eating & Drinking						
3	Mobility						
4	Continence & Elimination						
5	Skin & Tissue Viability						
6	Communication						
7	Drug Therapies & Medicines						
8	Psychological and Emotional Needs						
9	Seizures						
10	Challenging Behaviour						
Totals							

Recommendation to Panel			
Recommendation:			
Signature Nurse Assessor:			
Present at Continuing Care Panel			
Professionals Name	Designation	Signature	Date

Continuing Care Panel Decision	
Panel Decision:	
Panel Date:	

PART FOUR: FUNDING AUTHORISATION – TO BE COMPLETED BY NURSE ASSESSOR	
Total Amount Funding Agreed:	£
Care Package:	
Breakdown of Costs:	
Speciality - Is the CCG fully or Joint funding the package (Delete as appropriate)?	Fully Joint
What type of PHB (Circle/highlight as appropriate)	Notional Third Party Direct Payment
Funding description for QA (Circle/highlight as appropriate)?	<table><tr><td>Medical Equipment</td><td>Individual/ Complex</td><td>LAC Therapy</td><td>Continuing Care - Other</td></tr><tr><td>End of Life</td><td>CETR</td><td>LAC Placement</td><td>Continuing Care - Lifetime</td></tr><tr><td>Rehab Therapy</td><td>SEND</td><td>S.117</td><td></td></tr></table>
Cost Centre:	
Invoice to:	
Start Date:	
End Date/Review Date:	