Department of Health

National Framework for Children and Young People's Continuing Care

Decision Support Tool

2016

November 2018

	Title: National Framework for Children and Young People's Continuing Care – Decision Support Tool
	Author: SCLGCP/CMHI/IDC/14100
	Document Purpose: Guidance)
	Publication date: January 2016
	Target audience: public**,** clinical commissioning groups, local authorities, health and wellbeing boards, health and care professionals.
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Published to gov.uk, in PDF format only.
www.gov.uk/dh

Children's decision support tool

1. Please note that this is a Word® version of material which is also found in the Children and Young People's Continuing Care Framework, with which it should be used. The size and order of text boxes may be changed as required.

2. The Tool provides a framework for a reaching a decision. Information will need to be organised and documented to support that. Some suggested prompts are included where useful. Note that questions may not necessarily be answerable in chronological order (for example, judging the adequacy of the child and their family's accommodation for their needs), and that more than one section may correspond with a statutory section in an EHC plan. In every section, assessment should seek to identify needs **met and unmet**.

3. The nominated children and young people's health assessor will have worked alongside a multi-agency or multidisciplinary team to compile the information required to complete the Children's Decision Support Tool, drawing on the three key areas of assessment:

    - the preferences of the child or young person and their family;
    - holistic assessment of the child or young person and their family, including the carer assessment;
    - reports and risk assessments from the multidisciplinary team.

4. The nominated children and young people's health assessor should use the Children's Decision Support Tool to match, as far as possible, the child/young person's level of need with the relevant description. This approach should build up a detailed analysis of individual needs, in a family context, and provide the evidence to inform the decision on the provision of a package of continuing care.

5. The tool is not prescriptive, and evidence-based professional judgement should be exercised in all cases to ensure that the child or young person's overall level of need is correctly assessed.

6. This process and the information collected will provide the basis for recommendations to be presented to the multi-agency decision-making forum; this will inform the decision on whether a package of continuing care is needed.

7. The Children's Decision Support Tool sets out children's needs across 10 care domains, divided into different levels of need:

    - breathing
    - eating and drinking
    - mobility
    - continence and elimination
    - skin and tissue viability
    - communication
    - drug therapies and medicines
    - psychological and emotional needs
    - seizures
    - challenging behaviour

8. The nominated children and young people's health assessors will use their clinical skill, expertise and evidence-based professional judgement to consider what, for each care domain, is over and above what would be expected for a child or young person of that age and stage of development. For example, incontinence would only become

recognised as an issue when a child or young person has continence needs beyond those expected at his or her age.

9. The needs described in the domains of the Children's Decision Support Tool may not always adequately capture every child or young person and their family's circumstances, and an assessment should endeavour to describe everything of relevance. Professional judgement and clinical reasoning are paramount in ensuring that a child or young person's needs are accurately assessed, taken into account and given due weight when making a decision regarding their continuing care needs.

10. Assessors should have evidence to support all assessments, and should avoid simply cutting and pasting the text in a domain. In completing the tool, care should be taken to make sure that needs are not duplicated in different domains. It is also recommended that needs are described for each domain before the level of need is determined. For this reason, the box for the description precedes the suggested levels of need for each domain.

11. There may be circumstances where a child or young person may have particular needs which do not fall within the 10 care domains described in the Tool (an example might be a child who is unable to regulate their body temperature, or who has an unstable cardiac condition). Information on these needs should of course be included as evidence in the assessment if considered significant, usually drawn from risk assessments or professional reports. Some significant health needs may not of course result in a need for continuing care, if they are already supported by outpatient or other services routinely commissioned.

12. The assessment of the level of need must recognise that where a child or young person requires constant supervision or care which is largely provided by family members, there will be a need for professional support to allow the family time off from their caring responsibilities, and this may require a social care assessment, and agreement, between the CCG and the local authority (which is usually the commissioner of respite care), of the respective contribution.

13. The Tool provides a framework for reaching a decision on levels of need. Information will need to be organised and documented to support that. Some suggested prompts are included. Note that questions may not necessarily be answerable in chronological order, and we have tried to avoid questions which would be more for a social care assessments (some questions on family circumstances have however been included). More than one section may correspond with a statutory section in an EHC plan. In every section, assessment should seek to identify needs **met and unmet**, and current need, rather than past or anticipated need.

Child and family details

Child / young person	
Child's name	
Date of birth	
NHS Number	
Address	
Telephone number	
E-mail	
Mother's name	
Father's name	
First language	
Family • *Does any other member of the family have health or service needs?*	
Communication • *Is an interpreter needed?* • *How can professionals best communicate with the child*?	
Date referred for assessment *Clock start*	
Date of initial needs assessment	
Referred by *Give referring professional and provider organisation and relevant contact details*	
Responsible CCG (*CCG of which the child or young person's GP is a member*)	
Siblings • *Any issues relating to the child or young person's brothers or sisters which should be taken into account* • *Are siblings involved in care provision?*	
Family circumstances	
Family support • *What kind of help is available in the family's circle of friends and relations?* • *Are there any other organisations or groups that support the family/carer's family?* • *Summary of parents'/carer's occupation, employment/shift patterns.* • *Effect of the child/young person's condition on the parent/carer's ability to work.*	

Short breaks • *Details - including name and address of carer provider, and frequency*	
Housing • *Owned or rented?* • *Adequacy for the child's/family's/carer's family's needs?* • *Any adaptations required?*	
Transport • *Is the family/carer's family reliant on public transport?* • *Accessing hospital appointments, etc.*	
Recreation and leisure • *Is the child/young person able to choose leisure activities?* • *What is required to enable the child/young person to access leisure activities?* • *What are their interests or hobbies?* • *Are the recreational needs of siblings and other family/carer's family members being met?*	

Education and learning

Education	
Name of nursery, school or college attending • *Is the child/young person able to access an appropriate educational setting, either full or part-time?*	
Special Educational Needs • *Do they have a statement of SEN or an Education, Health and Care Plan?*	
Education and learning • *What additional support or reasonable adjustments are required in that setting?* • *If the child/young person is too ill to access a setting, what other provision is in place to ensure continuity of learning?*	

Team around the child

Health Professionals
Name, telephone number and location of the following where relevant: • registered GP • all consultants • Designated Medical or Health Officer for SEND • community paediatrician • psychologist • psychiatrist • community children's nurse • specialist nurse (e.g. for epilepsy). • Nurse consultant • CAMHS nurse • named ward nurse • health visitor • school nurse • district nurse • social worker • occupational therapist • speech and language therapists • physiotherapist • other therapists • teacher • short break services • lead professional • interpreter.

Clinical details	
Medical history • *Dates of significant health events/current health status.*	
Medication • *Current medication; allergies.*	
Equipment – disposable • *Type, manufacturer/ supplier ; distributor / quantity and frequency etc. Collection method.*	
Equipment – permanent • *Type, manufacturer/ supplier; distributor / quantity, maintenance.*	
Treatment / care needs • *Interventions; who provides and monitors the service; care plans.* • *Symptom management and pain control.* • *What is the 24-hour daily care routine?* • *How are the child/young person and*	

family/carers supported? • *Does the family have adequate information on the child/young person's condition/future?* • *What is the 24-hour daily care routine?* • *Competencies required to care for the child/young person.* • *Is there a lead professional, and is this working well?*	

Views and aspirations (section A of EHC plan)

This first section should also of course include the views and aspirations of the child or young person and their family – this is the major element of Section A of the EHC plan, and should have a correspondingly prominent position in any continuing care assessment. Chapter 2 provides a more detailed description of the key issues which should be considered in engaging with the child or young person and their family. In particular, this section should consider:

- The child/young person's issues, concerns, anxieties.
- The child/young person's preferences about care delivery.
- The family's preferences about care delivery.

Emotional and support needs

Assessment should consider the emotional support needs of a child, young person and their family.

- *What is the effect of the child/young person's condition on each member of the family?*
- *What times of the day/events are stressful?*
- *How does the family cope?*
- *Who does the family call on for support at these times?*
- *Are there times when the child or young person need particular support?*
- *How do they communicate as a family?*
- *What is the child/young person's understanding of his/her condition?*
- *What understanding do siblings have of the child/young person's condition?*
- *Is an assessment by the child and adolescent mental health service required?*

Outcomes

14. The assessment of a child's continuing care needs must consider the outcomes necessary to enable the child or young person to get the best from life, and outcomes relating to transition (where the child is 14 years or older), identifying unmet need.

15. They should be specific, deliverable and linked directly to the child's wishes. They should include where appropriate, outcomes for transition, through key changes in a child or young person's life, such as changing schools, moving from children's to adult

care and/or from paediatric services to adult health, or moving on from further education to adulthood.

16. Key issues would include:

- Maintaining a safe environment.
- Communicating.
- Breathing.
- Eating and drinking.
- Elimination.
- Personal cleaning and dressing.
- Controlling body temperature.
- Mobilising.
- Playing.
- Learning.
- Expressing individuality.
- Sleeping.
- Employment
- Independence
- Further education
- End of life.
- Pain management

Care domains

17. Health assessors should consider the needs of the child or young person across the following 10 domains of care. Care has been taken to avoid duplicating needs in two separate domains. However, assessors should consider how different but inter-related needs across more than one domain can complicate the child or young person's overall care needs and result in sufficient complexity, intensity or risk to demonstrate continuing care needs. Examples of this might include the relationship between skin integrity and continence, or cognitive impairment and behaviour and/or communication.

18. It is essential that clear evidence is obtained to support assessments in the relevant domains, and that this evidence is recorded as part of the continuing care assessment, and included in any subsequent care plan.

19. As a rule of thumb, a child is likely to have continuing care needs if assessed as having a severe or priority level of need in at least one domain of care, or a high level of need in at least three domains of care.

20. The level of need in a single domain may not on its own indicate that a child or young person has a continuing care need, but will contribute to a picture of overall care needs across all domains. Levels of need are relative to each other as well as to those in other care domains. It is not possible to equate a number of incidences of one level with a number of incidences of another level – that needs assessed as 'moderate' in two domains are the equivalent of one 'high' level of need, for example. In presenting recommendations and costed options to a multi-agency forum, nominated children and young people's health assessors should consider the level of need identified in **all** care domains in order to gain the overall picture.

21. These guidelines should not be used in a restrictive way. Nominated children and young people's health assessors should be mindful that even if the child or young person is assessed as not having continuing care needs, they may require other healthcare input from universal services or community children/young person's nursing or other specialist services.

Breathing

Describe the child or young person's specific needs relevant to this domain.

Breathing - assessors should indicate the level of need

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;	Moderate

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.	
Requires high flow air / oxygen to maintain respiratory function overnight or for the majority of the day and night; **or** is able to breath 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 frequent 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	Priority

tubes.	

Eating and drinking

Describe the child or young person's specific needs relevant to this domain.

Eating and drinking – assessors should indicate the level of need

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 not 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,. **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.	High
The majority of fluids and nutritional requirements are routinely taken by intravenous means.	Severe

Mobility

Describe the child or young person's specific needs relevant to this domain.

Mobility - assessors should indicate the level of need

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 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).	High
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

Continence or elimination

Describe the child or young person's specific needs relevant to this domain.

Continence or elimination - assessors should indicate the level of need

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; **or** is usually able to maintain control over bowel movements but may have occasional faecal incontinence.	Low
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

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 (i.e. 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 should be considered under **Breathing**.)

Describe the child or young person's specific needs relevant to this domain.

Skin and tissue viability - assessors should indicate the level of need

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

Communication

Describe the child or young person's specific needs relevant to this domain.

Communication - assessors should indicate the level of need

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
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. 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 or young person is rarely able to communicate basic needs, requirements or ideas.	High

Drug therapies and medication

Describe the child or young person's specific needs relevant to this domain.

Drug therapies and medication – assessors should indicate the level of need

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; **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).	Severe
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

Psychological and emotional needs (beyond what would typically be expected from a child or young person of their age)

Describe the child or young person's specific needs relevant to this domain.

Psychological and emotional needs (beyond what would typically be expected from a child or young person of their age) – assessors should indicate the level of need

Interpretation point: a separate domain considers **Challenging Behaviour**, and assessors should avoid double counting the same need.

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

Seizures

Describe the child or young person's specific needs relevant to this domain.

Seizures – assessors should indicate the level of need

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

Challenging behaviour

Describe the child or young person's specific needs relevant to this domain.

Challenging behaviour – assessors should indicate the level of need

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. running away, eating inedible objects), despite specialist health intervention and which have a negative impact on on the child and their family / everyday life.	High
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