NHS Continuing Care:
the legal limits of social care responsibilities for children & young people

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Children Act 1989 s29

Recoupment of costs

(1) Where a local authority provide any service under section 17 or 18, other than advice, guidance or counselling, they may recover from a person specified in subsection (4) such charge for the service as they consider reasonable.

,…

(4) The persons are—

(a) where the service is provided for a child under sixteen, each of his parents;

(b) where it is provided for a child who has reached the age of sixteen, the child himself; and

(c) where it is provided for a member of the child's family, that member

2

Care Act 2014 ss 58 - 59

Duty to disabled children under 18

Where it appears to a LA that:

- it is 'likely' that a person will have care & support needs after transition and it will be of significant benefit to be assessed;
- It must assess

3

Children's services funding?

- Registered nurses
- Tracheotomy care
- Stoma care
- PEG feeding
- Ventilators
- Hydrotherapy
- Invasive tasks eg invasive tasks ~ anything that goes into the body (in, up and down!)

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Key issues

1. **An area regulated by the law;**
2. **The law gives only a general 'steer' as to where the boundary lies;**
3. **Accordingly decisions of the court and Ombudsmen important - the '*benchmark cases*';**

5

Legal regulation

Example

s275(1) NHS Act 2006 (interpretation)
"illness" includes mental disorder and any injury or disability requiring medical or dental treatment or **nursing**,

s1(2) Mental Health Act 1983
"mental disorder" means any disorder or disability of the mind;

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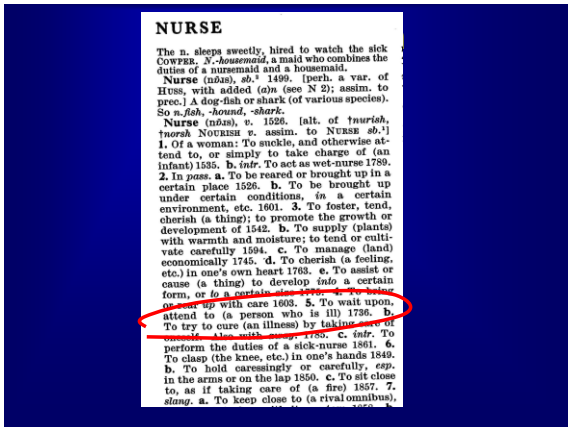
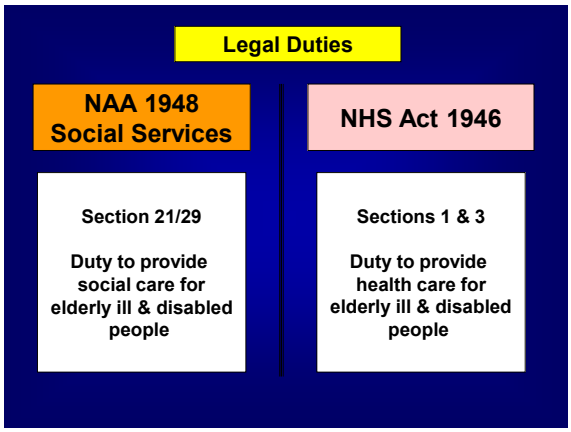
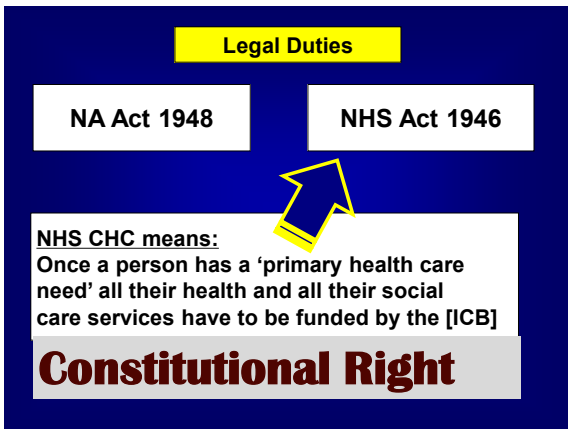

NURSE
The n. sleeps sweetly, hired to watch the sick
COWPER. N.-housemaid, a maid who combines the duties of a nursemaid and a housemaid.
Nurse (nɔ̈s), sb.[2] 1499. [perh. a var. of HUSS, with added (a)n (see N 2); assim. to prec.] A dog-fish or shark (of various species).
So n.-fish, -hound, -shark.
Nurse (nɔ̈s), v. 1526. [alt. of †nurish, †norsh NOURISH v. assim. to NURSE sb.[1]]
1. Of a woman: To suckle, and otherwise attend to, or simply to take charge of (an infant) 1535. b. intr. To act as wet-nurse 1789.
2. In pass. a. To be reared or brought up in a certain place 1526. b. To be brought up under certain conditions, in a certain environment, etc. 1601. 3. To foster, tend, cherish (a thing); to promote the growth or development of 1542. b. To supply (plants) with warmth and moisture; to tend or cultivate carefully 1594. c. To manage (land) economically 1745. d. To cherish (a feeling, etc.) in one's own heart 1763. e. To assist or cause (a thing) to develop into a certain form, or to a certain
up with care 1603. 5. To wait upon, attend to (a person who is ill) 1736. b. To try to cure (an illness) by taking
perform the duties of a sick-nurse 1861. 6. To clasp (the knee, etc.) in one's hands 1849. b. To hold caressingly or carefully, esp. in the arms or on the lap 1850. c. To sit close to, as if taking care of (a fire) 1857. 7. slang. a. To keep close to (a rival omnibus).

7


Legal Duties
NAA 1948
Social Services
NHS Act 1946
Section 21/29
Duty to provide social care for elderly ill & disabled people
Sections 1 & 3
Duty to provide health care for elderly ill & disabled people

8


Legal Duties
NA Act 1948
NHS Act 1946
NHS CHC means:
Once a person has a 'primary health care need' all their health and all their social care services have to be funded by the [ICB]
Constitutional Right

9

Legal duties

Pre-14.10.1991	Post-14.10.1991
NAA 1948 Cradle to Grave Healthcare right Everyone entitled to NHS CHC funding	CA 1989 applied to children & YP

- **Children Bill 1988** ~ No mention of any change to NHS entitlement in debates
- **NHS CHC Guidance** the first guidance (1995) applied to adults & children. Only in 2010 was separate guidance issued.

10

s22 Care Act 2014

- **A LA may not meet needs under the CA 2014 if those needs are required to be met under the NHS Act – unless**
  - The provision falls within the *Coughlan* criteria

But - nothing in the Children Act 1989 that prohibits social services providing healthcare

11

Leeds Ombudsman case 1994

- **incontinent and unable to walk, communicate or feed himself: a kidney tumour, cataracts and occasional epileptic fits, for which he received drug treatment.**
- **had reached the stage where active treatment was no longer required but that he was still in need of substantial nursing care, which could not be provided at home and which would continue to be needed for the rest of his life**

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Leeds Ombudsman case 1994

- Stable
- Substantial low level nursing
- No need for specialist input
- Adequately cared for in ordinary nursing home

13

Leeds Ombudsman case 1994

Government Response

- HA's to prepare CC statements
- If in the light of the guidance, some HA's are found to have reduced their capacity to secure continuing care too far – as clearly happened in the case dealt with by the Health Service Commissioner – then they will have to take action to close the gap

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NHS Guidance

Statutes eg NHS Act 2006	Court cases eg *Coughlan*
Regulations / directions	

Practice Guidance

15

Coughlan (1999)

- **She is tetraplegic;**
- **doubly incontinent,**
- **requiring regular catheterisation;**
- **partially paralysed in the respiratory tract,**
- **with consequent difficulty in breathing; and**
- **subject not only to the attendant problems of immobility but to recurrent headaches caused by an associated neurological condition**

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Coughlan (1999)

The distinction between those services which can and cannot be so 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:

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Coughlan (1999)

(1) merely incidental or ancillary to the provision of [social care] which a local authority is under a duty to provide [under the social care legislation] and

18

Coughlan (1999)

(2) 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 (by SS).

The Quantity / Quality test

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IN THE SUPREME COURT OF JUDICATURE
COURT OF APPEAL (CIVIL DIVISION)
Royal Courts of Justice
Date: 16 July 1999

R. v. NORTH AND EAST DEVON HEALTH AUTHORITY
- Respondent

Ex parte PAMELA COUGHLAN
- Applicant

- **SECRETARY OF STATE FOR HEALTH**
- Intervener

- **and**
- **ROYAL COLLEGE OF NURSING**

118. …. . Miss Coughlan needed services of a wholly different category.

20

Wigan Patient 2003

- **Several strokes**
- **No speech or comprehension**
- **Unable to swallow**
- **PEG fed**

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Wigan Patient 2003

I cannot see that any authority could reasonably conclude that her need for nursing care was merely incidental or ancillary to the provision of accommodation or of a nature one could expect Social Services to provide. It seems clear to me that she, like Miss Coughlan, needed services of a wholly different kind.

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Pointon 2004

- Advanced dementia, (ie 'some of the severe behavioural problems, which had characterised his illness during its earlier stage, had now diminished');
- Unable to look after himself;
- His wife cared for him at home.

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Pointon 2004

- Mrs Pointon 'giving highly personalised care with a high level of skill ... nursing care equal if not superior to that that Mr Pointon would receive in a dementia ward'
- Complaint upheld: assessors had focused on acute care' rather than assessing the 'psychological needs of patients with illnesses such as dementia' (para 39)
- Severe psychological problems and the special skills required to nurse someone with dementia

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R (T, D & B) v Haringey LBC (2005)

- Disabled child
- Tracheostomy (a tube in the throat) which needed, suctioning about three times a night.
- "It is quite common now for children who have tracheostomies to be discharged from hospital and cared for at home (para 5)
- Great Ormond Street Hospital provides training for parents in how to manage those requirements at home; the Claimant mother has been trained fully in those areas" (para 7)

25

R (T, D & B) v Haringey LBC (2005)

Mother argued that the respite care should be funded by social services and not the NHS.

Mr Justice Ouseley (para 61) (citing *Coughlan*)

- the provisions of the Children Act are not to be regarded in general as reducing or replacing the important public obligations … set out in the [NHS Act]. I do not see that the impact there of section 21(8) of the NAA 1948 means that the principles enunciated were peculiar to that Act"

26

R (T, D & B) v Haringey LBC (2005)

The night sitting service required:

- *a trained carer (not a qualified nurse): someone (like the mother) who 'could be trained to carry out tracheal suction and would need to awaken the mother if she couldn't quickly clear the tube'. (para 16).*

Issue 1. Not who does it but what they are doing:

Issue 2. Is this really relevant once a YP is about the limits of social care?

27

R (T, D & B) v Haringey LBC (2005)

- there is a broad distinction to be drawn between health and social care provision and 'the provisions of the Children Act are not to be regarded in general as reducing or replacing the important public obligations' which were identified in *Coughlan* (para 61);

28

R (T, D & B) v Haringey LBC (2005)

- the 'quality / quantity' test in *Coughlan* applied to children. The 'scale and type of nursing care' are '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 authority can be expected to provide' (para 62);

29

R (T, D & B) v Haringey LBC (2005)

- the purpose of the care is important. 'From one viewpoint, the purpose of its provision is so that the mother can have a few nights of unbroken sleep per week or some time by herself a week or to look after T.

30

R (T, D & B) v Haringey LBC (2005)

- That could be seen as social care for the mother. But its nature and purpose is to provide medical care for D; the intention behind the provision of that medical care is her safety while her mother enjoys respite. There is nothing different in quality or care about the disputed provision'; (para 65)

31

R (T, D & B) v Haringey LBC (2005)

- although on a broad interpretation of s17(1) of the Children Act 1989 'to safeguard and promote the welfare of children by proving a range and level of services appropriate to' could cover what are essentially medical needs – but 'such an interpretation would turn the social services authority into a substitute or additional NHS for children'.

32

R (T, D & B) v Haringey LBC (2005)

- That would be … an impermissibly wide interpretation, creating obligations on a social services authority which are far too broad in the context of other statutory bodies and provisions covering the needs of children' (para 68).

33

R (Juttla) v Herts Valleys [ICB] (2018)

- a nurse-led respite unit for disabled children 'looked at literally' was 'the provision of health services as described in the 2006 Act'
- The fact that the care was provided in order to give the parents respite was not the issue;
- Nor was the fact that much of the care could, in theory, be delivered by trained social care staff (ie who provided it was not determinative)
- Relying on the *Haringey* (2005) judgment the court had 'no doubt that the services provided [the facility] are health services'

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R (JP) v NHS Croydon [NHS] (2020)

7 year old who suffered 'from a range of serious health issues including ... respiratory problems - and had been fitted with a tracheostomy and supported by mechanical ventilation during his night-time sleeping hours.

Court highly critical of irrational process which the NHS body sought to withdraw eligibility for CC.

> It 'completely misrepresented [a medical assessment] and the decision is taken on the wholly false basis that the tests have established that JP was definitely able to manage long-term without the aid of a ventilator.'

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R (JP) v NHS Croydon [NHS] (2020)

[NHS] argued that the Localism Act 2011 s1 empowers councils to provide medical care;

Mostyn J held that it was:

- inconceivable that section 1 could be used to usurp decisions reposed in the NHS ….

that this would drive

- a coach and horses through very carefully delineated frontiers of competence and function between the NHS on the one hand and local authorities on the other.

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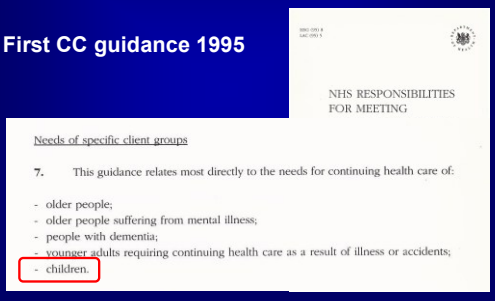
NHS CC Guidance

First CC guidance 1995



NHS RESPONSIBILITIES FOR MEETING

Needs of specific client groups

7. This guidance relates most directly to the needs for continuing health care of:

- older people;
- older people suffering from mental illness;
- people with dementia;
- younger adults requiring continuing health care as a result of illness or accidents;
- children.

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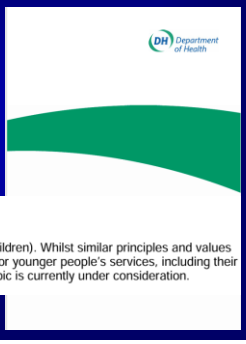
NHS CC Guidance

First Framework Guidance 2007



Links to Children's Policy

70. This guidance does not cover under 18s (children). Whilst similar principles and values apply, there are different legislative drivers for younger people's services, including their need for education, and guidance on this topic is currently under consideration.

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NHS CC Guidance

First Framework Guidance for Children & YP 2010 - revised 2016

Current Framework Guidance for adults 2022

C&YP Checklist

C&YP Decision Support Tool (DST) 2016

10 named care domains

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NHS CC Guidance

17 year old with ASD, ADHD and dyslexia; self-harmed, suicidal ideation, sensory processing, emotional dysregulation, and disordered eating.

CAMHS assessment found no acute MH problem, but long-term complex emotional and behavioural difficulties requiring a multiagency approach.

The LA sought joint funding, the ICB disagreed.

The LA did not challenge the validity of the 2016 C&YPs Framework but did argue that the 2022 Adult CHC was relevant.

40

NHS CC Guidance

The judge disagreed, stating that (para 98):

> There are different and distinct framework documents relating to adults and to children. It cannot be said that the framework relating to adults was an obviously material consideration when making a decision relating to a child. For that reason, the Defendant did not err by failing to have regard to the NF for Adults

R v Kensington & Chelsea & NHS North West London ICB [2025] EWHC 889 (Admin)

Lesson: difficult to challenge MH/neurodiverse cases in High Court (cf physical impairments etc) .

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2016 C&YP Framework

Problematic

- 'continuing care package will be required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone' (page 5).

What distinguishes it from the NHS simply meeting a person's healthcare needs

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2016 C&YP Framework

Problematic

- It does not explain what is or who is responsible for it.
- The judgment in *Haringey* makes clear that this is a package of health and social care support provided by the NHS

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2016 C&YP Framework

Problematic paras 1-2

- … some children and YP … may have very complex health needs … .
- These needs may be so complex, that they cannot be met by the services which are routinely available from GP practices, hospitals or in the community commissioned by … [ICB]s ….
- A package of additional health support may be needed. This additional package of care has come to be known as continuing care.

44

2016 C&YP Framework

Problematic omitted

para 42 the 2010 Framework

well managed needs were still 'needs' (repeating guidance in the adult Framework) and that only:

> the successful management of a continuing care need has permanently reduced or removed an ongoing need, this will have a bearing on the child or young person's need for continuing care.

45

2016 C&YP Framework

Well managed needs are still needs

- ie the continuing care process should not marginalise a need just because it is being successfully managed but where the underlying need continues unreduced.

46

2016 C&YP Framework

Problematic omitted (para 35 or 2010)

- Wherever possible, continuing care should be provided in the child or YPs home, but it may be provided in another setting such as a residential school, residential placement or hospice.

47

2016 C&YP Framework

Problematic omitted (para 35 2010)

- Establishment of a continuing care need is not determined either by the setting where the care is provided or by the characteristics of the person who delivers the care.

48

Framework for Children & YP 2016

The assessment process

Health dominated (in contrast to the adult assessment process that is undertaken by a multi-disciplinary team (MDT) which includes a social care professional.

assessment is led by a children & YP's health assessor nominated by the [ICB], who will draw on the advice of other professionals ...' (para 7)

49

Framework for Children & YP 2016

The outcome of the assessment is 'a recommendation from the assessor as to whether or not the child or young person has continuing care needs' (para 8)

If so there is then a 'multi-agency forum or panel' that decides as to whether the child or young person has a CC need (para 10).

If the LA disagree it is able to challenge this through a disputes process

50

Framework for Children & YP 2016

Care Planning

the development of a package of care. .. should always be considered after a decision has been made on whether or not there is a CC need.

The establishment of a CC need should not be determined by the existing package of care a child or young person receives, or who provides or pays for it. (para 11)

51

Framework for Children & YP 2016

- Problematically the 2016 framework fails to distinguish between health / social care overlaps and health / education overlaps.
- There cannot be an overlapping responsibility to provide services between health and social services once a person has been held to be eligible for NHS CC,
- There can however be an overlap between health and education responsibilities.

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Framework for Children & YP 2016

Para 15 it states:

- Children with complex needs may not only need support from health services. They may also have special educational needs, and need support from social care.

53

Framework for Children & YP 2016

'Support'

'support' must mean:

- helping their family with the emotional problems of caring for a disabled children,
- providing carer's assessments,
- addressing any safeguarding concerns
- complying with the LAC regulations and
- the guidance where a child is in residential care .

54

R (T, D & B) v Haringey LBC (2005)

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Accommodated children

- Looked after children have the same rights to NHS CC funding as any other child.
- LA required to provide funding (and supervision) for a foster parent etc and for the cost of any social care accommodation (CA 1989 s20) but the NHS duty to provide services applies as with any other child.
- LA responsible for ensuring the child has an IRO (CA 1989 s25) & complies with its obligations under the LAC regs

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NHS v Education overlaps

No '*Coughlan*' type legal rule relating to education / NHS

Accordingly all children and YP eligible for NHS CC will have separate needs for education.

Children and Families Act 2014 s42(3) places unprecedented duties on health bodies in relation to children with an EHC plan.

60

NHS v Education overlaps

Section 42(3)

Any health care support specified in a children or YP's EHC Plan must be provided

ie that it is a specifically enforceable duty to provide.

61

NHS v Education overlaps

High Court

An EHC Plan placed obligations on the NHS to provide support. The court held that it was lawful for the NHS to delegate the production of the care plan to the provider commissioned to provide the care.

BUT this did not excuse the NHS from ensuring such a plan was in place, was properly monitored and was adequate. (ie detailed)

s42(3) C&F Act 2014 is an absolute, non-delegable duty on the NHS to arrange the specified healthcare provision and is not a 'best endeavours' obligation.

R (A) v North Central London ICB [2024] EWHC 2682 (Admin)

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Timescale for assessment

the 'clock starts at the point of recognition that a child or YP should have a full CC assessment' (para 49).

The aim is that the assessment be within 6 weeks (para 50).

Although there are benefits in aligning NHS CC and EHC assessments the framework stresses that the CC assessment should not 'be delayed in order to fit within the timescale for an EHC plan assessment' (para 51).

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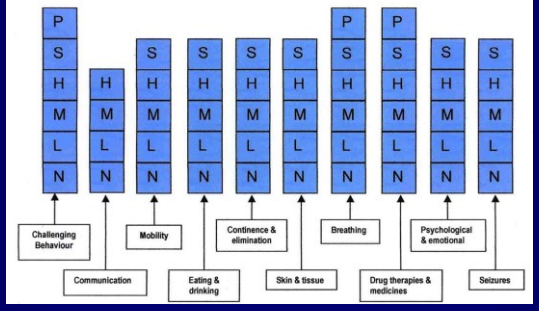
Full DST Checklist



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Checklist

Checklist not mandated

- 'a suggested template for this checklist is published alongside this framework. [ICB]s should be flexible in how they approach this; it may be appropriate to obtain professional advice to inform a pre-assessment decision (para 62).

65

Checklist

Decisions should be made quickly 'should not take more than a day or two'.

- Since there appears to be no statement as to what 'scores' on the checklist should trigger a full DST assessment, it is difficult to know what value it has.

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Fast track assessments

54. Children & YP who require fast-track assessment because of the nature of their needs (such as a palliative care need) should be identified early and the child or young person's needs met as quickly as possible.

The CC process should not restrict access to end-of-life care for children and YP who require immediate support over a shorter period, and should not result in any delay to appropriate treatment or care being put in place

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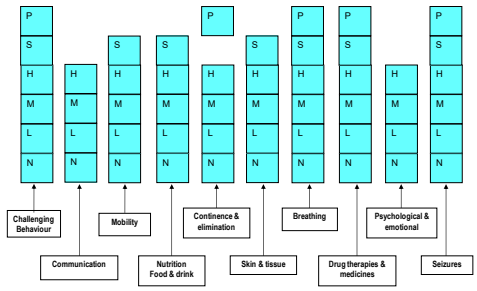
Children's NHS CC DST 2010



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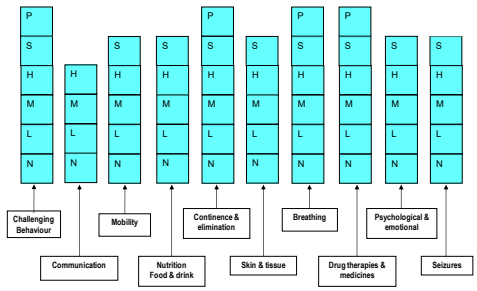
Children's NHS CC DST 2016



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[DST] What it's NOT

- An another assessment
- **A decision MAKING tool**
- Suitable for every individual's situation
- **A substitute for professional judgement**

DoH Resource pack: Introduction Module 1: slide 19

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Children & YP DST

Framework para 148
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 three domains of care.

DST para 19
This advice is described as 'a rule of thumb'

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Children & YP DST

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 peoples nursing or other specialist services (para 150).

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Children & YP DST

Challenging behaviour

An assessment may identify behaviours under **Challenging behaviour** which cannot be met by health services or which would be more appropriately met by special educational support, or social care. In such cases, there should be a dialogue with the local authority, and if necessary, agreement of a joint package of care, in line with respective commissioning policies.

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Children & YP DST

Where a child has a Statement of SEN or an Education, Health and Care plan, there may of course be a pre-existing package of educational support which requires no additional support from health or social care services.

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Challenging behaviour

Moderate
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.

High
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.

Severe
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.

Priority
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).

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Communication

Moderate
Communication about basic needs is difficult to understand or interpret, even when prompted, unless with familiar people, and requires regular support.
Support is always required to facilitate communication, for example, the use of choice boards, signing and communication aids.
Ability to communicate basic needs is variable depending on fluctuating mood or level of pain; or
the child/young person demonstrates severe frustration about their communication, for example, through challenging behaviour or withdrawal.

High
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, even with familiar people.

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Interaction of domains / needs

A 2014 Welsh Ombudsman's report

- patient with Parkinson's Disease - symptoms included night time wakefulness, noisiness, restlessness, increased lethargy and increased physical rigidity.
- Over period of review these symptoms increased.
- Although individually minor he considered that they should have been properly recorded by the NHS body
- cumulatively they were significant and the NHS body had failed to consider 'how a need in one domain might intensify or complicate needs in another'.

Powys Teaching Health Board No. 201303895

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Interaction of domains / needs

A 2019 English Ombudsman's report

- A YP with a number of 'severe symptoms … including intractable epilepsy, developmental delay, scoliosis and reflux.
- The parents considered the assessment inadequate - it failed to score sufficiently highly the unpredictability of the YP's seizures and his risk of aspiration (both given a moderate score).

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Interaction of domains / needs

The ombudsman agreed.

- There was no evidence that 'the panel considered in any detail the cumulative impact' of the young person's seizures, reflux and hip dysplasia on his night care needs'.
- The Framework requires that that consideration be given to the fact that 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.'

Central Bedfordshire Council (no 16 002 323)

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Mobility.

High
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).

Severe
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.

80

Eating and drinking

Moderate
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.

High
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.

Severe
The majority of fluids and nutritional requirements are routinely taken by intravenous means.

81

Continence or elimination

Moderate
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.

High
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.

Severe
Requires dialysis in the home to sustain life.

82

Skin and tissue viability

Moderate
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.

High
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.

Severe
Life-threatening skin conditions or burns requiring complex, painful dressing routines over a prolonged period.

83

Breathing

High
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
Severe
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.
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.
Priority
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.

84

8. Drug therapies and medicines

High
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.

Severe
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).

Priotrity
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.

85

9. Psychological and emotional needs

Moderate
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).

High
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.

86

10. Seizures

Low
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.

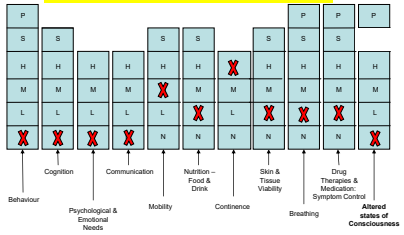
Moderate
Occasional seizures including absences that have occurred with the last three months which require the supervision of a carer to minimise the risk of harm;
or
up to three tonic-clonic seizures every night requiring regular supervision.

High
Tonic-clonic seizures requiring rescue medication on a weekly basis;
or
4 or more tonic-clonic seizures at night.

Severe
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.

87

1 Priority; or
2 Severe; or
3 1 severe + needs in a number of other domains, or
4 A number of highs and/or moderates,



Miss Coughlan needed services of a wholly different category

88

Who decides?

NHS CC

- The panel decides – ie primarily an NHS decision;

The limits of social care

- The local authority decides.

89

[ICB] v LA Disputes

92. [ICB]s & LAs should agree a local dispute resolution process to resolve cases where there is a dispute ... over a child or YPs CC needs and/or over responsibility for the funding of a package of CC in a robust and timely manner.
93. Disputes should not delay the provision of the care package, and the arrangements should be clear on how funding will be provided pending resolution … and arrangements for reimbursement to the agencies involved once the dispute is resolved.

90

ICB v LA Disputes

Ombudsman complaint

A dispute between the ICB and LA meant that a disabled person received no support and experienced significant harm as a result.

The social worker requested funding to reinstate night-time support to avert risks of pressure sores.

LA funding panel rejected all night-time care requests, saying it was for the NHS to fund night-time care.

Maladministration

Croydon LBC (23 020 786) 21 Feb 2025

91

Duty to cooperate

S27 Children Act 1989

(1) Where it appears to a LA that any authority mentioned in subsection (3) could, by taking any specified action, help in the exercise of any of their functions under this Part, they may request the help of that other authority specifying the action in question.

(2) An authority whose help is so requested shall comply with the request if it is compatible with their own statutory or other duties and obligations and does not unduly prejudice the discharge of any of their functions.

92

Co-operation

If a ICB fails to comply a local authority – the authority can request NHS England to 'direct' the ICBs to take appropriate action

s13YB(7) NHS A 2006
Inserted by s13 Health and Care Act 2022

Local authorities can require a ICB member (ie its CEO) to appear in front of a Health Scrutiny Panel

reg 27(1) Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 SI 218

93

Transitions

Key guidance for health professionals on managing the transition process includes:

- DCSF & DH Guidance (2008) *Transition: moving on well – A good practice guide*.
- DCSF and DH (2007) *A transition guide for all services: key information for professionals about the transition process for disabled young people*

94

Transitions

2016 Guidance advises:

future entitlement to adult NHS CC '*should be clarified as early as possible in the transition planning process, especially if the young person's needs are likely to remain at a similar level until adulthood' and this should be done 'at a suitable point when aged 16-17*' (para 116).

95

Transitions

2016 Guidance (para 117):

At 14 years of age, the YP should be brought to the attention of the [ICB] as likely to need an assessment for NHS CC.

At 16 -17 years of age, screening for NHS CC should be undertaken using the adult screening tool, and an agreement in principle that the young person has a primary health need, and is therefore likely to need NHS CC.

At 18 years of age, full transition to adult NHS CC or to universal and specialist health services should have been made, except in instances where this is not appropriate.

96

Transitions

2016 Guidance (para 120):

when the YP is 16 eligibility for NHS CC should be determined in principle 'so that, wherever applicable, effective packages of care can be commissioned in time' for their 18th birthday (or later, if it is agreed that it is more appropriate for responsibility to be transferred then)'

97

Dispute delayed care

It was agreed that a young adult with LD transitioning to adult services should move from her parents home into a residential placement.

The NHS and LA disagreed as to whether she was eligible for CHC and (pending this being resolved) their contributions to a care placement.

The ombudsman – in finding maladministration – held that this dispute prevented her placement from proceeding. The report cites extensively from the Framework Guidance.

Complaint 20 009 117 Derbyshire CC (2021) para 64

98

Aneurin Bevan LHB (2013)

Ombudsman (when deciding that a transitional assessment by the NHS was flawed – was particularly concerned about statements in DST domains that:

- M's needs had not recently changed'; and
- no health interventions being needed'

This is not the test. The test is whether someone has a primary health need, not what interventions they are receiving or who is providing them'.

99

S117 Mental Health Act 1983

Patients detained under:
- s3 MHA 1983 or
- MHA 1983's criminal provisions.

On discharge entitled to s117 MHA 1983 after care services
1. Free
2. Joint NHS / SS

100

S117 Mental Health Act 1983

Patients entitled to s117 unlikely to be eligible for NHS CC
- unless distinct non-mental health care need

s117 patients can be taken to 'panel' - to answer the question:
- "but for entitlement to s117 would this person have been eligible for NHS CC?"

If 'Yes' then NHS should fund 100% of the MHA 1983 costs - ie "100% s117 funded"

101

Rare conditions

2012 Regulations list '*rare and very rare conditions*' for which [ICB]s must arrange services:

144 separate conditions itemised, eg:
- severe obsessive compulsive disorders;
- specialist morbid obesity services;
- specialist rehabilitation services for patients;
- spinal cord injury services

NHS Commissioning Board & [ICB]s (Responsibilities & Standing Rules) Regulations 2012 SI 2996, Reg 11 & Sch 4 .

102

Parent carers

Duty to assess PC 'on the appearance of need'

- A PC is an adult 'who provides or intends to provide care for a disabled child for whom the adult has parental responsibility'
- The PC assessment must have regard to the well-being of the PC;
- "well-being" has same meaning as in Care Act 2014.
- LAs must identify the extent to which there are PCs within their area who have needs for support

s97 C & F Act 2014 amends Children Act 1989 (s17ZD)

103

Parent carers

2019 ombudsman report.

- A YP with a number of severe symptoms and related health conditions'
- Parents under intense physical / mental strain - argued that the assessment flawed as their needs had not been taken into account.
- [ICB] stated: the 'DST domains do not score parental wellbeing as part of the eligibility criteria'.

The ombudsman disagreed

- The Framework's refers to the need for an holistic assessment of YP and their family.

Central Bedfordshire Council (no 16 002 323)

104