

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

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Setting the scene

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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

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Who Pays

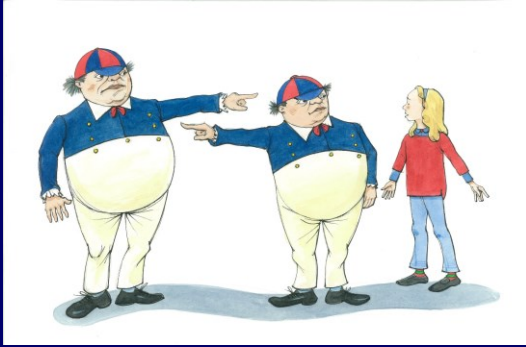
Frequently irrelevant for children / young people

Problems often arise due to inter authority squabbles about which agency is responsible



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Who Pays



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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*';

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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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Nursing

Nursing is a verb. It describes an activity, not the person doing it. Who does the nursing is irrelevant (ie it could be a family member, a residential care worker etc)

The question concerns the nature of the nursing – not the characteristics of the person who delivers it.

NURSE

The n. sleeps sweetly, hired to watch the sick
COVER. *N. housemaid*, a maid who combines the
duties of a nursemaid and a housemaid.

Nurse (*n*), *sb.* 1499. [*perh.* a var. of
HUSS, with added (*oh*) (see *N 2*); assim. to
prec.] A dog-fish or shark (of various species).
So *n. fish*, *-hound*, *-shark*.

Nurse (*n*), *v.* 1526. [*alt.* of *nurisch*,
through *NURISH* *v.* assim. to *NURSE sb.*]

1. Of a woman: To suckle, and otherwise at-
tend to, or simply to take charge of (an
infant) 1585. **b.** *infr.* To act as wet-nurse 1789.
2. *In pass.* **a.** To be reared or brought up in a
certain place 1626. **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 1642. **b.** To supply (plants)
with warmth and moisture; to tend or culti-
vate 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, etc. **4.** To bring up, rear, or rear up
with care 1608. **5.** To wait upon,
attend to (a person who is ill) 1736. **b.**

To try to cure (a nurse) by tending
oneself. Also with *away*, 1785. **c.** *infr.* To
perform the duties of a sick-nurse 1801. **6.**
To clasp (the knees, etc.) in one's hands 1849.
b. To hold carelessly 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),
1862.

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2022 [adult CHC] Framework

64 NHS CC may be provided ... in any setting (including, but not limited to, a care home, hospice or the person's own home). Eligibility ... is therefore not determined or influenced by either the setting where the care is provided nor by the characteristics of the person who delivers the care.

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Legal Duties

NA Act 1948

NHS Act 1946

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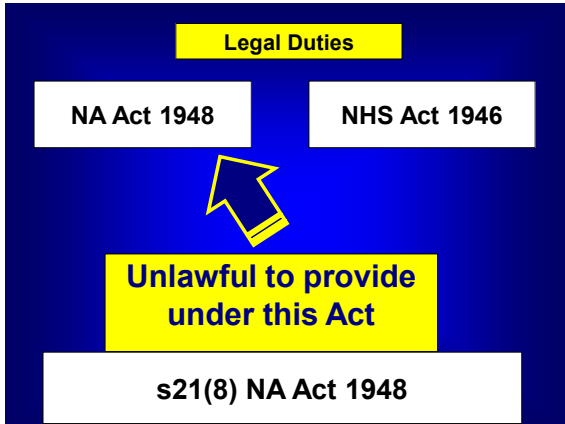
Legal Duties

NA Act 1948

NHS Act 1946

Originally adults & children until CA 1989

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Legal Duties

Children Act 1989

NHS Act 1946

CA 1989 contained no 'limits of social care' provision

In 1991 the Children Act 1989 came into force. All disabled children's social care needs met under this Act
The NA Act 1948 only applied to adults

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Legal duties

<p>Pre-14.10.1991</p> <p>NAA 1948 Cradle to Grave Healthcare right Everyone entitled to NHS CHC funding</p>	<p>Post-14.10.1991</p> <p>CA 1989 applied to children & YP</p>
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- **Children Bill 1988** ~ No mention of any change to NHS entitlement in debates
- **NHS CHC Guidance until 2010** did not specify any difference in entitlement

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NHS CHC Guidance

- The first guidance on NHS CHC issued in 1995 applied to adults and children alike
- No separate guidance was issued for children until 2010

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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 the [social care] which a local authority is under a duty to provide to the category of persons to whom section 21 refers and

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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

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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

Ex parte PAMELA COUGHLAN

• SECRETARY OF STATE FOR HEALTH

• ROYAL COLLEGE OF NURSING

• Respondent
 • Applicant
 • Intervener

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

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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)

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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"

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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?

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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 providing 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'.

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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).

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

- [NHS] wanted to close a nurse-led respite unit for disabled children
- 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
- Relying on the *Haringey* (2005) judgment the court had 'no doubt' that the services provided by the facility were health services.

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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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National Framework for NHS Continuing Care

Adult Framework

- 2007 - revised 2009, 2012, 2018 and 2022

Children & YP

- 2010 revised 2016: 'non-statutory guidance' *R (JP) v NHS Croydon [NHS] [2020]* para 43

Decision Support Tool (for children)

- 10 named care domains

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2016 C&YP Framework

Fails to:

- explain what NHS Continuing care is;
- explain what the consequences (in terms of NHS responsibilities) that follow when someone is held to be eligible;
- explain key principles – ie those detailed in the adult guidance (and also contained in the 2010 guidance)

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2016 C&YP Framework

R (JP) v NHS Croydon CCG [2020] para 11

- If a child scores one severe mark or three high marks he or she will be designated as “eligible” for continuing care. But such a designation does not answer the question of how much continuing care. Conversely, a failure to score one severe mark or three high marks does not shut out a child from all care, continuing or otherwise.

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2022 [adult CHC] Framework

66 The reasons given for a decision on eligibility should not be based on the:

- individual's diagnosis
- setting of care;
- ability of the care provider to manage care;
- use (or not) of NHS employed staff to provide care;
- need for/presence of ‘specialist staff’ in care delivery;
- fact that the need is well managed;
- existence of other NHS-funded care; or
- any other input-related (rather than needs-related) rationale.

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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 [NHS], who will draw on the advice of other professionals ...' (para 7)

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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 CHC need (para 10).

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

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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.

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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 .

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Health social services interface

Once a child or YP is held to be eligible for NHS CC then all their health and social care services needs are the responsibility of the NHS.

This does not mean that social services 'walk away' as clearly they will continue to have 'support' responsibilities – ie non-service provisions responsibilities.

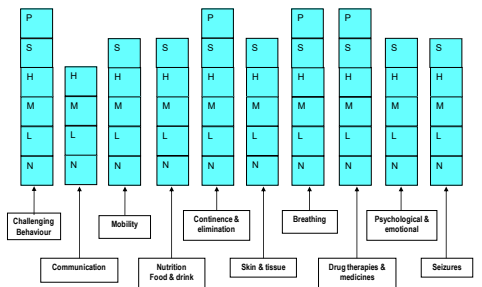
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Accommodated children

- 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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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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Who decides?

NHS CC

- The panel decides – ie primarily an NHS decision;

The limits of social care

- The local authority decides.

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Family / NHS Disputes

88. Where a child or YP is found not to have a need for continuing care, a clear written explanation of the rationale for the decision should be provided
89. The ... family should be informed of ... the complaints procedure

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NHS v LA Disputes

- 92. [The NHS] & LAs should agree a local dispute resolution process to resolve cases where there is a dispute ... over a child or YPs CHC 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.

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[NHS] v LA Disputes

- 93. Given the requirement on [the NHS] and local authorities to have, as part of their joint arrangements for SEND, arrangements for resolving disputes, it would be sensible for such arrangements to also cover disputes relating to continuing care.

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Co-operation

Duty on NHS to cooperate when requested shall unless this would be incompatible with its statutory or other duties and does not unduly prejudice the discharge of any of its functions. s27 Children Act 1989

If a [NHS] fails to comply a local authority – the authority can request NHS England to 'direct' the [NHS] to take appropriate action s14Z21 NHS A 2006

LAs can require a [NHS] member (ie its CEO) to appear in front of a Health Scrutiny Panel reg 27(1) LA (Public, Health & Wellbeing Boards & Health Scrutiny) Regs 2013

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Parent carers (PC)

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.

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

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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.
- [NHS] 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)

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Endnote

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Defining the limits of social care for children & young people

- There has been no suggestion in debates concerning the Children Act 1989 that the right of children to NHS support should be less than the rights of adults.
- For such a fundamental change there would have had to have been a major debate – to explain / justify discrimination of this kind against children (and their families)
- Local authorities are legally entitled to charge parents for children's social services – and it appears that a few local authorities do charge for such support

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Defining the limits of social care for children & young people

When the courts have heard arguments that social services can fund such services – as in

- *R (T, D & B) v Haringey LBC* (2005)
- *R (Juttla) v Herts Valleys CCG* (2018)
- *R (JP) v NHS Croydon CCG* (2020)

They have rejected these arguments in strong terms

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Children's Services have 3 options

1. Continue with the status quo
2. Apply the adult criteria;
ie if you are above the limits of social care – all your health and all your social care needs fall to be funded by the CCG
3. A middle way – funding determined not by who you are but what you are doing

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Resources

www.lukeclements.co.uk

What's new tab (scroll down)

- Means testing children's healthcare ~ by stealth

Resources tab (scroll down right column) –

- NHS Continuing Care (England) PowerPoint

Publications tab

- Disabled children: a legal handbook

Lecture Series tab (YouTube)

- Lecture 6 NHS Continuing Care (Adult)
www.lukeclements.co.uk/lecture-series/
