

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

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Resources

Resources and Information

- Care Act 2014: overview guide
- Challenging care home evictions / restrictions on visiting
- Challenging demands to repay direct payments
- Challenging home care charges
- Challenging reductions in care services
- Costs ceilings and choice over home care packages
- Council funding panels
- Disabled Children's rights guide
- Disabled Facilities Grants and young people in England
- Finding a local lawyer
- Identifying a new (appropriate) care package
- Misuse by local authorities of their 'protection' powers
- Personal Budgets
- Stephen Sobkow 'Toolbox': Carefree visits to

Precedent Letters

Cerebra template letters - social care, health & education [click here](#).

IPSEA education precedent letters [click here](#).

Irwin Mitchell template letters & factheets [click here](#).

Cerebra Research Project

The School of Law, Leeds University has developed a Legal Evidence and Problem-Solving (LEPS) Project with the National Charity Careless.

The programme helps disabled children and their families who are encountering difficulties in accessing their statutory entitlements to health and social care support.

For copies of the research reports [click here](#). For details of how to access the project [click here](#).

PowerPoint Presentations

- Care Act 2014 Overview;
- NHS Continuing Healthcare: PowerPoint (England)
- Social Services & Well-being (Wales) Act 2014 overview;

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Means testing children's healthcare - by stealth

January 28, 2018 admin

In England and Wales social services provide significant amounts of healthcare to disabled and ill young people which should be funded by the NHS. Although unlawful it has been condoned by the Department of Health and the Welsh Government. The result is not only that young people are assigned to a second tier 'substitute' health service, but also (in England) their entitlement to 'free at the point of need' NHS care is replaced by a service that can be means tested. In addition it has the result that many social services departments are spending very substantial sums on the healthcare needs of young people, when this should be funded by the NHS.

This post outlines how this state of affairs has arisen in England and why, in my opinion, the law severely restricts the power of social services to provide healthcare for young people. The legal position in Wales is

Stephen Sobkow 'Toolbox': Carefree visits to

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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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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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Legal duties

Pre-14.10.1991

NAA 1948 Cradle to Grave Healthcare right
Everyone entitled to NHS CHC funding

Post-14.10.1991

CA 1989 applied to children & YP

- **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
• and
• 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

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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2018 [adults] Framework

65 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.

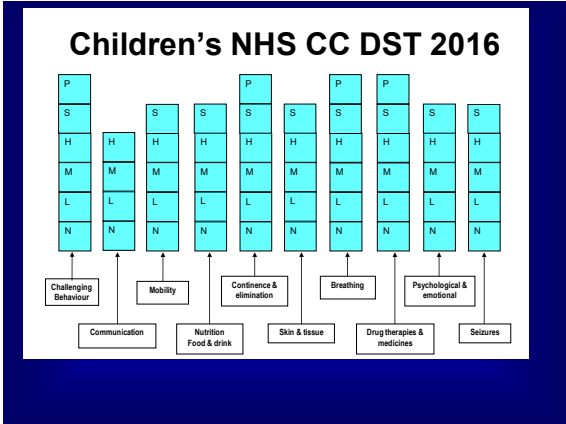
This does not mean that social services 'walk away' as clearly they will continue to have 'support' responsibilities – ie non-service provisions responsibilities.

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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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[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]s 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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Resources

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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 5 NHS Continuing Care (Adult)
- *tbc NHS Continuing Care (children & YP)*
