



Children & young people's continuing care in Wales

the legal limits of social care responsibilities for children & young people

Luke Clements
www.lukeclements.com

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Charging

Social Services & Well-being (Wales) Act 2014, s60

Empowers local authorities to charge for care and support services they provided under the Act.

This includes charging parents for care and support provided to disabled children

The Care and Support (Charging) (Wales) Regulations 2015 reg 3:

States that local authority may not impose a charge for care and support provided or arranged—
(a) to meet the needs of a child;

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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

s206 (1) NHS (W) 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 regulation

'Parental responsibility'

Children Act 1989 section 3(2)

Used to be termed the right of 'custody' ie the right to: discipline a child; decide on the child's education; agree to the child's medical treatment; name the child; look after the child's property.

If families feel they cannot cope with the demands of a disabled child local authorities have a duty to accommodate the child (SSW-b Act 2014 s74)

In such cases local authority do not acquire 'parental responsibility' rights.

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Legal regulation

'Parental responsibility'

Irrelevant concept for NHS CC purposes:

- Children have the same right to healthcare as adults;
- Social welfare Acts place duties on many public bodies to support disabled children – to provide education / social care / healthcare / financial support etc.
- Simply nonsense for any of these bodies to argue they don't have to do this because of 'parental responsibility'.

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Defining the limits of social care for children & young people

- The SSW-b (W) Act 2014 s47 places a limit on what social services can do - in the same way that the NA Act 1948 s21(8) placed a limit.
- In 1999 the Court of Appeal in *Coughlan* defined that limit and held that once above that limit all a person's health and social care service needs were the responsibility of the NHS.

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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 or the SSW-b (W) Act 2014 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 justify discrimination of this kind against children (and their families)
- Although children's social services are currently free in Wales this could be changed by regulation (ie without amending the NHS (W) Act 2006.

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The benchmark cases

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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 [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
• 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.

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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)

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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 CCG (2018)

- NHS body 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 CCG (2020)

NHS body argued that Localism Act 2011 (the equivalent of the LG Act 2000 in Wales) empowers councils to provide medical care;

Held that it was:

- inconceivable that the Act 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.

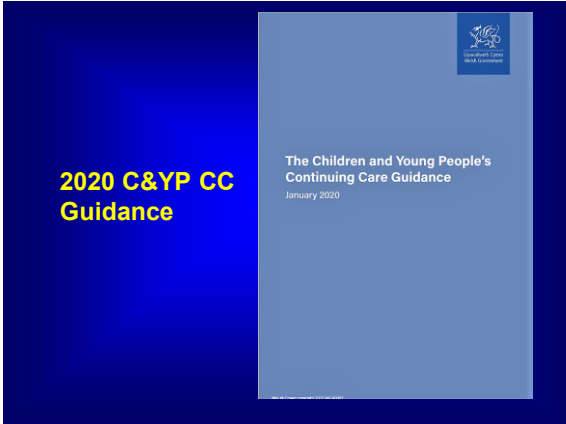
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Learning disabilities and NHS CC

SS Work & Pensions v. Slavin (2011)

- 30 yr old severe LD & Fragile X Syndrome;
- residential care home (not a nursing home);
- Challenging behaviour requiring continuous supervision 1:1 and sometimes 2:1;
- Staff trained to meet the needs of residents but did not have any medical or nursing qualifications;
- C of A held:
his healthcare needs qualify him for an NHS-funded residential placement at a care home where he is provided with the specialist care he requires by reason of his illness' (para 52).

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2020 C&YP CC guidance

The status of the guidance
 Good practice non-binding guidance

- It 'supports agencies ... in meeting their statutory duties' under the NHS (W) Act 2006 and the SSWB (W) Act 2014 but LHBs have autonomy on how they fulfil this function and what process they adopt but adherence to the principles of this framework should ensure consistency and fairness

Para 1.3

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NHS Law & Guidance

Statutes eg NHS (W) Act 2006	Court cases eg <i>Coughlan</i>
Regulations / directions	
2020 CYP CC Guidance Checklist / DST	

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2020 C&YP CC guidance

'Continuing care' describes a service, not the limits of social care

- Most needs can be met by the care which is routinely provided by LHBs However, for a small number of children, their needs are such that they cannot be met by these existing universal or specialist services An additional package of support may be needed. This package of additional support has come to be known as continuing care (para 22).

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2020 C&YP CC guidance

Does the guidance explain what are the limits of social care?

No

Is the preference of a family as to 'who provides the support' relevant to the decision about which body funds the support?

No

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2020 CYP CC guidance

3.60 In instances where 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. However, the continuing care process should not marginalise a need just because it is being successfully managed but where the underlying need continues unreduced.

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2018 English Adult 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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To recap ~ 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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Defining the limits of social care for children & young people

- 'such an interpretation would turn the social services authority into a substitute or additional NHS for children'.
 - inconceivable that the Act could be used to usurp decisions reposed in the NHS
- [such an argument 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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Defining the limits of social care for children & young people

Once a child or YP's need are above the limits of social care then all their health and social care services needs are the responsibility of the NHS (ie on the same basis as for adults).

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

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Defining the limits of social care for children & young people

Children's services retain responsibility for safeguarding /associated social work functions:

- helping parents with the emotional problems of caring for disabled children;
- providing carer support services ie services delivered solely to the parents / siblings;
- giving information
- signposting.

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Defining the limits of social care for children & young people

Looked after children (s74) have the same rights to NHS CC funding as any other child.

- In most cases (unless there is a care order) LAs don't acquire PR – which is, as noted above, irrelevant in any event;
- LA required to provide funding (and supervision) for a foster parent etc and for the cost of any social care accommodation (s76) but the NHS duty to provide services applies as with any other child.
- LA responsible for ensuring the child has an Independent Reviewing Officer etc

Care Planning, Placement and Case Review (Wales) regs 2015

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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 funding

- The panel decides – ie primarily an NHS decision;

The limits of social care

- The local authority decides.

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LHB v LA Disputes

Disputes

- 3.51. LHBs and LAs must-have dispute resolution built into their agreed continuing care pathway.
- 3.52. Best practice supports that disputes are resolved as quickly as possible. The interests of the child are paramount and no child should be denied access or have access to the appropriate health care delayed as a result of a dispute

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Social services & transitions

- 4.8 Children's services should identify those children with potential eligibility for NHS Continuing Healthcare and should notify the appropriate adult complex care teams. Ideally, this should occur when the child reaches the age of 14 years, especially if the young person's needs are likely to remain at a similar level into adulthood.
- 4.9 Once the young person reaches 16 years of age there should be a formal referral for screening to the appropriate adult NHS Continuing Healthcare team.

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Transitions

- 4.10 At 17 years of age the screening tool should be used to determine potential eligibility for adult NHS CHC, followed by a full assessment ... to determine a primary health need wherever applicable, so that an effective package of care can be commissioned in time for the individual turning 18 years of age.

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Aneurin Bevan LHB (2013)

Young man in 'transition' living with his adopted parents, attending school:

- 'severe' LD and limited mobility and a need for hoisting to transfer.
- incontinent, no verbal communication, unable to swallow, PEG fed, epilepsy, impaired sight and hearing,
- prone to chest infections, diarrhoea and sometimes required oxygen.

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Aneurin Bevan LHB (2013)

Transition planning did not begin until 'a few months' before his 17th birthday the summer of 2010

Ombudsman considered this a year too late;
Seriously flawed assessment (see next slide)
decided not eligible (when 17.5 years old)
Given the extent of M's disabilities and his complex needs, this is surprising.
Decision reversed and found eligible

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Aneurin Bevan LHB (2013)

DST recorded:

- **no needs** – in domains behaviour, cognition, mental health, skin and breathing.
- **low needs** – in domain for ASC
- **moderate needs** – in domains communication, mobility, nutrition, continence and medication

The MDT Panel ruled not eligible for NHS CC but recommended a joint package of care.

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Aneurin Bevan LHB (2013)

Ombudsman held this to be flawed
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'.

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s117 Mental Health Act 1983

NHS CC funding arises when a person's needs are above the limits of the SSW-b (W) Act 2014, section 47.

But there is no equivalent 'limit' under s117 MHA 1983

- s117 funding is however the responsibility of both social services & the NHS

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s117 Mental Health Act 1983

It is for LA and the NHS to agree how they will share their funding responsibilities;

In order to decide the extent of a LA / LHB funding responsibility, it is sensible to ask the question

"but for entitlement to s117 would this person have been eligible for NHS CC?"

If 'Yes' then 100% NHS s117 funded
Especially if previously NHS CC eligible

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s117 Mental Health Act 1983

s117 arises when a patient detained under:

- s3 MHA 1983 or
- MHA 1983's criminal provisions.

is discharged from their psychiatric ward

Patients entitled to s117 will only be eligible for NHS CC

- if a distinct health care need arises;
- ie a stroke; a serious physical injury etc

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Learning disabilities and NHS CC

Adult's (2014) Framework

3.119 ... The question is not whether learning disability is a health need, but rather whether the individual concerned, whatever client group he or she may come from, has a primary health need'.

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Carers

Social Services and Well-being (Wales) Act 2014

- Social services have a duty to undertake carers assessments of people entitled to NHS CC funding and
- A duty to provide carer's services

BUT NB

- Respite / short break care is not a carers service
- CYP CC concerning carer support is very troubling / legally questionable (eg paras 5.26 – 5.27)

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Joint funding

If there is an upper limit to social care packages – is it lawful for a the NHS / SS to enter into a joint funding arrangement for someone considered to be at (or near) this upper limit?

The Court of Appeal in *Coughlan* held that it was:

Either a proper division needs to be drawn (we are not saying that it has to be exact) or the Health Service has to take the whole responsibility. TheLA cannot meet the costs of services which are not its responsibility because of the terms of section 21 (8) of the 1948 Act.

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