NHS Continuing Care (CHC) responsibilities for Children and Young People in Wales

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Introduction

In Wales social services provide significant amounts of healthcare to disabled and ill young people which should be funded by the NHS. Although this is (in my opinion) unlawful it has been condoned by the Welsh Government. The result is not only that young people are assigned to a second tier 'substitute' health service but 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.

In order to understand the interface in Wales between the NHS responsibilities for providing continuing care funding for young people and the social services responsibilities for this group – it is necessary to understand the relationship between the two principal statutes: for social services, the Social Services and Well-being (Wales) Act 2014 ('SSWBA 2014') and for the health service, the NHS (Wales) Act 2006.

The 2014 Act (which came into force in April 2016) contains a provision that clearly demarcates the boundary between the respective responsibilities of NHS bodies (Local Health Boards – 'LHBs') and social services authorities for the care of young people. Unfortunately this boundary was not detailed in the young persons' social services legislation that immediately preceded the 2014 Act (the Children Act 1989) and this has left a difficult legacy – primarily due to two particular problems:

1. that the current guidance issued by the Welsh Government – *The Children and Young People's Continuing Care Guidance* (2012) – has not been updated to take account of the 2014 Act; and
2. that this guidance was unfit for purpose even before the 2014 Act came into force.

One other difficulty needs to be highlighted: namely that there has been little litigation concerning the NHS / social services interface for young people. Most of the litigation and most ombudsman complaints on this question have involved adults. The reason for this is straightforward. It is people with significant capital assets who generally have most interest in obtaining NHS CHC funding: if they are the responsibility of the NHS their care will be (to them) free, whereas if they are not, then any support from social services will be means tested. Since most young people are without significant capital assets this has, historically, been of less concern to them and their families.

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The relevance of NHS guidance & decisions concerning adults

The principal NHS guidance in Wales distinguishes between the rights of adults to 'Continuing NHS Healthcare' funding[2] and the rights of young people to 'continuing care'[3] funding. This paper argues that there is very little difference between the legal rights of adults and young people to NHS continuing care funding and so throughout the same phrase is used for both concepts – and paraphrased to 'NHS CHC'.

Problems with the present NHS CHC guidance for young people

Although the principal statutes regulating the respective responsibilities of LHBs and social services for the funding of young people in Wales now contain a clear 'limits' of social care provision, the relevant guidance does not address this. The main reason is that the 2012 guidance predates the SSWBA 2014. However, it is almost certainly the case that such a 'limits of social care provision' existed under the previous legislation and this point needs to be explained, in order to highlight the problems with the 2012 guidance.

1. Understanding the National Assistance Act 1948

The original demarcation of responsibilities between NHS bodies and (what we now refer to as) social services derives from the National Assistance Act (NAA) 1948. This Act applied in Wales until April 2016 and is the statute on which most NHS CHC decisions have been made.

Part III of the Act placed duties on local authorities to provide (what came to be known as) social care services. The 1948 Act and the NHS Act 1946 came into force on the same day and were the foundation stones of the new Beveridgean Welfare State: the NAA 1948 repealing the Poor Laws.

The new settlement was that support under the NHS Act was to be free at the point of need but support under the 1948 Act was to be means tested. Both Acts applied irrespective of age and the 1948 Act contained (in sections 21(8) and 29(6)) a 'limits' of social care provision. This provision was interpreted in by the Court of Appeal in *R v. North and East Devon health authority ex p Coughlan*[4] and phrasing used by the court when explaining what the provision meant is now found in the SSWBA 2014 (section 47).

The 'limits' of social care provision in the 1948 Act applied to young people until the Children Act (CA)1989 came into force.[5] Thereafter the obligations on social services to provide social care services for ill and disabled young people were governed by the 1989 Act. As with the NAA 1948 Act, the 1989 Act (section 29) provided for the social care support to be means tested.

There is nothing in the legislation to suggest that the amendment was intended to water down the rights of disabled children to NHS care – or convert those 'free at

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[2] Welsh Government *Continuing NHS Healthcare. The National Framework for Implementation in Wales* (June 2014).
[3] Welsh Government Children and Young People's Continuing Care Guidance (2012).
[4] R v. North and East Devon health authority ex p Coughlan [2000] 2 WLR 622: [2000] 3 All ER 850.
[5] On the 14th October 1991.

the point of need' services to means tested services. Had it been Parliament's intention to undermine this fundamental, quasi constitutional right, at the very least one would have expected the Government to have been explicit about this and for it to have been the subject of Parliamentary debate. However, the transfer of functions attracted almost no debate.[6] It is not unreasonable to suggest that if any significant change to the responsibilities of the NHS was intended, this would not have been the case.

For whatever reason, however, the explicit 'limits' of social care provision in the 1948 Act was not transposed into the CA 1989: the Act is simply silent on this question.

This problem was however resolved with the enactment of the SSWBA 2014 – section 47 of which again makes explicit that such a 'limit' applies to both adults and young people.

2. Understanding *R (T, D & B) v Haringey LBC (2005)*[7]

The *Haringey* case concerned a young person who had a tracheostomy (a tube in her throat) which needed to be kept clear by regular suctioning. On the basis of the case law there was little or no doubt but that she would have been eligible for NHS CHC funding if she had been an adult with this health care need. On her behalf it was however argued that her care needs could be funded by social services because the 'limits' of social care provisions in the NAA 1948 did not apply, as her care could be provided under the CA 1989 and that the adult case law concerning the 'limit' was not relevant. This argument was rejected by Ouseley J who held that:

> The discussion in *Coughlan* is helpful as to the indicators relevant here: the provisions of the Children Act are not to be regarded in general as reducing or replacing the important public obligations, with their qualifications and their target nature, set out in the 1977 NHS Act.[8] 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, incapable of sensible application to the Children Act. (para 61).
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> The scale and type of nursing care is 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);
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> [although on a] broad interpretation, [the provisions of the CA 1989] could cover what are essentially medical needs. Such an interpretation would turn the social services authority into a substitute or additional NHS for children. That would be to provide 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).

[6] The only reference appears to be at Hansard H.L vol 502 1306 where the Lord Chancellor noted that the '1948 Act is to be modified by amendments in Schedule 9 [Schedule 13 in the final Act] to the [Children] Bill to limit its provision to disabled adults, local authorities' responsibilities to disabled children being placed with their responsibilities to other children in need in this Bill.'
[7] [2005] EWHC 2235 (Admin) 21st October 2005.
[8] As we see below the relevant provisions of the NHS Act 1977 are now found in the consolidated NHS Act 2006.

The *Haringey* judgment was followed in *R (Juttla) v Herts Valleys CCG* (2018)[9] where the court held that a nurse-led respite unit for children with complex health needs was a health service. In doing so the court rejected arguments that this was a social care service because its purpose was to provide respite for the parents and that much of the care provided could, in theory, be delivered by trained social care staff. In the court's opinion, 'looked at literally' what this concerned 'the provision of health services as described in the 2006 Act' and that:

> the fact that the care happened to be provided by nurses was not determinative. On this reasoning, with which I fully agree, there can be no doubt that the services provided [the facility] are health services (paras 10 – 11).

3. Understanding the CHC guidance

The first formal guidance concerning the provision of NHS CHC was issued by the Welsh Office 1995 (ie after the CA 1989 had come into force). This guidance applied to both adults and children[10] and did not differentiate on grounds of age. Follow up guidance in 2004[11] also applied to adults and young people, stating that:

> [W]hile the principles underpinning this guidance are essentially the same for children and adults, the arrangements for decision-making and the delivery of care are likely to be different.

In 2010 the Welsh Government issued revised guidance for adult NHS CHC.[12] This only applied to adults and at para 1.6 it stated that the 'assessment of and provision for care for children and young people will be addressed in detail in a separate document'. In 2012 young people's 'continuing care' guidance[13] was issued (the '2012 guidance') and in 2014 the adult guidance was revised[14] (the 'adults 2014 guidance').

Sadly the 2012 guidance is of poor quality and (notwithstanding the *Haringey*[15] judgment in 2005 and the 2004 CHC guidance) suggested that quite different principles applied to NHS CHC for young people as compared to those for adults. Although the enactment of SSWBA 2014 has rendered this guidance obsolete – its inappropriate advice has created a 'culture of ineligibility' in relation to disabled young people seeking NHS CHC funding. Many Welsh local authorities are funding substantial packages for profoundly disabled and ill young people – not infrequently the cost of one such package representing a significant portion of an authority's entire disabled children's services budget.

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[9] [2018] EWHC 267 (Admin)
[10] Welsh Office 'NHS Responsibilities for Meeting Continuing Health Care Needs' WOC 16/95 & WHC (95)7 para 8 (in England the same guidance was issued as LAC (95)5 / HSG (95)8)).
[11] Welsh Health Circular and National Assembly For Wales Circular *NHS Responsibilities for Meeting Continuing NHS Care Needs: Guidance* 2004 (2004) 54 NAFWC 41/2004 (para 4).
[12] Welsh Assembly Government Continuing NHS Healthcare: The National Framework for Implementation in Wales May 2010 EH/ML/018/10 WAG Circular: 015/2010.
[13] Welsh Government Children and Young People's Continuing Care Guidance (2012)
[14] Welsh Government *Continuing NHS Healthcare. The National Framework for Implementation in Wales* (June 2014).
[15] [2005] EWHC 2235 (Admin) 21st October 2005.

The 2012 guidance (which must comply with the 'law' as stated in the *Haringey* judgment) fails to explain why 'continuing care' is of any relevance or importance. In response to the question it asks 'What is continuing care?' it states (para 5):

> Continuing care is defined as care provided over an extended period of time to a person to meet physical or mental health needs which have arisen as a result of illness (any disorder or disability of the mind and any injury or disability requiring medical or dental treatment or nursing).

What this fails to explain is what the purpose is of the guidance. At law the reason must be that once a young person's health care needs are outside the limits of social care – then (by virtue of the *Haringey* judgment[16] and now confirmed by the 2014 Act) – funding responsibility shifts to the NHS. This legal fact is nowhere made clear in the guidance.

Discussion

Once a young person is held to be eligible for NHS CHC then (as with adults) the effect of section 47 of the 2014 Act is that all their health and social care 'service' needs are the responsibility of the NHS. This does not mean that social services 'walk away' as clearly young people in this situation will continue to have non-service provision needs for which social services retain responsibility, such as:

- helping parents with the emotional problems of caring for ill or disabled young person;
- providing carer support services ie services delivered solely to the parents / siblings;[17]
- giving information and so on.

So, for example, if the challenging behaviour of a young person eligible for NHS CHC funding gave rise to a safeguarding issue, then social services would have a role to fulfil. The safeguarding role might flag up that the mother needed to have regular breaks from her caring role and that she wanted to improve her skills in addressing the behaviour. It would be a health function to provide support to manage challenging behaviour (ie skilled assistants); it would be a combined health and social services function to ensure that the mother's carer's needs were assessed and addressed;[18] it would be a health function to provide the skills training the mother was seeking as well as the replacement care that was required in order that she have regular breaks. This could be provided by skilled assistants coming to the home or the young person going to a residential or overnight fostering placement.

'Looked after' children and NHS CHC

[16] [2005] EWHC 2235 (Admin); (2006) 9 CCLR 58 and now the 2014 Act.

[17] Bearing in mind that respite care services are generally not of this nature since they are normally delivered to the child (eg a sitting service or overnight care).

[18] Section 24 SSWBA 2014 and see Department of Health and Social Care *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care October 2018 (Revised)* (2018) para 326.

Looked after young people children have the same rights to NHS CHC funding as any other young person – regardless of whether they were eligible for such funding before or after they became 'looked after'.

Local authorities are required to secure and supervise foster placements for a looked after child (under the SSWBA 2014 section 74) but the NHS duty to provide support applies as with any other child (including paying for additional care related skills a foster parent may require to care for such a child or more specifically for specialist health related accommodation).

The local authority will be responsible for ensuring that the child has an Independent Reviewing Officer to ensure that the authority complies with its obligations under the LAC regulations and the guidance.[19] In this context the NHS 'responsible commissioner' regulations[20] identify which LHB's are responsible for young people whose placements have been commissioned by a LHB or a local authority (in the LHBs area) even if the young person is accommodated outside the LHB area.[21] These regulations also cover young people who (although not 'looked after') have their accommodation commissioned by a LHB in another LHB area due to their CHC needs.

Heath / education overlaps

Many disabled children will have both health and special education needs. If they have a Statement of Special Educational Needs (SSEN) under the Education Act 1996, then their non—educational provision needs will be set out in Part 6 of their SSEN.[22]

There is no legal rule relating to education provision similar to that operating to social services (ie no 'limits' of education provision). Accordingly all young people eligible for NHS CHC will have separate needs for education. Problematically the 2012 guidance fails to distinguish between the role of the education service when a young person is eligible for NHS CHC funding and the role of social services. In relation to education, the local authority duty is unaffected whereas in relation to social services the position is (as explained above) quite different. An example of this 'failure to distinguish' is found at para 11 of the 2012 guidance which states:

> All agencies, Health, Education and Social Care have a clear role in providing services for these children. However for the purposes of the continuing care process LHBs are responsible for leading the interagency process set out in this guidance, mindful that a child or young person with continuing care needs will have a primary health need but also require services planned and delivered by a multi agency team that may include the LHB, Social Services, Education.

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[19] The principal regulations are The Care Planning, Placement and Case Review (Wales) Regulations 2015 and the principal guidance is contained in the Part 6 Code of Practice (Looked After and Accommodated Children).
[20] Local Health Boards (Directed Functions) (Wales) Regulations 2009 SI 2009/1511.
[21] Local Health Boards (Directed Functions) (Wales) Regulations 2009 SI 2009/1511 reg 3: young people who are looked after by a local authority within the meaning of SSWBA 2014 s74(1) or fall into category 2 of s104(2) of the 2014 Act or qualify for advice and assistance under s104 in so far as that section relates to category 5 and 6 young persons.
[22] See National Assembly for Wales *Special Educational Needs Code of Practice for Wales 2004* para 8.44 et seq.

Conclusion

Given the inadequacies of the 2012 guidance, practitioners will need to look to the *Haringey* judgment, the adult case law and the ombudsman reports when seeking to identify the limits of social care: the boundary separating the responsibilities of the NHS and local authorities for the care of people with significant healthcare needs.

The need for revised NHS CHC guidance for children and young people is urgent. The current guidance was unfit for purpose when it was issued in 2012 but once the 2014 Act came into force it became self-evidently redundant. The Welsh Government must now take issue new guidance and pending this, should issue formal notice that the 2012 guidance is withdrawn with immediate effect.