Revising the national framework for Continuing NHS Healthcare (CHC)

Consultation response of Professor Luke Clements[1]

This paper is submitted in response the Consultation documents published by the Welsh Government concerning its proposed revision of the national framework for Continuing NHS Healthcare.

The consultation follows a review of the Welsh (2010) National Framework for Continuing NHS Healthcare (CHC)[2] by the Wales Audit Office[3] (WAO) which identified failings in CHC decision making and care planning processes in Wales.

The WAO report focussed on the implementation of the 2010 Framework rather than its fitness for purpose – although it did identify its limitations in relation to people with learning disabilities, mental health problems (including those entitled to s117 MHA 1983 funding) and self funders.[4] Had such a 'fitness for purpose' assessment been undertaken, a number of failings would have been apparent: failings which underplay the NHS's CHC obligations and overstate: (a) its role in the decision making process and (b) the extent of social services responsibilities.

This lack of even handedness (between health and social services bodies in Wales) is particularly apparent when one contrasts the guidance issued in England and the action taken by the Department of Health. Tangential evidence of this difference is that since the implementation of the English 2007 Framework the numbers of people eligible for CHC in England have grown steadily (almost doubled) whereas since the implementation of the Welsh 2010 Framework the numbers in Wales have fallen steadily.[5] The impression one is left with is that the Welsh Government's primary concern is to limit the extent of NHS responsibilities for CHC.

A crude measure of the even handedness of the guidance in Wales compared to that in England is given in the extent to which the guidance addresses the detail of the *Coughlan* case.[6] In relation to the key finding that the determination of eligibility for CHC requires a clear assessment of the quality and the quantity of an individual's nursing care needs, the English 2012 Framework[7] makes 9 references to 'quality'

---

[1] Cerebra Professor of Law and Director of the Centre for Health and Social Care, Law Cardiff Law School.
[2] Welsh Government, Revising the national framework for Continuing NHS Healthcare (CHC) at http://wales.gov.uk/consultations/healthsocialcare/continuing/?lang=en accessed 1st February 2014.
[3] Wales Audit Office, Implementation of the National Framework for Continuing NHS Healthcare 13 June 2013 at http://www.wao.gov.uk/publication/implementation-national-framework-continuing-nhs-healthcare accessed 1st February 2014.
[4] Ibid at paras 1.9 – 1.15.
[5] Ibid para 1.30 and Figure 5.
[6] *R. v North and East Devon HA Ex p. Coughlan* [2001] Q.B. 213; [2000] 2 W.L.R. 622; [2000] 3 All E.R. 850.
[7] Department of Health *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care* November 2012 (Revised).

and 6 to 'quality' (in the *Coughlan* context) whereas the Draft 2014 Framework in Wales makes only 3 and 2 references respectively.

The 2010 CHC Framework

There are three principle problems with the 2010 Framework Guidance in Wales: problems that are also evident in the proposed revised (2014) Welsh Framework.

1. Embedded ambiguity

On a number of occasions the Framework introduces a level of ambiguity that has resulted in significant confusion / conflict between health and social care bodies in Wales. Two examples of this problem are the way the Framework deals with (a) 'General household support and social services'; and (b) 'well-managed' needs.

General household support and social services'

The Court of Appeal in *Coughlan* made it clear that once an individual's needs for nursing care exceeded the 'quality / quality' threshold – it was unlawful for a social services authority to provide support services. This was 'because of the terms of section 21(8)' National Assistance Act 1948.

The Welsh 2010 Framework accepts (as indeed it must) this statement of the law and defines (correctly) CHC as a 'complete package of ongoing care arranged and funded solely by the NHS, where it has been assessed that the individual's primary need is a health need'(para 2.1). This is replicated in the draft 2014 guidance (para 3.1). Inexplicably,[8] however paras 7.4 and 7.8 of the 2010 guidance undermine this simple legal statement. Para 7.4 (replicated in para 8.4 of draft 2014 guidance) states that:

> … while the overall responsibility for the care provision for those individuals who are eligible for CHC will lie with the LHB there will be ways in which other agencies, such as (but not only) social services may become involved …

Para 7.8 (replicated in para, 3.7, 6.11, 8.21 and K10 of draft 2014 guidance) states:

> Where a person returns to their own home (or that of a carer) the LHB fully funds the cost of their health and personal care needs but not the accommodation, food or general household support

These statements embed in the Framework unnecessary ambiguity and consequent uncertainty: ambiguities that are not found in the English 2012 Framework. In what way would 'social services … become involved'; what does 'general household support' encompass'? The guidance provides no answer to these questions – but the problem is exacerbated by para K.10 of the draft 2014 Framework which states:

[8] Arguments that the 'incidental and ancillary test' is not a principle of general application – ie that it applies only to care home placements under s21 of the 1948 Act (and not for example to support in the home / community under s29 of the 1948 Act or to services under the Children Act 1989) were rejected in *R (Harrison) v Secretary of State for Health* [2009] EWHC 574 (Admin) and *R (T, D & B) v Haringey LBC* [2005] EWHC 2235 (Admin).

> Where CHC is provided in a person's own home, it means that the NHS funds all the care that is required to meet their assessed health and social care needs to the extent that this is considered appropriate as part of the health service

What does 'the extent that this is considered appropriate as part of the health service' mean and who is to decide what is 'appropriate'? The guidance does not explain this – nor indeed does it explain the legal basis of this assertion.

The law is clear. Where an adult is eligible for CHC funding the NHS is responsible for providing support services that would have been provided by social services – eg services under the Chronically Sick and Disabled Persons Act 1970, s2 (eg practical assistance in the home or recreational facilities outside the home) and/or National Assistance Act 1948 Part III (eg facilities for social rehabilitation, and adjustment to disability – or social, cultural and recreational activities). It is correct that it is the NHS which decides in these cases what is 'appropriate'[9] – but the guidance should make explicit, that if the NHS determines that one of the above mentioned services is not 'appropriate' it would be unlawful for this service to be provided by the social services authority.

'Well-managed' needs

A proper understanding of 'well-managed' needs is of considerable importance to any assessment of eligibility for CHC funding. A person may have severe challenging behaviour or be at considerable risk of pressure sores or other adverse healthcare symptoms. However, due to the competence of their healthcare regime these risks are minimised – so they do manifest their challenging behaviour or develop pressure sores etc. The needs persist – but they are well managed and so the health of the individual is maximised. It is the need that triggers CHC eligibility, not whether the risk is manifested: were it otherwise, CHC eligibility would depend upon patients healthcare needs being badly managed.

In this context the 2014 Welsh draft framework at para 6.5[10] states that the 'fact that somebody has a health need that is well managed does not mean that it should be disregarded in the assessment.' (para 6.5)

What does 'should [not] be disregarded' mean? It gives no indication as to how assessors should deal with 'well-managed needs' (apart from not ignoring them) and gives no indication as to what weight should be attached to such a need, once identified. It is entirely Delphic and the evidence suggest that this important concept is not fully appreciated in Wales.[11] In contrast the 2012 English Framework guidance is clear, direct and helpful. It states: (para 56):

---

[9] *R (S) v Dudley PCT* [2009] EWHC 1780 (Admin).
[10] Repeating the wording of the 2010 Framework (para 4.5).
[11] See for example Report no 2010001820 concerning Aneurin Bevan HB & Caerphilly CBC 21 June 2012, para 29 where the LHB had an erroneous perception that the test for NHS CC was whether or not a person's 'needs are currently being met'.

> The decision-making rationale should not marginalise a need just because it is successfully managed: well-managed needs are still needs. Only where the successful management of a healthcare need has permanently reduced or removed an ongoing need, such that the active management of this need is reduced or no longer required, will this have a bearing on NHS continuing healthcare eligibility.

The 2014 guidance should adopt this wording verbatim.

2. The primary decision maker

The Court of Appeal in *Coughlan* identified s21(8) of the 1948 Act as the crucial provision in the CHC determination: that when the quality / quantity of a person's nursing care needs were greater than it would be reasonable for social services to provide, he or she became eligible for CHC and it became unlawful for their care to be funded by social services. There is nothing in this judgment to the effect that the 'NHS is the primary decision maker'. Indeed, given that the boundary is found in the social services statute and that the test is based on what it is reasonable for social services to provide, there is an argument that the decision as to the 'limits of social care' is primarily one for social services to make.

In this context, the only occasion on which a court has identified the NHS as the primary decision maker was in the *St Helen's* case.[12] This is a case that is discussed in para 3.14, 5.39 and Annex 3 A3.6 of the 2010 guidance and is found again at para A2.6 of draft 2014 guidance. Nowhere in the discussion in these documents is it stated that the case has never been relevant in Wales (being based on Directions issued by the English Secretary of State) and that when judgment was given, the Court of Appeal noted that it had ceased to be relevant even in England.[13] The English 2012 framework (correctly) makes no reference to the case.

Reference to the *St Helen's* case should be removed from the 2014 guidance.

3. The relevance of the 'incidental and ancillary test'

The practice guidance accompanying the 2010 Framework[14] (at para 4.2) misstates this test and then creates an impression that the 'incidental / ancillary' test has a lesser status – because it is not found in any 'legislation'.

The guidance asks a clear and straight forward question: '*Does the 'incidental and ancillary test' still apply now that we have a primary health need approach?*' The first matter that is of importance is that the Court of Appeal did not use the word 'and': the test it formulated was whether the nursing care was 'incidental or ancillary'.

---

[12] *R (St Helen's BC) v Manchester PCT and another* [2008] EWCA Civ 931, (2008) 11 CCLR 774.
[13] For an detailed analysis of the case's relevant see Luke Clements and Pauline Thompson, Community Care and the Law (LAG 2011) para 14.181.
[14] Welsh Assembly Government, Continuing NHS Healthcare for Adults Practice Guidance to support the National Framework for Implementation in Wales. Frequently Asked Questions (2010).

Assuming that the correct phrase is used, the answer to this question could be either be a succinct 'yes' or a more lengthy explanation as to what is law (ie a Court of Appeal judgment) and what is not law (ie Government guidance – in this case the use of the phrase 'primary health need': a phrase that does not appear in the legislation or indeed in the *Coughlan* judgment).

Neither answer is given. Having first misstated the Court of Appeal test, the answer is as detailed below. It is not unreasonable to suggest that the answer creates the impression that the 'incidental /ancillary test' no longer applies.

> **4.2 Does the 'incidental and ancillary test' still apply now that we have a primary health need approach?**
>
> Para 3.11 of the Framework describes the "incidental or ancillary" test in the Coughlan case. This "test" is not contained in the National Assistance Act 1948 or any other legislation, although it was developed to give an indication as to the limit of local authority powers to provide nursing care under section 21 of the 1948 Act.
>
> At the time the Coughlan case was decided in 1999, local authorities did have powers to arrange for the provision of general nursing services in nursing homes. However, Section 49 of the Health and Social Care Act 2001 now prohibits local authorities from providing or arranging for the provision of nursing care by a registered nurse in connection with the provision by them of community care services (see para 3.9)
>
> Chapter 4 of the framework describes the primary health need approach. This is the sole criterion for determining eligibility for CHC. In assessing whether a person has a primary health need, it is not necessary to consider whether a person has needs for nursing services which are beyond the powers of a local authority to provide - therefore the "incidental or ancillary" test in Coughlan is not relevant to this.

The 2014 guidance should state unambiguously that the 'the 'incidental or ancillary' test is (together with the 'nature' of the nursing care need ie the 'qualitative' element) the key legal test.

The Decision Support Tool (DST) and Checklist

The Consultation document[15] accompanying the draft 2014 NHS CHC guidance states that Wales will adopt the same DST as England (para 39) and the indication is that it will also adopt the English Checklist.

This paper reviews the particular shortcomings of the 2010 Welsh DST and considers the problems associated with the current English DST. It then considers the English Checklist

The DST

The 2010 Welsh DST is based on the English 2007 DST and – it follows – that many of the defects associated with the English DST are also found in the Welsh DST. There are however additional failings which warrant comment, notwithstanding that it is proposed that the current Welsh DST be abandoned in favour of the English DST. Such comment is required because: (1) an outcome of the consultation might be that

[15] Welsh Government Continuing NHS Healthcare (CHC) – Consultation on the 2014 National Framework (2013)

the Welsh DST is retained; and (2) these failings also suggest a lack of even handedness in Welsh Government documents when describing the scope of health and social services responsibilities.

Specialist input

The Court of Appeal and the High Court[16] in *Coughlan* considered that the need for (or the presence of) a 'specialist' in the care regime was not a helpful factor in determining eligibility for CHC. This is confirmed in para 4.4 of the 2010 Framework and para 6.4 of the 2014 draft Framework. However in the Welsh 2010 DST 'behavioural' domain (1) [Priority] and the 'Mental Health' domain (3) [severe] the need for a specialist healthcare professional / specialist response is given as a specific requirement. A similar problem is found in the 'nutrition – food and drink' domain (6) where the severe band requires 'ongoing skilled professional intervention'. This latter requirement is all the more problematical given that in *R (T, D and B) v Haringey LBC*[17] the care provided was by the applicant's mother (a non-professional) and yet Mr Justice Ouseley considered that the care she provided was outside the limits of what could be provided by social services.

Mental Health domain (3)

A significant shortcoming of the English DST is the lack of a specific mental health domain. The Welsh DST has such a named domain – albeit that it derives from the English 'Psychological and Emotional Needs' domain (3). The fact that in Wales the domain has a 'severe' banding is to be welcomed – in that it provides greater recognition than in England that severe mental health problems may in themselves be sufficient to create eligibility for CHC. However the severe band describes such an extreme level of mental ill-health – that it creates the opposite impression. If (as appears to occur in practice) NHS bodies consider that one severe score is in itself insufficient for CHC eligibility[18] then it is difficult to see how anyone (other than a person already in a hospital setting) would ever qualify – the severe band being:

> Significant changes in mental health which manifests in extremely challenging unstable, unpredictable and repetitive behaviour over 24 hours on a prolonged basis. Requires the continual intervention of specialist healthcare professionals over and above what can be provided by core NHS services. High risk of suicide

Absurdly high as this indicator is pitched, its removal (as the English DST only has a 'high' band) may well be interpreted (incorrectly) by Welsh NHS bodies as meaning that a mental health difficulty can no longer, in itself trigger eligibility for CHC funding.

Up-banding

The above 'severe' mental health descriptor describes such a profound healthcare need that on any reading of the case law (and *Coughlan* in particular) it would create a very strong presumption as to eligibility for CHC funding. On this basis, at the very

[16] (1999) 2 CCLR 51 27 – 52 at 51H
[17] [2005] EWHC 2235 (Admin); (2006) 9 CCLR 58.
[18] See comments below and WAO report para 2.42.

minimum it should be scored as a 'priority' if one is to adopt the indicative advice concerning the DST that 'clear recommendation of eligibility for continuing NHS healthcare would be expected' if a level of need was found in the priority band (para 31 of 2010 guidance and para 31 of the 2013 English DST Guidance)

The 'priority' and the 'severe' bands in all the domains of the English and Welsh DSTs describe the most severe health care needs and this approach is inappropriate for a tool designed to identify the limits of social care. As the Court of Appeal's *Coughlan* determination makes clear – the limits of social care are encountered in the healthcare foothills and not its peaks.

It is not difficult to understand how this incongruity has arisen: it is a fear of opening the floodgates – if the DST was seen to place the bar to CHC eligibility too low. Unfortunately instead of the resulting DST erring on the side of caution (which would be understandable) it verges on absurdity – and would almost certainly hold Pamela Coughlan ineligible for CHC funding – someone who the Court of Appeal considered to have needs 'well outside the limits of what could be lawfully provided by a local authority':[19] to have needs of a 'wholly different category'.[20]

The same problem was identified by the High Court in *R (Grogan) v. Bexley NHS Care Trust and others* (2006)[21] where Charles J held that the Department of Health's Registered Nursing Care banding (concerning the Health and Social Care Act 2001 s49) had been set at an unreasonable level:

> that as a matter of fact registered nursing care falling within the high band (and perhaps the medium bands) falls outside that limit set by Coughlan, particularly when it is remembered that the focus of Coughlan was on nursing care and the decision of the Court of Appeal was that the care she needed was well outside the limits of what could be lawfully provided by a local authority.

The up-banding identified in this paper and by Charles J in *Grogan,* permeates the Welsh DST. In the 'Altered States of Consciousness' domain (11) for example, the suggestion is that being in a coma is not a direct passport to CHC eligibility (it is scored only as a 'severe'). Whilst this is, on one level, an absurdity (and one that will be corrected if the English DST is adopted) it is also cogent evidence of the inappropriate inclusion in the tool of the 'peaks' of healthcare need.

If Multi Disciplinary Teams (MDTs) are advised that being in a coma or having necrosis extending to the underlying bone or being unable to take food / drink by mouth (or via a PEG) do not create a presumption of CHC eligibility, it is little wonder that the number of people being found eligible in Wales is falling.

The DST statement concerning a 'clear recommendation of eligibility'

The problem with the 'up-banding' in both the English and Welsh DSTs is compounded by the statement in both the Welsh 2010 Framework (para 31) and the English 2012 DST Guidance (para 31) that 'a clear recommendation of eligibility' to CHC would be 'expected in each of the following cases':

---

[19] *R (Grogan) v. Bexley NHS Care Trust and others* [2006] EWHC 44 (Admin) at para 61.
[20] *R. v North and East Devon HA Ex p. Coughlan* (para 118) [2001] Q.B. 213; [2000] 2 W.L.R. 622; [2000] 3 All E.R. 850.
[21] [2006] EWHC 44 (Admin) at para 61.

- A level of **priority** needs in any one of the four domains that carry this level.
- A total of two or more incidences of identified **severe** needs across all care domains.

[Where / if] there is:

- one domain recorded as severe, together with needs in a number of other domains, or
- a number of domains with high and/or moderate needs,

In one respect this guidance is incontestable: one would most certainly 'expect' eligibility for CHC in these situations. Sadly, however the phasing is (again) ambiguous. It creates the impression that absent such a scoring the expectation would be that the person is not eligible, and by so doing encourages practitioners to use the DST mechanistically: as a Decision MAKING Tool. Nowhere in the guidance is this important point made explicit: that the DST is a way of recording information in a standardised way – but (1) does not make decisions and (2) is not a substitute for professional judgment: that it should not be used as a 'tick box' scoring tool.

It is not only the above advice that has encouraged LHBs to use the 2010 DST as a Decision Making Tool. The suggestion that eligibility is determined by the number of Severes and Highs arises out of the advice concerning 'counting' eg:

- **Behaviour … .** To avoid double weighting, if the individual presents with behavioural concerns that are primarily to do with their emotional or mental health, this should be reflected in domain 3 rather than domain 1 (page 71):
- Any disagreement on levels used or areas where needs have been counted against more than one domain should be highlighted (p119)

This failing within the DST would explain that evidence provided by Crossroads, health board CHC leads and a number of health and social service practitioners to the WAO that the DST is 'often used too prescriptively, with an overreliance on 'the scores' within a DST and little professional judgement being used on whether the person meets the primary health need requirement.' (para 2.42). This failing is also evidenced by the Public Services Ombudsman's report concerning a LHBs over-focus on physical healthcare needs rather than looking at 'care needs holistically'.[22] Given the evidence that health and social care bodies in Wales are using the DST inappropriately as a Decision Making Tool – the revised guidance needs to be much stronger in challenging this behaviour. At the very least it needs to state explicitly that it is not a 'Decision Making Tool'.

The English 2013 Checklist

There appears to be significant evidence that CHC assessments in Wales are being delayed[23] and of a reluctance of some health professionals to undertake these.[24] Arguably, however, this problem stems from a de-professionalisation of assessors

[22] Report no 2010001820 concerning Aneurin Bevan HB & Caerphilly CBC 21 June 2012, para 30.

[23] See for example Public Services Ombudsman for Wales Report no 200802454 concerning the former Gwynedd LHB 22 February 2010 at para 75 and 80 which concerned a failure to ensure that requests for assessments are passed promptly to the district nursing service.

[24] See for example Public Services Ombudsman for Wales Report no 201101810 concerning Cardiff and Vale University Health Board, 24 April 2013 which concerned a failure by the LHB to initiate an assessment when the social worker raised the issue of her possible eligibility.

and their use of the DST as mechanistic tool for determining CHC eligibility. This problem would be exacerbated by the adoption in Wales of the English checklist. Health and social care practitioners should be educated in CHC case law and the determinations of the Ombudsmen. They should have shared training and encouraged to develop a respect for their colleagues expertise in heath / social care. This respect would extend to accepting that if one of them thought that a CHC eligibility assessment was required – then that it should be undertaken. Given the prevalent high caseloads, it is unlikely that a professional would ask for a CHC assessment unless she or he considered the case to be arguable.

The introduction of an additional tool – the Checklist' (based on the flawed DST) is likely to create further opportunities for disagreement, bureaucracy and delay. This is what appears to have happened in England, where the conflict associated with disputed / delayed panel hearings has migrated to disputes over the process by which a Checklist is completed.

It is difficult to understand the factual basis for the comments made in the WAO report that the adoption of such a screening tool in Wales could somehow reduce conflict between NHS and social services staff as to when a person needed to be assessed for CHC (para 1.22). The WAO report suggests that the Checklist could help avoid social services social services triggering a CHC assessment 'when there was no NHS involvement with the individual' (para 1.22) – but this is mistaken. The Checklist can be completed by social services alone and there is no evidence that its use has reduced conflict: anecdotally it would appear to have had the opposite effect.

Panel processes and training

The WAO report noted problems concerning the failure of LHBs to develop adequate policies and procedures (para 2.6) and of the extent to which LHBs returned cases presented to scrutiny panels for further evidence (para 2.49): a rate that varied but in one area was almost 50% (para 2.49). The evidence also suggested that (notwithstanding the Framework guidance) some MDT recommendations on eligibility were being changed before panel[25] or being overturned at panel (para 2.52). These are problems that have been highlighted by a series of reports issued by the Public Services Ombudsman – for example a 2009 report that suggested the only explanation for a panel's behaviour was that it was 'trying to avoid making a decision'[26] and a 2010 report[27] that found systemic failure by a LHB in its application of CHC criteria and recommended (amongst other things) that: (1) staff of the successor LHB who contribute to MDT assessments 'are made fully aware of the role and responsibilities of the MDT' and (2) 'all Chairs of its Independent Continuing Care Review Panels receive adequate training to assist them to effectively carry out their roles.'.

[25] The Public Services Ombudsman for example commented in a 2013 report on the lack of evidence as to why a professionals who undertook the initial assessment had changed her mind (to 'agree that [the resident] was not eligible') – see Public Services Ombudsman for Wales Report no 201101810 concerning Cardiff and Vale University Health Board, 24 April 2013.

[26] see Public Services Ombudsman for Wales Report no 200800779 concerning Carmarthenshire LHB 2009 15 December 2009 para 56.

[27] see Public Services Ombudsman for Wales Report no 200802583 concerning the former Carmarthenshire LHB, 17 September 2010, para 84-85.

The revised (2014) Framework should provide stronger guidance concerning the functioning of MDTs and Panels, including:

- The importance of MDT members not being subjected to pressure to change their opinions after they have expressed them in the MDT meeting/ discussions;
- The need for Panels to make decisions on the available evidence and not to adjourn hearings for 'further information' unless there are compelling reasons to do so.

Postscript

Social Services and Well-being (Wales) Bill

At law, the boundary between NHS and social services responsibilities for nursing care needs is detailed in s21(8) National Assistance Act 1948. The Social Services and Well-being (Wales) Bill – currently progressing through the Assembly will repeal the 1948 Act. Unless it is the will of the Assembly to move this boundary, it is imperative that the current phrasing in s21(8) be transferred to the new legislation. Currently this is not the case. As at March 2014, clause 38 of the Bill adopts materially different language. This problem was also identified in early drafts of the English Bill (Care Bill clause 22) but due to action in the Westminster Parliament, it has been addressed.[28]

Professor Luke Clements

Cerebra Professor of Law and Director of the Centre for Health and Social Care, Law Cardiff Law School

Date 11th March 2014

[28] Public Bill Committee Report on the Care Bill Thursday 16 January 2014 (page 205) at http://www.publications.parliament.uk/pa/cm201314/cmpublic/care/140116/pm/140116s01.htm