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NHS Funding for continuing care in England the revised (2009) Guidance

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Abstract

This paper considers the eligibility criteria for NHS Continuing Healthcare Funding in England – with particular focus on the revised Framework issued by the Department of Health in July 2009. It commences with a brief review of the tensions that exist between the guidance and the law (in the form of Court judgments) and provides an overview of the aspects of the guidance of most relevance to those working with disabled people with severe head and spinal injuries.

The paper advises as to how professionals involved in this difficult area, should interpret the new materials so as to reach an outcome in individual cases that is in accordance with the law. It suggests, however, that even with the July 2009 revisions, the Framework and the associated Decision Support Tool remain problematical.

The paper concludes with a cautionary note, that the recent increase in the numbers of patients qualifying for NHS Continuing Healthcare funding may be attributable, not to the detail of the Framework, but to Department of Health's rhetoric of change and the additional monies it has made available to PCTs for this sector.

Introduction

This paper reviews the eligibility criteria for NHS Continuing Healthcare (NHS CC) Funding in England – with particular focus on the revised guidance issued by the Department of Health in July 2009 (DoH, 2009a). The situation in Wales is not considered, primarily because it is expected that the current, highly unsatisfactory,

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criteria will be abolished and replaced by a Framework not dissimilar to that in England (Welsh Assembly Government, 2007).

NHS CC is the term given to the NHS's responsibility for funding 'all the care and support that is required to meet [an adult's] assessed health and care needs' (DoH, 2009a). When a person qualifies for such funding, the full package of care, including any previous care funded by social services, becomes the responsibility of the relevant Primary Care Trust, (PCT) regardless of where that person is living – e.g. in the community, a care home, a hospice or hospital.

NHS CC is controversial territory, largely because of its financial implications – both for private individuals and for the social services / PCT officers who police its frontier. By way of example, the Regulatory Impact Assessment accompanying the October 2007 NHS CC reforms (DoH, 2007a), estimated that the changes would result in an additional 5,500 people (per annum) qualifying, at a net cost to PCTs of £219 million. In the first two years of the new Framework it appears that an additional 16,000 people qualified for NHS CC (DoH, 2009b) although there is some doubt as to the methodological robustness of the individual PCT counting procedures.

Background

The boundary that defines the responsibilities of the NHS / social services has been contested since the formation of the Welfare State. Those drafting the two foundation statutes, the National Assistance Act (NAA) 1948 and the NHS Act 1946 sought to ensure that they meshed harmoniously. Both statutes came into force on the same day (5th July 1948) and both placed a responsibility on their separate authorities (today known as social services departments and PCT's) to accommodate (amongst others) ill, injured and disabled people. Given the potential for overlapping responsibilities, s21(8) of the 1948 Act states that where a service can be provided by a social services authority or a PCT, then it must be provided by the PCT: that in simple terms, it is unlawful for social services to provide a service that could be provided by the NHS. In this paper, this crucial principle is referred to as the 's21(8) boundary' – ie the point at which a social services authority is not permitted at law, to provide services. Although the NHS Act has been twice codified since originally enacted in 1946 and the NAA 1948 much amended over the last 60 years, for the purposes of this paper, their material responsibilities remain unchanged.

The UK's move away from caring for patients with long term conditions in 'hospital' settings is mirrored throughout most of the developed world. The particular difficulty that arises in the UK is the dichotomy that has arisen between institutional and

individual expectations of the NHS's role. Individuals have expected the NHS to respond on the basis of a person's need for health care, whereas institutionally the NHS has sought to limit its responsibility for providing 'free' NHS care, to care in a hospital setting – and to argue that other forms of care (for example care provided in community and domiciliary settings) is the responsibility of the social services means tested system. Accordingly, as it has become acceptable and feasible to care for all but the most acutely ill, in non-hospital settings, the NHS has admitted responsibility for fewer and fewer patients, even though the 'disenfranchised' are objectively in need of 'health care'.

The NHS has therefore redefined its role: its *raison d'être* is not to care for ill people but rather, to care for certain limited categories of ill people: most particularly, acutely ill people. Such a re-branding has had the effect of 'shunting costs' to social services: ie the funding responsibility for patients who in former times would have been its responsibility (Means *et al,* 2002) – a trend that underwent a marked acceleration in the 1980's and 1990's, with the dramatic fall in the number of hospital based geriatric beds (Bridgen and Lewis, 2009). During this period many people who were denied NHS support and who found themselves subject to social services means testing, expressed their dissatisfaction by making complaint to the NHS Ombudsman. It is for this reason that a number of the so-called 'benchmark' cases (Clements and Thompson, 2007) derive from NHS Ombudsman reports, although important Court decisions do exist, most notably the Court of Appeal judgment in *Coughlan* (*R v. North and East Devon Health Authority ex p Coughlan* (1999) [2000] 2 WLR 622).

The NHS Ombudsman decisions and the Court judgments have, in general, placed the bar for qualifying for NHS CC support at a relatively low level, whereas the guidance issued by the Department of Health has put it much higher, suggesting in effect, that eligibility for NHS funding is limited to a very few patients with unusual conditions. This divergence has caused significant inter-authority tensions, with PCT's following the restrictive guidance and social services (and patients) seeking to rely on the case law and Ombudsman's findings. It has been suggested that the cause of this tension is political – that the present government's priorities have been almost exclusively short term acute health care (primarily the cutting of waiting lists) and that 'diverting resources to fund the long term needs of chronically ill and disabled people does not advance this dominant agenda': that the NHS CC guidance issued by the Department of Health over this period could be construed as an attempt to 'blunt the impact of the *Coughlan* judgment – to use guidance in effect to frustrate the law' (Clements and Thompson, 2007).

Guidance cannot, of course, undermine or trump the law and in 2006 the High Court made this very point in *R (Grogan) v. Bexley NHS Care Trust* (2006) 9 CCLR 188. As a

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consequence the Department of Health felt compelled to undertake a radical review of its NHS CC policies and to produce new guidance. By the time of the judgment the Government had had over seven years of investment to address its dominant 'waiting lists' agenda and so felt able to consider other issues – such as NHS CC. In October 2007 the new National Framework for NHS Continuing Healthcare and NHS funded Nursing Care in England (DoH, 2007b) came into force accompanied by a Decision-Support Tool (DST) (DoH, 2007c) designed to provide a unified procedure for establishing individual entitlement to NHS CC. The reforms were underpinned by subordinate legislation in the form of Directions which have been amended as a result of the 2009 revisions referred to below (DoH, 2009c).

The 2007 and 2009 Reforms

The implementation materials accompanying the new Framework emphasised that it was a clean break with what had gone before and the local authorities and PCTs would need to 'think and act differently' and that the expectation was that the new policy would result in 'more people [being] eligible for full funding' (DoH, 2007d). As already noted, it appears that this has proved to be the case, although the reasons for this increase have yet to be the subject of independent research.

The Department of Health undertook to evaluate and consult on the effectiveness of the 2007 reforms and to make any changes that were considered necessary. In consequence, minor changes were made to the key documents in July 2009 and in the following analysis, where appropriate, the changes made by the 2009 review are highlighted. In general however the changes were minor in nature, and primarily directed at recasting some of the descriptors in the DST to accentuate the distinguishing features between the various bands.

The benchmark cases

An understanding of the law concerning NHS CC requires an appreciation of three key issues: (1) the 's21(8) boundary', described above; (2) the details of the key 'benchmark cases' - ie patients who have been assessed by the Courts or NHS Ombudsman to be eligible for NHS CC; and (3) that (as noted above) where guidance appears to conflict with the law, the law prevails.

Clements and Thompson (2007) highlight five benchmark cases, as practical examples of patients whose needs have been assessed as lying on the NHS side of the s21(8) boundary. Whilst the 2009 Framework (at para 79) cautions against the unquestioning

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use of such cases as guides, Clements and Thompson (2007) argue that this device has been considered valuable by the Secretary of State, the NHS Ombudsman and the Courts and that it is at 'least arguable that the reason why the Department of Health is cautious about the use of comparators is that they might thereby expose the shortcomings of the [2009] Framework.'

Of the five suggested benchmark cases, *Coughlan* is, without question, of greatest importance. In this case, the Court of Appeal sought to define the s21(8) boundary by reference to two factors: the quality and the quantity of the health care that is provided. In its opinion, social services authorities can fund the care of patients provided that the health care element is:

- merely incidental or ancillary to the provision of the accommodation which a local authority is under a duty to provide to the category of persons to whom section 21 [NAA 1948] refers and
- 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 under section 21.

In ordinary terms, therefore, if the health care needs are qualitatively and quantitatively of a low level, then (and only then) can a social services authority fund the package. Turning its attention to Pamela Coughlan, the Court held that her care needs were of a 'wholly different category': that is to say, were well outside what could be funded by social services. It is this particular aspect of the case that is most intriguing, since Ms Coughlan's health care needs are objectively modest. Although she is tetraplegic; has recurrent headaches caused by an associated neurological condition; is doubly incontinent; requires regular catheterisation and is partially paralysed in the respiratory tract – in many respects she lives an autonomous life, being intellectually active and, with the help of care assistance, a redoubtable campaigner. Her condition is stable; she has little need for NHS 'specialists' and could live in many semi-independent settings. If, as the Court held, her care needs put her well outside that which could be funded by a social services authority, then the bar to accessing NHS CC would appear to be set at a low level.

It is by reference to the *Coughlan* judgment and to the other benchmark cases that the fitness for purpose of the revised Framework guidance and revised DST fall to be assessed.

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The Revised NHS Framework Guidance

A troubling aspect of the revised Framework guidance is its continued reliance on a number of concepts that were not thought to be of overarching value by the Court in *Coughlan*: concepts such as a 'primary health need' and the 'nature, intensity, complexity and unpredictability' of a health need. These have been criticised as unnecessarily complicating the assessment process (Law Society, 2006) and as the Framework acknowledges (at para 15) do not appear in the legislation. Ultimately however the guidance accepts (at para's 26 and 28) that these concepts can (and should) be equated with the Court's 'quality / quantity' test as the defining issue in identifying the s21(8) boundary.

Notwithstanding its failings, the Framework contains much valuable advice (such as stressing the importance of involving the disabled person, their representative and carers) and a number of vitally important requirements, including:

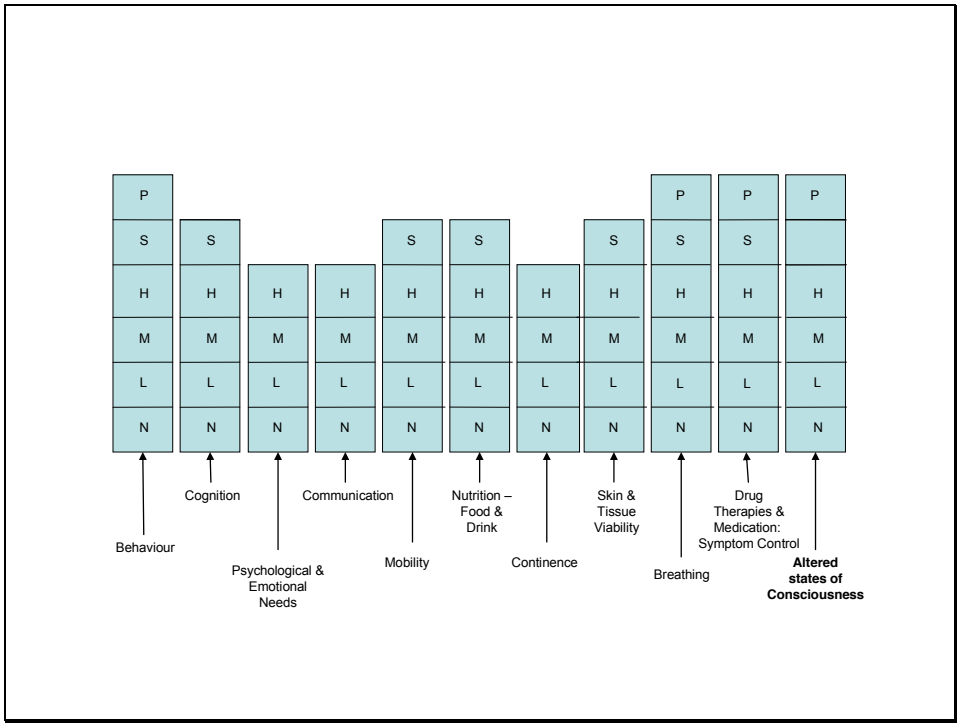
- The decision making rationale should not marginalise a need because it is successfully managed – well managed needs are still needs. Only where the successful management of a health care need has permanently reduced or removed an ongoing need will this have a bearing on NHS continuing healthcare eligibility (para 47);
- Neither the PCT nor local authority should unilaterally withdraw from funding an existing package without appropriate reassessment / agreement by the other body that it accepts funding responsibility (para 144);
- That the reasons for a decision on eligibility should not be based on: the person's diagnosis; the setting of care; the ability of the care provider to manage care; the use (or not) of NHS-employed staff to provide care; the need for/presence of 'specialist staff ' in care delivery; the fact that a need is well managed; the existence of other NHS-funded care; or any other input-related (rather than needs-related) rationale (para 49).

The revised Framework contains additional comment concerning the need for a seamless handover of responsibilities when a person who is in receipt of social services funding is adjudged to be entitled to NHS CC. This is particularly relevant where a person has had the benefit of a social services direct payment or personal budget and the advice (at para 135 - 136) stresses the desirability, where practicable, of the PCT retaining the same care providers as commissioned by the social services authority.

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The Revised Decision Support Tool (DST)

The revised DST (DoH, 2009d) is a standardised document that must be used by the relevant health and social care multidisciplinary team when collecting information about a patient's health care needs. It contains guidance notes and 31 pages of forms that are designed to capture, and categorise a patient's needs in relation to 12 care domains – namely (1) Behaviour, (2) Cognition, (3) Psychological and emotional needs, (4) Communication, (5) Mobility, (6) Nutrition, food and drink, (7) Continence, (8) Skin (including tissue viability), (9) Breathing, (10) Drug therapies and medication: symptom control (11) Altered states of consciousness, (12) Other significant care needs. Each domain is broken down into a number of bands (graded 'No Need'; 'Low'; 'Moderate'; 'High', 'Severe'; or, 'Priority'), and for each band the DST provides a descriptor of the condition / care needs that characterise that level. Not all domains have the same grading – some lacking the highest level 'Priority' and some the 'Severe'.



The Department of Health has stressed that the DST is not 'a decision making tool', nor is it 'suitable for every individual's situation' nor is it a 'substitute for professional judgement' (DoH, 2007d). Problematically, however, the advice within the DST then states that a person would be expected to qualify for NHS CC if his or her DST record contains a priority need in any one of the four domains that carry this level or a total of

two or more incidences in the severe category. In addition it advises that eligibility for NHS CC may arise where 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,

Whilst a standardised process for assessing eligibility for NHS CC is welcome, there has been criticism of the use of descriptors of the type in the DST on the ground that they can sideline crucial user information from the decision-making process (Huby et al, 2004). The choice of the descriptors can also have a distorting impact – for example the NHS Ombudsman has criticised local NHS CC criteria which were 'skewed in favour of physical and acute care' and failed to take into account the patient's significant psychological problems (Health Service Commissioner, 2004). A further risk is that the descriptors may be unreasonably demanding, and arguably this is the case with the revised DST. Perhaps the most obvious example of this incongruity, concerns the care needs of Pamela Coughlan, which were described in some detail by the Court of Appeal. On the basis of the revised DST it is unlikely that any of her care needs would be categorized as anything greater than 'high' and most would be below this level. Whilst the guidance envisages that a person with 'a number of domains with high and/or moderate needs' might qualify for NHS CC, it is by no means certain that the revised DST would support this finding for people with similar spinal injuries to that of Pamela Coughlan. However, since the Court of Appeal held that her care needs were of a 'wholly different category' – ie well into the territory of NHS CC, it follows that this view must prevail in such cases.

Whilst a detailed analysis of the 12 individual domains is beyond the scope of this paper, it is appropriate to comment on those in relation to which decided Court or Ombudsman cases exist, in order to assess whether there is a good 'match' between these decisions and the relevant descriptors

Behaviour domain

The Behaviour domain contains a 'priority' band – which would make the patient eligible to NHS CC. The 2009 revisions to the DST re-phrased the 'severe' descriptor – largely to make it more clearly distinguishable from the priority descriptor, which requires:

> "Challenging" behaviour of severity and/or frequency that presents an immediate and serious risk to self and/or others. The risks are so serious that they require an urgent and skilled response for safe care.

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In interpreting this provision (as with all DST descriptors) it is necessary to bear in mind the above cited Framework advice, that 'well managed needs are still needs'. It follows that the person being assessed need not be exhibiting the requisite 'challenging behaviour', but merely that this would resurface if the care regime were removed. It is also essential that any interpretation of the descriptor be consistent with the NHS Ombudsman's findings in the *Pointon* complaint (Health Service Commissioner, 2004). In that case she concluded that Mr Pointon was eligible for NHS CC on the basis of his challenging behaviour – which was managed in the family home by his wife and a rota of part-time care assistants. Mr Pointon suffered from the advanced stage of dementia characterised by mood changes and behavioural disturbance, although by the time of the decision the severe behavioural problems, which had characterised his illness (during the earlier stage of dementia) had diminished.

Cognition domain

The Cognition domain does not contain a 'priority' band, only a 'severe'. The 2009 revisions to the DST re-phrased the 'severe' descriptor – largely to add clarity, by inserting the following words in italics into the description:

> Cognitive impairment that may include, in addition to any short-term memory issues, problems with long-term memory or severe disorientation. The individual is unable to assess basic risks *even with supervision, prompting or assistance*, and is dependent on others to anticipate even basic needs and to protect them from harm, *neglect or health deterioration*.

The revised DST cautions against the 'double counting' of symptoms (para 26), advising that where a 'condition could be reflected in more than one domain' it should be so recorded, but the fact that there is duplication 'should be recorded' and considered in the multidisciplinary teams final recommendation. In general, however, duplication will be rare. What has to be asked in such cases is whether the two conditions always co-exist. Thus a person with severe cognition difficulties does not always have severe behavioural difficulties – and vice versa, and so in this context, there would be no duplication.

Mobility domain

The Mobility domain does not contain a 'priority' band, only a 'severe'. The 2009 revisions to the DST made a minor grammatical change to the 'severe' descriptor, (shown in italics in the following) which states:

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> Completely immobile and/or clinical condition such that, *in either case*, on movement or transfer there is a high risk of serious physical harm and where the positioning is critical

The Court of Appeal's assessment in *Coughlan* is of direct relevance to this domain, given that a restricted interpretation of the severe descriptor might otherwise suggest that it excludes someone with Pamela Coughlan's impairments. Given the Court's finding that her needs were well outside what could be provided by social services (ie that she was unquestionably entitled to NHS CC) it must follow that a liberal interpretation of the descriptor is required.

Nutrition, food and drink domain

The Nutrition domain does not contain a 'priority' band, only a 'severe'. The 2009 revisions to the DST were minor (merely adding an additional descriptor in the 'High' band of 'Significant weight loss or gain due to identified eating disorder'). The descriptors for this domain however give a general indication of how unreasonably high the Department of Health is endeavouring to place the qualifying bar for NHS CC. In 2003 the NHS Ombudsman reported on a complaint concerning the refusal of NHS CC funding for a patient who had had several strokes, as a result of which she had no speech or comprehension and was unable to swallow and required feeding by a PEG tube (Health Service Commissioner, 2003). The Ombudsman concluded that no health body 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'. Notwithstanding this trenchant criticism, the revised DST only accords a 'high' band to persons who have 'problems relating to a feeding device (for example P.E.G.) that require skilled assessment and review.' The severe category is only available to those who are either:

> Unable to take food and drink by mouth. All nutritional requirements taken by artificial means requiring ongoing skilled professional intervention or monitoring over a 24 hour period to ensure nutrition/hydration for example I.V. fluids; or are unable to take food and drink by mouth, intervention inappropriate or impossible

It defies reason to suggest that such a person (who in the latter case must be destined to die of starvation) cannot be deemed to be entitled to NHS CC (in that they are only accorded a 'severe' not a 'priority' by the DST). If the NHS is not responsible for the care of such persons, one wonders as to its purpose.

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Skin (including tissue viability) domain

The Skin domain (and the breathing domain – see below) are further examples of how inappropriately high the Department of Health is endeavouring to pitch the qualifying bar for NHS CC. The Skin domain does not contain a 'priority' band, only a 'severe'. The 2009 revisions to the DST added another descriptor for the severe category, which essentially comprises severe open wounds / pressure ulcers that are not responding to treatment or severe wounds / pressure ulcers that include necrosis extending to underlying bone (ie the bone is actually visible). As with the comments made in relation to the Nutrition domain above it challenges reason to suggest that such a person cannot be described as having a primary health need.

Breathing domain

The Breathing domain is perhaps the ultimate example of the indefensibility of the line at which the Department of Health seeks to draw the s21(8) boundary. The domain contains a 'priority' band – which requires that the patient be 'unable to breathe independently, requires invasive mechanical ventilation' – in essence that the patient is on a ventilator. To suggest that such a descriptor 'supports' NHS CC decision making is little short of fatuous: it merely gives the impression that NHS CC is only available to those whose conditions are of an exceptional order of gravity.

The 2009 revisions to the DST were significant in relation to this domain, in that they downgraded from a 'high' band to 'moderate', patients on CPAP (Continuous Positive Airways Pressure - where a person's lungs are ventilated by compressed air blown through a nasal of full-face mask) . In 2005 the High Court considered a claim made on behalf of two sisters (aged 3 and 19 at the hearing) concerning their eligibility for NHS CC (*R (T, D and B) v Haringey London Borough Council* (2006) 9 CCLR 58). They both had tracheostomies (a tube in the throat) which needed suctioning about three times a night and replacing once a week. The children were living at home and their mother had been trained by the hospital to make the daily routines and cope with the emergencies that might arise. Mr Justice Ouseley considered that these functions were indicative of a primary health need – and that to suggest otherwise would be 'to provide an impermissibly wide interpretation, creating obligations on a social services authority which are far too broad'. It would indeed be difficult to find many people who could disagree with this view – and yet given that such a need would only register as a 'severe' on the Breathing domain, absent other needs, the revised DST would indicate no entitlement to NHS CC.

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Conclusions

The above analysis suggests that there is considerable correspondence between the revised Framework guidance and the findings of the Courts and NHS Ombudsman in individual NHS CC complaints – but that this is not so in relation to the revised DST. It follows that were an objective application of the criteria in the revised DST would lead to conflict with the findings of the Court or Ombudsman (for example in respect of one of the benchmark cases) practitioners should give priority to the Court or Ombudsman decisions. The DST is not, as the Department of Health emphasise, a decision making tool: it is merely a Decision Support Tool. In disputed cases, therefore, the 'quality / quantity' approach of the Court of Appeal should inform the decision making process and NHS CC eligibility should only be denied to those whose health care needs are marginal (or in the Court's terms 'merely incidental or ancillary' to the provision of the social care) and quantitatively of a low level (or in the Court's terms 'of a nature which it can be expected that an authority whose primary responsibility is to provide social services can be expected to provide').

On the basis of the above analysis, it is arguable, that the new guidance – especially the DST – continues to place the bar to qualifying for NHS CC considerably higher than that suggested by the Courts and Ombudsman. If this is so, it may be that the increase in the numbers of patients held to be entitled to NHS CC funding since October 2007 is largely attributable to (1) the Department of Health's rhetoric of change in the Framework guidance and (2) the additional funding paid to PCTs to meet the expected increased numbers: in effect that, rather than being due to the detail of the new Framework, the expectation of an increase in numbers has proved to be self fulfilling. If this is so, it may be that the Framework provides little resistance to attempts by PCTs to reverse this trend, in the present harsher funding environment.

Whatever the merits and de-merits of the revised guidance, it is inevitable that eligibility for NHS CC will remain contested territory, and that this will continue until such time as a wider settlement is reached on the funding of long term care. At present, there are simply insufficient funds within the NHS and social services to meet all the legal obligations created by the welfare settlement 60 years ago. Paraphrasing the comments of Lord Lloyd in an early community care case 'The solution lies with the government. The passing of the [legislation] was a noble aspiration. Having willed the end, Parliament must be asked to provide the means' (R v. Gloucestershire, 1996).

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