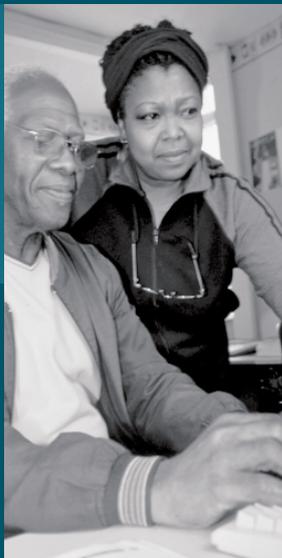


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NHS Continuing Care in England



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NHS CONTINUING CARE IN ENGLAND

Melanie Henwood

King's **Fund**

This is one of a series of appendices to *Securing Good Care for Older People*. Download full report from www.kingsfund.org.uk/publications

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First published 2006 by the King's Fund

Charity registration number: 207401

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Typeset by Andrew Haig and Associates

Front cover image by Sara Hannant www.sarahannant.com

Introduction

NHS continuing care is a term that refers to care that is fully funded (that is, to which the service user or patient makes no financial contribution). Continuing care is for people who do not need to be cared for in an acute hospital but who have a high level of health care needs. Typically such care is provided in a care home or hospital, but it can be provided in any setting including the patient's own home. Whether or not people receive continuing care is determined by reference to 'eligibility criteria' that were introduced in 1995.

Over time there has been a significant change in the nature and location of continuing care provision. The closure of many long-stay hospital wards and community hospitals has been paralleled by the development of considerable provision of private and voluntary sector residential and nursing home care. It is widely believed that many people who in the past would have been cared for in continuing care beds in hospital are now more likely to be accommodated in care homes. However, while the former was free of charge, the latter is more likely to be viewed as 'social care' and to entail means testing and charges for the service user. This issue has been the focus of growing controversy for several years and was critical to the establishment of the Royal Commission on Long Term Care in 1997.¹ The central recommendation that all nursing care *and* personal care should be provided free of charge was rejected, and controversy has continued.

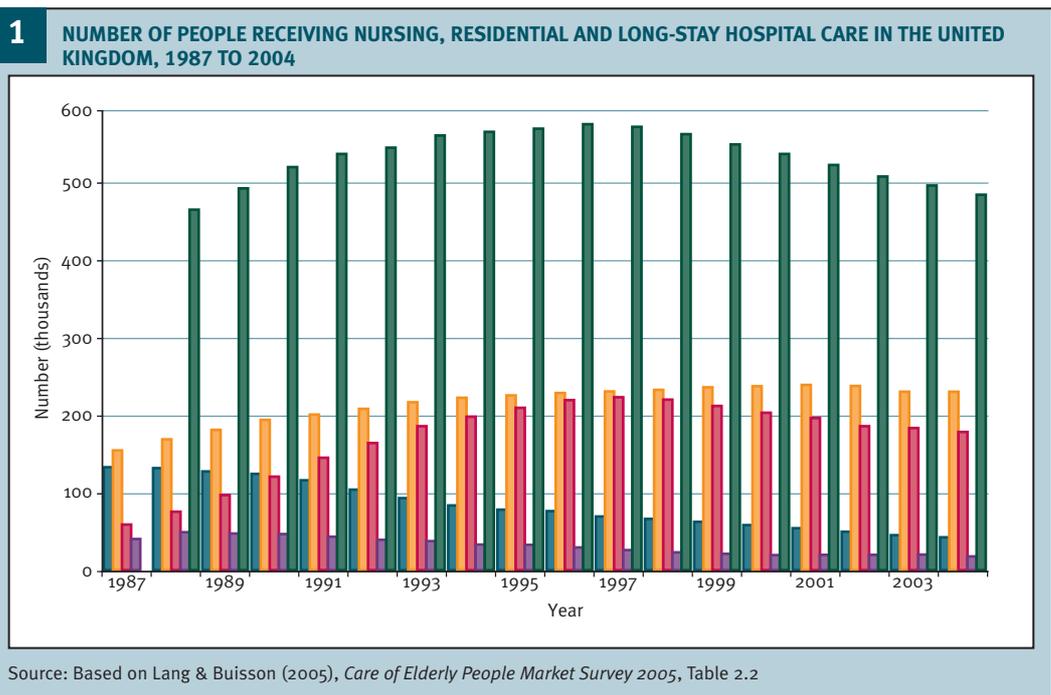


Figure 1 charts the changing pattern of care provision and shows the declining role of the local authority and the National Health Service alongside the expansion of private and voluntary sector care provision (the detailed figures are included in Annex 1).

This paper explores the present position with NHS continuing care and the context to it. It highlights the key issues and debates that are central to any exploration of this area and to any consideration of reform.

Background and policy context

In 1995 the Department of Health issued guidance on the development of eligibility criteria for NHS continuing care.² This was in response to a number of concerns that had been raised in a report from the Health Service Commissioner investigating the failure of Leeds Health Authority to make available long-term care for a seriously incapacitated patient who no longer needed acute health care, but who did require full-time nursing care.³ At the heart of the case was the question of ‘what provision should be made by health authorities for patients like him who need care on a continuing basis.’ The 1995 guidance stated clearly that arranging and funding services to meet continuing physical and mental health care needs was ‘an integral part of the responsibilities of the NHS.’ The box below presents the definition of eligibility for continuing care.

BOX DETERMINING ELIGIBILITY FOR NHS CONTINUING CARE

The NHS is responsible for arranging and funding continuing inpatient care on a short or long-term basis for people:

- where the complexity or intensity of their medical, nursing care or other clinical care or the need for frequent not easily predictable interventions requires the regular (in the majority of cases this might be weekly or more frequent) supervision of a consultant, specialist nurse or other NHS member of the multidisciplinary team
- who require routinely the use of specialist health care equipment or treatments which require the supervision of specialist NHS staff
- have a rapidly degenerating or unstable condition which means that they will require specialist medical or nursing supervision.

Source: Department of Health (1995), *NHS Responsibilities for Meeting Continuing Health Care Needs*, HSG(95)8 LAC(95)5.

With the benefit of hindsight it might be argued that the guidance in fact generated as much confusion as clarity. While it was stated that the NHS *did* have critical responsibilities for continuing care needs, it was also observed that this included but was not limited to ‘the responsibility to arrange and fund an appropriate level of care from the NHS under specialist clinical supervision in hospital or in a nursing home.’ In addition, ‘equally important responsibilities’ were identified in respect of: rehabilitation, palliative health care, respite health care, community health services support, and specialist health care support in different settings. To include all of these dimensions under the banner of ‘continuing care’ was at best confusing, and at worst highly misleading.

However, the guidance *did* require health authorities to develop their own eligibility criteria for continuing health care that would be operational by April 1996. These were to

take account of the complexity, intensity or unpredictability of a patient's health care needs, requiring the regular supervision of a consultant, specialist nurse or other members of the NHS multi-disciplinary team. However, what this also meant from the outset was that health authorities would all establish their own diverse sets of criteria, immediately raising the prospect of inequity between patients living in different parts of the country (and even between adjacent health authorities and neighbourhoods).

In 1999 a further development in the complex story of continuing care took place with the publication of a judgment from the Court of Appeal (*R v North & East Devon Health Authority ex parte Coughlan*). This particular decision on whether the NHS or local authority was responsible for the continuing care of a particular patient (Pamela Coughlan) turned on the determination of whether the nursing care provided was 'incidental or ancillary' to the provision of accommodation, in which case it was the responsibility of the local authority; but if the primary need was for health care, the NHS was responsible for meeting those needs..

Further guidance duly followed from the Department of Health requiring health authorities to satisfy themselves that their continuing health care policies and eligibility criteria were compliant with the judgment and with existing guidance.⁴

Yet more guidance followed in 2001 what was effectively consolidating guidance in the light of the Coughlan judgment. Health authorities were required to review their criteria and ensure they were compliant with the guidance. Further directions took effect in 2004 which placed responsibility on the newly established strategic health authorities (SHAs) for ensuring that they should align the various sets of eligibility criteria from their health authorities and produce a single set of SHA-wide criteria. This reduced at a stroke the number of different sets of eligibility criteria operating across England from 95 to 28.

What is immediately striking about the policy territory of NHS continuing care is the manner in which it has been driven by and had to continually adapt to external developments: with the health service commissioner, the Court of Appeal, and – increasingly – the intervention of the NHS Ombudsman. This process of incremental adjustment has highlighted the inherent uncertainties of the policy, and underlined the particular concerns that the policy is flawed and that its application has led to fundamental injustice.

In February 2003 the NHS Ombudsman published a report based on four complaints it had investigated on NHS funding for long-term care. The report concluded that the cases all highlighted problems resulting from criteria that either were not compliant with guidance or legal judgements, or had been applied over-restrictively. On the basis of this investigation (and reflecting on many other cases that were also under consideration) the Ombudsman offered some highly critical conclusions. In particular:

- the guidance and support from the Department of Health was inadequate to enable a fair and transparent system of eligibility for funding long-term care to operate across the country
- guidance had been mis-interpreted and mis-applied by some health authorities when developing and reviewing their eligibility criteria, and in applying those criteria to individual circumstances.

For some individuals the consequences had been 'injustice and hardship'.

The response of the Department of Health was swift. In part it was also familiar and reiterated the need for SHAs to complete their work on integrating criteria and ensuring they were consistent with guidance. However, new requirements were also announced that were unprecedented. SHAs were required to review the criteria that had been operational in their area since 1996, *and* to develop procedures to investigate cases where people might have been wrongly denied NHS continuing care. Where this *was* found to be the case, financial recompense was to be made to the patients concerned, or to their estates if the person was deceased.

These requirements to review past policies and their application and to provide appropriate restitution can be seen as a clear admission that there were significant difficulties with the policy. However, the consequences of the requirements on review and restitution were extensive and far-reaching. The process of review was initially expected to be completed by the end of December 2003; this was later revised to 31 March 2004. However, it was apparent that there were still outstanding cases long after this date. It appears that there was little appreciation of the scale of the task or the complexity of investigating and resolving cases.

An independent review was commissioned by the Department of Health in 2004 that involved detailed examination of continuing care processes in a sample of one-third of the SHAs. This confirmed that the review and restitution process had been highly demanding in practical and emotional terms for all involved. There were concerns that some people for whom there was little or no realistic prospect of restitution would have had their hopes raised inappropriately by an ill-informed media debate. There was also widespread recognition of the moral importance of the principles of the restitution process and a belief that people who had been wrongly denied NHS funded care *should* be reimbursed. Nonetheless, there was doubt about whether the overall costs of undertaking the exercise justified the relatively small number of cases that were found (nationally 12,000 cases were reviewed and 20 per cent were awarded full or partial restitution at a total cost of £180 million). Other conclusions drew attention to the fact that the process automatically favoured the well-informed and articulate who were best equipped to present their case, and that many of those who had been most unfairly treated by past decisions would have been least likely to go through the review process.⁵

The independent review also underlined the difficulties that SHAs faced in developing a single set of criteria to replace those previously operated by health authorities, particularly when criteria had previously been inadequate or widely divergent. There was a strong sense across the SHAs that while the development of 28 sets of criteria was preferable to the previous diversity, unacceptable variation still existed. This could be especially problematic for cross-boundary working between SHAs with differing criteria. The review found an almost universal belief that continuing care would be easier to manage, applied more consistently, and more transparent and fair if there were national criteria and a national implementation framework.

When the independent review was published by the Department of Health in December 2004, Health Minister Dr Stephen Ladyman announced the commissioning of a 'new national framework' for continuing care to improve consistency and ease of understanding.⁶ Responsibility for developing the framework has been assigned to the health and social care Change Agent Team and is being developed through two workgroups (one focusing on the overall framework, eligibility criteria and assessment and the other addressing information, communication, training and development).

Responsibilities for long-term care

The Royal Commission on Long Term Care

The Royal Commission on Long Term Care was established in December 1997 with the following terms of reference:

To examine the short and long term options for a sustainable system of funding of Long Term Care for elderly people, both in their own homes and in other settings, and, within 12 months, to recommend how, and in what circumstances, the cost of such care should be apportioned between public funds and individuals...

In analysing the current funding system, the Royal Commission drew attention to ‘complexity and unfairness’ of operation, and argued that ‘confusion and uncertainty’ were intrinsic to the system. The downward trend since the early 1980s in numbers of NHS long-stay beds, combined with the *growth* of private nursing home places is well-documented (see Figure 1 above, and Table 1 in the Annex). It is also known that some of this was encouraged by the availability of social security payments to pay for care home placements (a situation that lasted from the early 1980s to 1993). The Royal Commission observed:

Only 8% of these additional private nursing home places are paid for by Health Authorities and Health Boards. The rest are paid for by individuals or by Local Authorities. The total saving to the NHS over this period (...) was considerable (...). It is difficult to tell, but there remains a lingering suspicion that, in order to concentrate its resources on acute care, the NHS has been increasingly reluctant to provide long-term care for older people.⁷

Where long-term care is arranged by the local authority, the individual is means-tested to determine the contribution they should make to the costs of their care. This takes account both of income and of assets (including capital). The current rules on income and assets are as follows:

- more than £20,500 in capital: person liable to pay total fees until capital is reduced to £20,500
- capital between £12,500 and £20,500: a ‘tariff’ income is assumed for every £250 of capital between these limits and counted as an extra £1 per week income
- no tariff income is assumed on capital below £12,500 for charging purposes
- the value of a property is also counted (subject to certain disregards), although a deferred payment agreement may be allowed if a person does not wish to sell their home (a legal charge is then placed on the property and the amount is claimed back at a later date when the property is sold).

The Royal Commission concluded that the current system fails to meet the reasonable expectations of old people who believe they have paid into the system through their National Insurance contributions:

At a key point in people's lives they find that they are expected to pay for themselves out of assets they have accumulated over a lifetime for care they had previously expected would be free. We do not say this belief is logical: that it exists is a fact, and the sense of betrayal cannot be denied.⁸

It was on the basis of such apparent confusion and sense of injustice that the Commission reached its central conclusion and recommendation for a major restructuring of the system of paying for care. This entailed distinguishing between the three cost components of long-term care (living costs, housing costs, and personal care costs). It was argued that people in residential settings should be responsible for the costs of the first two components, but *not* for the costs of personal care:

The costs of personal care as such are however quite different. These are the costs which, unpredictably and through no fault of their own, old people have to incur when unfortunately they can no longer be looked after at home or cannot be sent home after hospital treatment. They reflect the true risk and 'catastrophic' nature of needing long term care. In our judgment it is right for the state to exempt personal care from means-testing altogether. This is our key recommendation.⁹

As noted at the start of this paper, this central recommendation was *not* accepted by the government, primarily on the grounds that this would not help the poorest or the sickest whose care was already funded, and that it would be a costly policy that would divert resources from helping people to remain independent and in their own homes. However, a number of other recommendations made by the Royal Commission *were* implemented, including the introduction of 'free' nursing care. This has, however, added to the confusion and complexity of the situation over who is responsible for what in long-term care.

'Free' nursing care

At the time that the Royal Commission was reviewing long-term care it was apparent that there was an anomaly in the approach to nursing care. Nursing care in a hospital or community setting would be provided free of charge. However, when this care was provided in the context of care in a residential or nursing home, it was charged for as part of the overall fee for care.

The Registered Nursing Care Contribution (RNCC) was duly introduced on a phased basis from October 2001 through Section 49 of the Health and Social Care Act 2001 which removed the responsibility of local authorities to provide nursing care by registered nurses. The RNCC intended to recognise the nursing care needs of people in care homes providing nursing care, and it covers care provided, planned and supervised by a registered nurse. It *does not* cover services that do not need to be provided by a registered nurse and that are undertaken by a care assistant. People's needs are assessed as being in a high, medium or low band, taking account of the predictability and stability of their condition. From 1 April 2005 these bands are worth £40, £80 and £129 respectively per week.

The Health Committee Inquiry and a new national framework

A recent inquiry by the House of Commons Health Committee into NHS continuing care drew attention to 'considerable confusion and significant overlap' between the RNCC system and continuing care. This is largely due to very similar terminology being used in

the guidance on criteria for both systems. Particular confusion exists between people qualifying for high-band RNCC and those meeting the criteria for NHS fully funded continuing care. This was a feature that was repeatedly identified in evidence to the inquiry, and was also highlighted in the Department of Health's independent review.¹⁰ The following comment from John Pye of the Royal College of Nursing typifies the problem:

*(...) the relationship between the RNCC and continuing health care. it was never thought about when RNCC came out, and we have ended up with two policies and two procedures matching in everything including the words, which places a great difficulty on us within the nursing sector and certainly within PCTs in trying to disseminate and make decisions on who funds and who does not.*¹¹

This confusion had also been reported by the Ombudsman who argued that:

*(...) it is difficult to see how a person with healthcare needs that properly place him or her at high band RNCC would even have reached the stage of an RNCC assessment, had he or she been properly assessed for NHS continuing care.*¹²

The Committee believed it was 'a nonsense' for two separate systems to exist for assessing eligibility for fully funded NHS continuing care and for nursing care contributions since both are effectively doing the same thing. It is evident that much of the confusion that has arisen is a reflection of poor understanding in the field about continuing care. The confusion over the RNCC bandings and eligibility for NHS continuing care is partly the result of similarity of wording in the guidance relating to both. In practice, decisions have sometimes been made which place people in medium or high band RNCC apparently without consideration of the Primary Health Need Approach, and whether all of the nursing needs could have been properly provided by the local authority, were it not for Section 49 of the Health and Social Care Act 2001. The Department of Health stated in its response to the Health Committee report that assessment for NHS continuing care *must* be made prior to assessing eligibility for other health and social care support (including RNCC). Moreover, the forthcoming national framework 'will make this relationship and process very clear' and 'will be an opportunity to tackle implementation issues that surround continuing care and RNCC assessments.'¹³ The box below presents the key objectives for the national framework that have been developed by the Change Agent Team.

CONTINUING CARE NATIONAL FRAMEWORK PROJECT OBJECTIVES

The project aims to deliver:

- an appropriate response to the Independent Review, the Ombudsman's report and the Health Select Committee report
- nationally agreed eligibility criteria and nationally consistent approaches to assessment
- a range of compatible national determination tools to aid in the decision making process
- information and guidance to facilitate delivery and promote shared understanding and consensus amongst professionals
- improved information for service users and the people that support them
- an examination and clarification, where necessary, of the interaction of continuing care policy with other policies.

Source: *Continuing Care National Framework Newsletter. Edition 1 – June 2005.*
Department of Health.

Challenges in developing national criteria

Assessment

In developing national criteria for NHS continuing care the framework will need to address a number of requirements. The quest for greater consistency will require a common approach to assessment *and* adequate training to ensure that people using the assessment methodology understand its purpose. Without such preparation it is hard to believe that the objectives will be achieved. Dr Ladyman told the Health Committee of his aspiration:

*Broadly speaking we want to end up with a system where absolutely everybody in England will be able to say, the assessment I have had would have come to exactly the same conclusion, whether it was held in London or Carlisle or wherever it was.*¹⁴

INCLUSIVE CRITERIA

Achieving greater consistency is not the only challenge. One of the main concerns over the lack of apparent ‘fairness’ in eligibility for continuing care is indicative of the restrictive nature of criteria. In particular, there is considerable evidence that criteria are insufficiently responsive to the health needs of older people, others with chronic degenerative and progressive conditions (such as motor neurone disease and Parkinson’s disease) and people with mental health needs. Another case investigated by the NHS Ombudsman (the Pointon case) has been especially significant in focusing awareness of these issues. Barbara Pointon was caring for her husband Malcolm, who had dementia and it was deemed that Mr Pointon did *not* meet the criteria for continuing care; this decision was revised only after the Ombudsman upheld the complaint. The key issue was the extent to which criteria concentrate too heavily on physical health care needs and fail to take adequate account of mental health care and psychological needs.¹⁵ Moreover, when eligibility is determined by reference to instability of condition, there is an inbuilt bias against conditions that may be stable and predictable but where there are nonetheless considerable care needs. People in the late stages of dementia often become more stable and predictable, with the result, as the Health Committee remarked, that ‘as their condition worsens, they in fact become less likely to qualify for NHS continuing care.’¹⁶

The Pointon case also drew attention to the anomalies that arise when continuing care is wrongly defined by *who* provides care, rather than by care *needs*. In this case, as in many others, it was wrongly believed that NHS continuing care could not be provided to people in their own homes. The Department of Health has stated that people should *not* be denied fully funded continuing care at home simply because their carers are not registered nurses.¹⁷

The government’s response to the Health Committee emphasised that eligibility for continuing care ‘must always be on the basis of need not diagnosis.’ The Department of Health restated its belief that national eligibility criteria *can* be designed to cover all client groups, including older people with mental health needs, younger adults with physical or mental health needs and people with a learning disability. The apparent disadvantage of some groups in the past was believed to reflect:

*...inconsistent assessment of needs and inconsistent awareness of continuing care among the health and social care professionals who work with these groups.*¹⁸

It is evident that many of the issues that have been identified as problematic in determining eligibility for NHS continuing care *are* now being addressed by the development of a national framework which is expected to be issued for consultation in spring 2006. Further interim guidance (pending the publication of the National Framework for NHS Continuing Care) was issued by the Department of Health in March 2006¹⁹ in response to a further High Court judgment on continuing care (Grogan V Bexley NHS Care Trust)²⁰. The High Court ruled that the criteria for continuing health care used by the care trust were unlawful since there was no guidance on the test or approach to be used in determining the eligibility of a person's health care needs. The criteria were deemed to be 'fatally flawed'. The judgment also highlighted the confusion which surrounds continuing health care eligibility and the RNCC bands of nursing care. The Department of Health guidance on action following the Grogan judgment indicated that strategic health authorities should (once again) 'review their local eligibility criteria for NHS continuing healthcare' and satisfy themselves that they are in line with the Grogan judgment. The over-arching test that should apply in determining eligibility for continuing healthcare is the primary health need test established by Coughlan (where nursing and other health care needs are more than incidental or ancillary to the provision of accommodation which a local authority is under a duty to provide). The latest guidance advises that this test 'should feature very prominently in SHA's eligibility criteria.' Where there is a need to revise eligibility criteria or local procedures as a result of this review, 'they should also consider whether there are services users who should be re-assessed in consequence.' If the framework succeeds in developing national criteria and accompanying assessment tools that can be applied consistently throughout the country, and if those criteria take full account of physical *and* psychological needs, and the interface between NHS continuing care and RNCC is clarified, this will be a major achievement that resolves many of the long-standing problems around long-term care. However, it will *not* address the fundamental underlying tension that results from the operation of two parallel but largely separate systems for meeting health and social care needs.

Conclusions and future options

The controversy over who qualifies for fully funded NHS continuing care and who must meet the costs of care for themselves encapsulates the tensions in trying to manage a shifting boundary between health and social care. People requiring long-term care are less likely to have these needs met by the NHS than was the case in the past. As the Health Committee observed:

In practice the boundary between the two services has shifted over time, so that the long term care responsibilities of the NHS have reduced substantially, and people who in the past would have been cared for in NHS long stay wards are now often accommodated in nursing homes. This means that responsibility for funding long term care has to a major extent been shunted from the NHS to local authorities and individual patients and their families.²¹

No one should argue for a return to long-stay provision in NHS wards, and in many ways the closure of outdated NHS facilities is to be welcomed. However, the central issue is the fact that most of the development of alternative facilities is in the independent sector and has not been paid for by the NHS. Whether it is right that the boundary between health and social care should have shifted in this way is the subject of a much wider debate. At the heart of this is whether it is possible to distinguish clearly between health and social care needs. There is considerable agreement that there is a substantial 'grey' zone between these where needs are highly ambiguous. The Department of Health's response to the Health Committee report on continuing care defended the maintenance of two systems of care on the grounds that this has been the structure of the welfare state since 1948 and changing it would be fundamental and costly.

The forthcoming national framework for NHS continuing care *should* provide greater clarity and consistency in assessment for eligibility, and it should reduce disputes caused by poor awareness and understanding of continuing care. However, unless the revised criteria are considerably more inclusive than those currently in operation, the new framework will not succeed in resolving the underlying sense of injustice that characterises debate in this area. Whatever improvements are achieved by the new national framework, some people will qualify for 'free' long-term care from the NHS while others will have to contribute some or all of the costs of their care. If the care needs of people in these different categories are not clearly distinguishable the legitimacy of operating two separate systems will continue to come under scrutiny and to face increasingly adversarial and judicial challenge.

Options for the future

What then should be done about long-term care? It is apparent that the difficulties which have developed around long-term care over the last couple of decades cannot be resolved by incremental revision. Changes that have been introduced have often added to

complexity and brought further confusion. Moreover, there have also been unintended consequences. For example, the development of the RNCC to contribute towards nursing costs has failed in many instances to provide any financial advantage to self-funding clients, who have seen their fees increased by an amount equivalent to the RNCC payment. It was essential that some means of acknowledging the anomaly around nursing costs for people in care homes was found, but the solution has been problematic in many respects (although arguably it has also had the benefit of more rigorous assessment and review of residents' needs).

The development of national eligibility criteria should be welcomed as this will address the criticisms about a 'postcode lottery' that have bedevilled NHS continuing care since at least 1995. If the criteria also address needs less restrictively than is currently the case, more people should qualify for fully funded care. This will reduce, but not remove, the concerns about unfairness.

The operation of two parallel systems (of health and social care), and the impossibility of distinguishing between needs at the interface of these systems, means that controversy is endemic. In giving evidence to the Health Committee the Minister agreed that the divide is problematic:

*'(...) this grey area between the two is a real problem. The question we then have to grapple with is the best way of resolving that (...). In the end it comes down to how closely social care and health professionals are working together; how well they understand each other's needs and are discussing these issues and are making sure they understand where funding of particular types of care should come, and the structure does not much matter.'*²²

Free personal care?

Clearly, the structure *does* matter to patients and service users if it is used to determine whether they have to pay for the costs of long-term care. One solution would be, as the Health Committee, the Royal Commission and others have argued, to remove the distinction altogether and provide personal care free of charge. This has been ruled out absolutely by the Labour government, and indeed Dr Ladyman told the Committee:

*'We do have to keep a distinction between the two, because I am afraid it is inevitable under any flavour of government that people will have to contribute towards the cost of their social care.'*²³

The affordability, or otherwise, of any fundamental change in financial responsibility for long-term care is essentially a political decision. What would be the consequences for the tax and national insurance systems of removing charging for care? Although there would be significant costs, it is also true that an integrated system would offer certain savings by removing the administrative and bureaucratic costs associated with defending the boundary between health and social care. Approximately 20,000 people currently receive fully funded NHS continuing care. In addition, approximately 42,000 people are self-funding residents, and a further 90,000 residents have had their care arranged following an assessment of need by social services. The government estimates that providing free long-term care (that is, removing means-testing from those currently receiving long-term care) would cost an additional £1.5 billion (rising to £3 billion by 2020). Moreover, this represents only the cost of personal care, and does not include the additional costs of 'board and lodging', which are also met for NHS continuing care patients.

In the short to medium term it is unreasonable to change the rules and expect people to make additional tax contributions for the cost of care. However, the introduction of a compulsory ear-marked contribution (such as exists in the Netherlands and Germany) deserves fuller consideration. Essentially, this would provide a system of collective risk-sharing that would remove the perceived unfairness of charges as a penalty on care needs.

Interim solutions?

The national framework for continuing care is likely to provide a compromise that is fairer but still flawed. It would be fairer still if the RNCC was reviewed and set at a level that more accurately reflects the full nursing care costs (and a flat rate payment such as operates in Wales might also be preferable to a banded system, which inevitably contains perverse incentives). Work on calculating the 'fair costs of care' undertaken by William Laing has estimated that the benchmark of 8.1 qualified nurse hours, and 18.9 care assistant hours per resident per week indicates a weekly cost of £89 for nursing input and £108 for care assistant input. The RNCC is *part* of a package of continuing health and social care, and the Department of Health has restated that 'the "high band" of nursing funding does not represent an extensive input by registered nurses' and is equivalent to 'approximately an hour and a half of a registered nurse's time per day in providing, planning, supervising and delegating care'.²⁴ The medium band similarly assumes an average of an hour a day of nurse involvement. Evidence to the Health Select Committee inquiry on continuing care argued frequently that the *actual* nursing needs of residents are often considerably higher than this notional hour or hour and a half. It is also essential that the benefit of such payments is passed to the patient and is not merely a subsidy to the care sector. Alongside the implementation of a more inclusive and transparent national framework, it is also important to raise public awareness and understanding about the costs of care. The popular notion that personal care is 'free' in Scotland (following their implementation of the recommendations of the Royal Commission) is a misnomer. There needs to be wider understanding that the system in Scotland still requires people to contribute towards elements of their long-term care.

Future generations are likely to be more accepting of the notion that they will need to contribute *something* towards their care costs; the real issue for the present is the situation of older people who are required to pay for their care which in previous years they would have received free of charge in hospital. For such a fundamental change to be acceptable, it has to be the result of public debate and clear policy decisions. That has not been the case with continuing care where the policy has, until recent years, developed by default and where the withdrawal of the NHS took place by stealth.

The longer term?

If the objective is to establish a fair system of paying for long-term care that does not penalise people for needing care and does not maintain two classes of people receiving care in either the health or care systems, there will be significant implications. The development of closer working between the health and social care systems and the opportunities around pooled budgets offer a positive way forward. The only way to ensure complete equity in the system is for the difference between health and social care to be removed. Although this is debated in terms of making social care 'free', the other side of this coin is that care provided by the NHS might need to be approached in a similar way so that people in either system would have their care needs 'free', but would contribute

towards other elements of their accommodation. Essentially long-term care could be developed as a co-payment. The development of insurance products to cover the gap between care costs and full costs of long-term care might then be addressed in order to reduce the financial liability falling on the most vulnerable. However, introducing changes of this order and the establishment of a 'level playing field', which sought to remove the distinction between long-term health and social care, would introduce additional challenges. There would be gainers, but also some losers. In particular, the principle that people should contribute towards the 'hotel' elements of their care wherever that was provided (including within the NHS) might prove unpalatable.

The challenge of changing the fundamental principles which underpin the NHS would be formidable and politically a high risk. However, *any change* in the organisation and funding of long-term care is risky and there are no easy solutions. The pattern of incremental revision that has characterised this policy field cannot be sustained and does not provide a firm foundation for the longer term. The national framework for continuing care offers the prospect of more radical change but still ultimately fails to tackle the underlying problem of operating two different systems to meet care needs. The nettle which must be grasped is to bring the two models into closer alignment. This will require greater transparency about financial responsibilities for the costs of care and a redistribution of those responsibilities between individuals and the state in a way that treats all citizens equally regardless of the nature of their needs for care.

Appendix 1

TABLE 1: TRENDS IN LONG-TERM CARE PROVISION, BY SECTOR, 1988 TO 2005¹

Year	Long-term care places								Total ²
	Local authority	Residential (private)	Residential (voluntary)	Residential (private and voluntary)	Nursing (private)	Nursing (voluntary)	Nursing (private and voluntary)	NHS (long-stay geriatric)	
1988	133,500	127,900	43,000	170,900	68,700	9,600	78,300	51,400	465,800
1989	129,800	143,200	39,900	183,100	88,600	10,400	99,000	49,500	492,100
1990	125,600	155,600	40,000	195,600	112,600	10,500	123,100	47,200	521,000
1991	117,400	161,200	41,900	203,100	135,200	12,100	147,300	44,400	539,100
1992	105,200	162,400	46,900	209,300	152,800	13,700	166,500	40,200	547,000
1993	94,600	165,800	52,400	218,200	172,100	15,800	187,900	37,800	562,900
1994	85,900	168,400	55,700	224,100	184,300	17,200	201,500	34,500	568,100
1995	80,100	169,300	56,700	226,000	193,400	17,900	211,300	33,000	570,500
1996	77,200	172,700	57,500	230,200	201,900	18,300	220,200	29,800	575,500
1997	71,000	177,100	56,100	233,200	205,900	18,500	224,400	27,300	572,600
1998	68,500	180,700	53,500	234,200	203,200	18,200	221,400	24,600	564,100
1999	64,000	184,000	53,100	237,100	195,300	17,900	213,200	22,100	550,900
2000	59,700	185,000	54,500	239,500	186,800	18,000	204,800	21,000	538,200
2001	55,600	185,100	55,100	240,200	178,800	18,000	196,800	20,400	525,300
2002	50,100	183,100	55,600	238,700	170,000	17,500	187,500	20,200	508,200
2003	46,400	177,900	53,900	231,800	168,200	18,000	186,200	19,800	495,600
2004	44,200	182,400	49,700	232,100	164,300	15,000	179,300	18,800	485,000
2005	40,700	179,200	52,800	232,000	160,500	15,000	175,500	18,100	476,200

Source: Based on Laing & Buisson (2005), *Care of Elderly People Market Survey 2005*, Table 2.2

¹ Table shows the number of long-term care places provided by sector, but does not show who is paying for these. It is generally estimated that the NHS pays for approximately 20,000 continuing care places in England.

² Total figure is larger than the sum of the columns shown since it also counts NHS long-stay figures for psych-geriatric places and for younger physically disabled.

Notes

- ¹ Royal Commission on Long Term Care (1999), *With Respect to Old Age: Long Term Care- rights and responsibilities*. Cmnd 4192-I. London: The Stationery Office.
- ² Department of Health (1995). *NHS Responsibilities for Meeting Continuing Health Care Needs*,. HSG(95)8. London: Department of Health
- ³ Health Service Commissioner (1994). *Failure to provide long term NHS care for a brain damaged patient*, Second Report for Session 1993–94. London: HMSO.
- ⁴ Department of Health (1999)., *Ex parte Coughlan follow-up action. Continuing health care follow up to the Court of Appeal judgment in the case of R v North and East Devon Health Authority*. HSC 1999/180. London: Department of Health.
- ⁵ Henwood M (2004). *Continuing Health Care: Review, revision and restitution*. London: Department of Health.
- ⁶ *New National Framework on Continuing Care*, 9 December 2004, Press release notice 2004/0437.
- ⁷ Royal Commission on Long Term Care (1999). Op cit, para 4.8.
- ⁸ Royal Commission on Long Term Care (1999). Op cit, para 4.36.
- ⁹ Ibid, para 6.32.
- ¹⁰ Henwood (2004). Op cit.
- ¹¹ House of Commons Health Committee (2005). *NHS Continuing Care*, Sixth Report of Session 2004–05, Volume 1, HC 399-1, para 92. London: The Stationery Office.
- ¹² Ibid, para 93.
- ¹³ Secretary of State for Health (2005). *Response to Health Select Committee Report on Continuing Care*. Cmnd 6650. pp 10–11. London: The Stationery Office.
- ¹⁴ House of Commons Health Committee (2005)., Op Cit, para 65.
- ¹⁵ Health Service Ombudsman for England (2003). *The Pointon Case*. Available online at: http://www.ombudsman.org.uk/improving_services/selected_cases/HSC/pointon.html#top (accessed on 24 March 2006).
- ¹⁶ House of Commons Health Committee (2005).Op cit, para 79.
- ¹⁷ Secretary of State for Health (2005). Op cit, p 4.

¹⁸ Secretary of State for Health (2005). Op cit, p 9.

¹⁹ Department of Health (2006), *NHS continuing health care: Action following the Grogan judgment*.

²⁰ *R v Bexley NHS Care Trust*, 25 January 2006.

²¹ House of Commons Health Committee (2005). Op cit, para 41.

²² Q266, Volume II, *Oral and Written Evidence*.

²³ *Ibid*.

²⁴ Department of Health (2005), *Ensuring that all recipients of high band NHS-funded nursing care have been correctly considered against eligibility criteria for fully funded NHS continuing care*, 28 November.