Who Cares, Who Pays?

How the sick and vulnerable are forced to sell their homes for care that should be free

By Paul Burstow MP
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Introduction

1. The system for funding and delivering essential services to those with long-term healthcare and support needs is in chaos; the source of this chaos is the uncertainty about who commissions, provides and pays for these services. The responsibilities are straddled between the NHS, local authorities, individuals and their families and vary wildly between different parts of the country.

2. In April 2001, Paul Burstow MP published a report that showed over the period of the previous year; approximately 70,000 elderly people had been forced to sell their home to pay for their care.[1]

3. Changes in the policies governing the provision of long-term care have shifted the boundary between Health and Social Services responsibilities. Health services must be free at the point of delivery whilst Social Services can charge by applying a means test, regardless of the setting in which such services are provided – hospital, or care homes, or indeed somebody's own home. Various care categories (intermediate, palliative etc) have developed to manage these responsibilities. However, with the shift of emphasis from hospitals to community and independent care home settings, Social Services have developed a wider role bringing more people into the charging net.

4. Government guidance has failed to clarify the position. Throughout this report we refer to the case of *R v North and East Devon Health Authority (ex Parte Coughlan)* in which parts of Government Guidance,[2] on which local eligibility criteria are based, were declared to be unlawful. In particular the judgement collapsed the distinction, on which many Health Authorities' rely, between specialist and general nursing care.

5. This study looks at the 'continuing care criteria' drawn up by Health Authorities and the process of revising these in the light of case-law, statutory guidance and the establishment of Strategic Health Authorities. It carries forward the conclusions of a report by the Royal College of Nurses (RCN) which examined the legality of Health Authorities 'continuing care criteria' and concluded that 90% have

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[1] Burstow: *The scandal of long-term care under Labour A survey of the number of people forced to sell their home to pay for nursing or residential care.*
[2] HSG (95) 8; LAC (95)

illegal arrangements for assessing and meeting the continuing care needs of their patients[3]. We surveyed both Health Authorities and Social Services and have found the process of change over the last two years to be slow and unsatisfactory.

Summary and recommendations

6. This report highlights the inadequacy of Government policy and guidance on long-term care policy, and the need for national eligibility criteria to clear up inconsistencies and avoid illegality. The Government has done little to ensure that Health Authorities meet their minimum legal obligations; indeed they have fudged the issue for fear that Health Authorities might be facing long-tail liabilities in refunds. **The funding regime for long term care in chaos, the law is being flouted and this report has found that up to 360,000 people over the last 6 years have been forced to sell their homes unnecessarily to pay for their care.**

7. The role of Social Services as a provider of long-term care is limited by statute to accommodation and ancillary services, they should not be providing care services that relate to health needs. Although nursing care provided by registered nurses is now the legal responsibility of the NHS, the funding regime provides only a contribution to free nursing which is often absorbed in higher nursing care fees. Otherwise the costs of long-term healthcare are – in the main, met inappropriately and often unlawfully by Social Services charges.

8. Department of Health guidance is supposed to clarify the funding boundary between health and Social Services. However, guidance has taken the most minimalist interpretation of the *Coughlan* case which, to date, provides the clearest interpretation of the legislative responsibilities of the NHS and Social Services. Ensuring that guidance is taken into account in revising eligibility criteria, is therefore not enough in crafting continuing care policies for the NHS which are lawful.

9. Our survey of found that the majority of current eligibility criteria fall far short of the tests set out in the *Coughlan* judgement. Some of these findings are also reflected in a recent report published by *Help the Aged 'Nothing Personal'*, which notes that eligibility criteria for nursing home care are structured around the principle of 'last resort' in which people will only qualify for free continuing care if they are close to death or have high levels of dependency on medical interventions. **The process of change has been absurdly slow since the RCN found two years ago that 90% of eligibility criteria were unlawful.**

[3] RCN Dec.2000 The RCN survey on the methodology of continuing care criteria, showed that several health authorities listed tasks that they excluded from NHS care--such as artificial feeding, pain control, care of the dying and catheter care, and in some extreme cases health authorities would not acknowledge situations in which the NHS would have responsibility for individuals in need of a nursing home place The survey also showed wide variations across the country in policies and approaches.

10. This report argues the case for eligibility criteria to clearly define the statutory responsibilities of Health and Social Services starting from the category of cases which can be lawfully be referred to Social Services for means testing, and using the Court of Appeal's distinction between ancillary services and care services to meet genuine health needs. The *Coughlan* case has major policy implications which have still not been taken on board, and the this means revisiting the vital missing link of personal care for those with long term health needs and disabilities.

Methodology and Findings

11. **We studied a number of Health Authority criteria and reports on the process of revising criteria, including surveying the role of Social Services Directorates in this process, and found that many cases Health bodies are still operating criteria based on the Department of Health guidance that was declared to be unlawful in the *Coughlan* case.** One Social Services department told us that the Health Authority: -

"… decided not to revise its eligibility criteria following the Coughlan judgement, and so we continue using its original continuing care criteria. We have always felt that these criteria are drawn very tightly, and for a long time (in common with the other 5 unitary authorities) *lobbied hard to ensure that* (the Health Authority) *funded even its most minimalist responsibilities."*

12. Another Social Services department told us: -

'The position remains somewhat fluid in that we have sought legal advice which would confirm that the "agreement" in place was in conflict with the Coughlan judgement and needed to be reviewed. However, the Health Authority's legal advisors have taken the view that the Health Authority should not sign up to any change until central government guidance emerges'.

The Social Services official told us: -

'I would probably argue as to whether there was a formal "agreement" in the first place locally, but have had to accept that progress would not take place until the newly forming Strategic Health Authority establishes a regional position….As an interim stance, we have continued to push hard on individual cases and challenged the Health Authority and in some cases, health providers around medical and health care needs'.

13. When sampling criteria as at March 1st 2002, we found that many take a 'banded' approach, establishing three or four 'bands' and placing in the worst category of life threatening conditions – artificial respiration and feeding, double incontinence, total immobility, round the clock medical interventions etc in band one, and then specify that it is only this band which unambiguously qualifies for NHS funding. **This approach is unsustainable in light of the *Coughlan* judgement which makes clear that all health needs qualify for NHS funding;**

the purpose of eligibility criteria should define category of cases which can be lawfully be referred to Social Services for means testing.

Case studies

14. The research for this report also involved the collection of a number of 'borderline' case studies from lawyers, advocates, organisations and elected representatives working in the field around the country. Many of these demonstrate real life situations in which patients, with worse conditions than Mrs Coughlan, have been handed over to social services and charged for their care**. It is clear that the message from the *Coughlan* case is not getting through to those undertaking the assessments; the reason is that the implications of the judgement have not been spelt out in guidance and reflected by eligibility criteria.**

The Coughlan Judgement

15. Mrs Coughlan is a woman with severe physical disabilities living in Mardon House, a purpose-built NHS nursing home in Devon. In 1998, North Devon Health Authority attempted to close the home and move the residents into independent sector nursing homes; Mrs Coughlan brought a case to prevent closure. The Health Authority, relying Department of Health guidance and local eligibility criteria, argued that they no longer had legal responsibility for purchasing long-term nursing care and was therefore entitled to transfer Mrs Coughlan's care to Social Services.

16. The Court of Appeal ruled that Social Services were able and obliged to contract for nursing care when the quantity and quality of care was such as to be only '**ancillary'** or '**incidental'** to the client's accommodation and other social care needs. [4] When someone was over that line, there was no legal power to pay or purchase the extra nursing services, because the Health Acts determine that Health Authorities must meet nursing care needs.

17. The judgement made it clear that consideration of healthcare needs must come first. The Appeal Court concluded that: -

"The eligibility criteria could be flawed because they reflected guidance of the Secretary of State, which itself was flawed."

18. **The effect of the judgement is to make clear that there is no intermediate category. Either the services are an NHS responsibility or they are capable of being charged by the local authority. Where a care package includes nursing tasks which the NHS is required to provide and carer's tasks which could be described as 'nursing tasks' or 'carer's tasks' and no division between the two sets of tasks is possible – the health authority has to take the whole responsibility.**

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[4] see Para 31 above

19. On the issue of specialist versus general nursing care, Lord Woolf concluded: -

"I therefore seriously doubt whether a coherent and consistent division could be maintained between what is a nursing task and what is a carer's task if it were proposed that there should be a different funding regime for the two types of care...The difficulty is particularly acute in the context of work carried out by nursing auxiliaries or other carers under the supervision of qualified nurses. This will generally parallel the equivalent arrangements in NHS hospitals where care is delivered by a range of individuals including nursing auxiliaries and others who are not professional nurses. I therefore seriously doubt whether a coherent and consistent division could be maintained between what is a nursing task and what is a carer's task."[5]

20. Thus, while Health Authorities were entitled to have discretionary criteria for the trigger point at which they would acknowledge that they would have to meet such needs, those criteria were supposed to be set with the legal limitations on local authorities' service purchasing powers in mind. Lord Woolf said: -

"We do not accept the argument that there cannot be variations between the services provided by the NHS in different areas. However, the eligibility criteria cannot place a responsibility on the local authority which goes beyond the terms of Section 21."[6]

21. Most Health Authorities' criteria had focused on the 'skill' factor following the guidance of circular *NHS Responsibilities for meeting Continuing Care Needs*[7], meaning that unless truly exceptional levels of specialist nursing care was needed, no-one qualified for continuing care in a nursing home setting, funded by the HA. Commenting on the circular Lord Woolf said: -

"Of those areas identified as specialist, none are recognised as such by the United Kingdom Central Council for Nursing[8]*. Those listed as non-specialist are arguably all examples of specialist nursing. It is not for us to resolve this difference of approach, but it is relevant to note that the notion of specialist nursing, introduced by way of policy guidance and not by statute, is, on any view, elusive... In spite of counsel's best endeavours it has proved impossible to locate the source of the recommendation upon which this passage of the policy is expressly based."*

22. The underlying implication of the judgement is that eligibility criteria must discount where the service is provided. It is not that a person could feasibly be cared for in a nursing home setting which determines that the local authority is properly liable for the funding; the NHS should still pay for some people in nursing homes by way of direct contracts with the home.

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[5] *R v North and East Devon Health Authority (ex Parte Coughlan)* C.A. 15th July 1999

[6] Section 21, National Assistance Act 1948

[7] HSG(95)8/LAC(95)5 *NHS Responsibilities for Meeting Continuing Health Care Needs*

[8] Now the Nurses and Midwives Council (NMC)

Implications of the Coughlan Judgement

23. The Court of Appeal in effect has laid down important general principles for Health Authorities to follow when making an assessment of whether an individual should receive NHS funded care; the two elements of the judgement comprise: -

- The '***quantity test'*** which looks at whether the health need is 'merely incidental or ancillary to the provision of accommodation'

- The ***'quality test'*** which looks at the type of service provided – whether it falls within the type of services provided under section 21 of the National Assistance Act

24. This judgment suggests that up to half the criteria in the country were drawn up unlawfully narrowly and need reviewing; and that half the nation's local authority criteria for nursing care, as opposed to residential, were set too high - higher even than the point where the judges envisaged that the NHS should be shouldering the responsibility.

25. Another most alarming implication was that where people were still placed and fully funded by a local authority, despite being clearly an NHS responsibility, they may wrongly have been expected to sell their home and fund their own care services through a charge by a local authority.[9] Hence they, or their estates, would have legitimate grievances, which may potentially result in health authorities or local authorities being taken to court to recover the money.[10] In the last three years 195,000 people have been forced to sell their homes.

26. Following the judgement, health authorities have been obliged to ensure that where a person's primary need is nursing care identified by looking at the range, frequency, intensity, specialism and continuity of the person's nursing needs rather than the professional status of the care giver, the costs must be met by the NHS.

Guidance

27. The Coughlan judgement prompted a new DoH circular which stated: -

"Health and local authorities, in consultation with each other and involving Primary Care Groups should satisfy themselves that their continuing and community care policies and eligibility criteria are in line with the judgement, taking advice where necessary."[11]

28. The position was confirmed by Department of Health circulars in June and September 2001 which stated that the Health and Social Care Act in no way alters the entitlement to 'free continuing care.'[12] Eligibility criteria are slowly being

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[9] Where a person is assessed as needing permanent residential or nursing home care, the local authority will apply means-test and a standard charge under National Assistance Act 1948 Section 22; the means-test includes income and capital, including the value of the home; in most cases the local authority's solicitors place a "legal charge" on the home to recover the money owed.

[10] Coughlan was a Judicial Review case, however it is equally possible to bring a civil action against a health authority or local council based on breach of statutory duty

[11] HSC 1999/180: LAC (99)30 *Ex parte Coughlan: Follow up Action*

[12] HSC 2001/15; LAC (2001)26 28 June 2001 *Continuing Care: NHS and Local Councils' responsibilities* www.doh.gov.uk/jointunit/015hsc2001.pdf

revised in light of these circulars and new geographical boundaries for Strategic Health Authorities.

29. Circular HSC 2001/015 required Health Authorities to agree joint eligibility criteria with local councils by the end of March 2002; over time the Strategic Health Authorities are required to align criteria across their area. However on the substantive issues, the circular suggests that the judgement did little more than confirm the status quo.

30. A further circular was issued[13] on the introduction 'free' registered nursing care contributions. It also revisited the definition and stated that 'free continuing care' is due if 'the primary need is for health care'. Whilst an improvement on the circular of 28th June which evades the definition entirely, this is still not consistent with the Court of Appeal's judgement. The emphasis on 'primary' is misplaced; if there are health needs the patient qualifies – they do not have to be 'primary' needs. The correct qualification should be 'Health Needs' rather than 'need for health care'; the distinction is vital for patients such as those with Alzheimer's for whom under present medical knowledge 'health care' cannot be provided; it is the 'need' which qualifies the patient for free care.

31. Circular HSC 2001/17; LAC (2001) 26 makes clear that, "Registered Nursing" under the Health and Social Care Act means that Health Authorities contribute to the cost of nursing care provided by a Registered Nurse according to the three bands, however the "self-funder" or Social Services Department pays for the rest. The scheme fails to plug the *Coughlan* gap because the judgement sets out a category of people whose health needs or disabilities are 'of a scale which are beyond the scope of local authority services." Patients in this category might not need regular nursing at all, but have ongoing care needs; providing for these needs parallels the arrangements in NHS hospitals where care is delivered by a range of individuals including, doctors, paramedics, nursing auxiliaries, care workers and others who are not professional nurses.

32. The scheme for registered nurse contributions came into effect from the 1st October 2001; up to 42,700 self-funders have been entitled to an assessment of their entitlement to a registered nurse care contribution. The financial contribution is divided into three bands. The higher band of 'free' nursing care suggests a level and intensity of nursing care that is clearly narrower than the *Coughlan* case definition. Yet in the former, a person receives £110 a week to help cover their nursing care costs only, while in the latter all of their personal care costs must be met by the NHS.

33. The new guidance for separate social services eligibility criteria[14] fails to mention *Coughlan* altogether, and the limitation which the judgement places on social services provided under the National Assistance Act. It also makes clear that Councils should prioritise eligible needs which are 'critical', this may involve 'life threatening conditions', and 'significant health problems' although these are clearly within the *Coughlan* definition of continuing care. However it does say that "Access

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[13] HSC 2001/17; LAC (2001)26, 23rd September 2001 *Guidance on free nursing care in Nursing Homes* www.doh.gov.uk/jointunit/freenursingcare/hsc200117.pdf

[14] LAC (2002)13 *Fair Access to Care Services Guidance on Eligibility Criteria for Adult Social Care* www.doh.gov.uk/scg/facs/lac200213.htm

to Care Services guidance applies to adult social care services that have been agreed as the responsibility of councils under local continuing care arrangements (HSC 2001/015; LAC (2001)18 refers**"** This paragraph means by implication that those with "Health Needs" and "Disabilities" cannot be passed to Social Services, although it also incorporates the defects of the previous circular.

The Problem of Eligibility

34. In order to assess the shortcomings of any individual criteria, it is necessary to evaluate the purpose of eligibility criteria. First, eligibility criteria are not creatures of statute. **The words 'eligibility criteria' do not even appear in any of the statutes relating to health care or community care services**. Yet they are the standard tool used by every public authority for encouraging consistency of decision-making in similar cases, and for managing the budget notionally allocated to funding particular services out of the total funds to which the authority has access. In effect they are care-rationing policies.

35. The Department of Health's Circular *NHS Responsibilities for meeting Continuing Care Needs* issued in 1995[15] gave the green light for the evolution of local eligibility criteria. The guidance required Health Authorities to develop local policies and eligibility criteria to serve as the basis, in individual cases, for decisions about need for NHS funded care, and the range, type, location and level of service which may be arranged and funded to meet continuing health care needs in each area. The annex to this guidance outlined the range of services that Health Authorities must address; these include rehabilitation and recovery services, palliative health care, respite health care and access to specialist or intensive medical and nursing support. It made clear that access to specialist medical and nursing services should be available and provided at the expense of the NHS for those persons who were no longer eligible for in patient care.

36. The outcome of the intrusion of rationing policies into the assessment process is that professional judgment is not the bottom line as to who gets what. The professionals concerned are employed to use objective indicators of a certain factual state of affairs, by the authority responsible for funding or arranging services. When asked for a professional opinion, it is the professional's job to give an opinion on the facts, measured against the authority's criteria, whatever their professional opinion might be about whether or not the person has a 'need', in the wider human, social or medical context.

37. In theory, public authorities' criteria can be challenged by way judicial review. This should provide bulwark against pure managerialism being allowed to run wild, and reign in a public authority's chances of getting away with ridiculousl*y* tight criteria or never acknowledging that anyone actually *meets* the criteria, no matter how bad their situation. Taking decisions simply so that a budget can be met will not suffice. **This is why *Coughlan* is such a landmark case.**

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[15] HSG (95) 8; LAC (95) 5

38. What remains an open question, and may have to be tested in law, is whether that person, having been regarded as qualifying, can still actually be denied a service on the grounds that the continuing care budget has run out. The Government's guidance on the administration of the continuing care and the free nursing care budget would seem to suggest that it thinks that this is the case.

39. In the past Health and Social Services have operated separate eligibility criteria. For example, eligibility criteria under the Chronically Sick and Disabled Persons Act are supposed to be about identifying incapacities constituting needs that the authority is prepared to consider meeting. At the second level, criteria are supposed to reflect different levels of seriousness of need, enabling care managers to recognise situations in which the authority is prepared to accept that it is satisfied that it is necessary in order to meet the assessed needs for the authority to make arrangements for certain services.

40. Following government guidance HSC 1999/180: LAC (99)301), the New Strategic Health Authorities must agree their criteria with the local authorities in their area.

Conclusions

41. **It is apparent from the results of our analysis of eligibility criteria, as they stand at present, that current policies are still being drawn too restrictively**. In simple language the vast majority are unlawful. The framework of Government policy lacks any clarity about 'who pays', which under *Coughlan* is treated as a totally separate issue from "where" and "by whom" the patient is treated.

42. **The implications that Health Authorities are continuing to fail in their obligations to ensure they are compliant raises the issue that over the past six years up to 360,000 of Social Services clients have been forced to sell their homes illegally**.

43. It is critically important that the new Strategic Health Authorities act decisively on this issue in order to avoid future damaging and ensure get what they deserve from the NHS. It is, after all, what they have paid for all their working lives.

Recommendations - Next steps for Strategic Health Authorities

44. Strategic Health Authorities should work with the Department of Health towards rationalising criteria. The criteria should start by defining the category of cases that can be lawfully referred to Social Services.

45. Strategic Health Authorities include the exact words of Lord Woolf in their "eligibility criteria".

46. Strategic Health Authorities should make their “eligibility criteria” and the advice of the “Patients’ Representative” available to every patient being assessed for transfer to a Nursing Home or detailed care in their own homes.

47. Local Authorities should scrutinise more carefully each case and become more willing to seek judicial review against Strategic Health Authorities to protect the interests of their tax payers. Elected Councillors should insist that their Councils do not agree to the new “eligibility criteria” from Strategic Health Authorities until the details have been debated in Committee and in full Council with detailed legal advice. Elected Councillors should insist that every disputable case is referred to an appropriate “Independent review panel”.

48. In the longer term the Government should work with strategic Health Authorities to produce **National Eligibility Criteria**. Last time MPs looked at the issue in the Heath Select Committee they concluded that local criteria created 'inequities' and national criteria were needed to define the NHS's basic responsibilities.[16]

49. Government should take the opportunity to revisit the central recommendation of the Royal Commission on Long Term Care to be available free of charge. This would enable Health Authorities to get around the *Coughlan* problem quite simply by not making artificial distinctions between nursing and related care tasks.

[16] Health Select Committee: *The Relationship Between Health and Social Services session* 1998-99 First Report

APPENDIX 1: Answers to Parliamentary Questions

Mr. Burstow: To ask the Secretary of State for Health (1) what guidance he has given to community health councils to assist them in advising self-funders in nursing homes of the decision in *Coughlan v. North Devon health authority*, C.A. 1999; [21392]

(2) when community health councils were given the information about *Coughlan v. North Devon Health Authority*, C.A. 1999 contained in circular HSC 1999/180: LAC (99) 30 of 11 August 1999; [21395]

(3) if health authorities pass confidential medical information to social services about potential self-funders before any decision accepted by the patient has been taken to withdraw free continuing care; [21394]

(4) if health authorities obtain the consent in writing of patients to become self-funders before free continuing care as defined by Coughlan *v.* North Devon *health authority* is withdrawn; [21396]

(5) if he will list the health authorities which have sought his Department's advice over applications for refunds made by self-funders since the decision in *Coughlan v. North Devon health authority, C.A.* 1999. [21391]

Jacqui Smith: It is for individual health authorities to ensure that their criteria for continuing national health service health care comply with guidance issued by the Department and to obtain their own legal advice where necessary. Since August 1999, only two health authorities have sought the Department's advice on the issue of 'refunds' for self-funders: West Surrey health authority and South Essex health authority.

The determinations of any individual's requirement for continuing NHS health care or free nursing care is made on the basis of an assessment to determine individual needs. The introduction of free nursing care may lead to the identification of individuals with exceptional health needs who may now qualify for continuing NHS health care. Health authorities neither obtain consent in writing, nor do they pass confidential medical information to social services before 'withdrawing' continuing care; it is not envisaged, nor has it ever been brought to the Department's attention, that any health authority has behaved in the way described in the two questions. Once provided, continuing health care should continue to be provided unless and until the individual's healthcare needs change.

Appendix II Case Studies

A with a neurological condition which made her totally disabled, was passed to Social Services for Means Testing and sent home with an expensive Care Package. She paid for it in part but it was subsidised by Social Services. Her support group suggested she sought advice. When he saw the "Coughlan" definition, the Consultant confirmed that Mrs A had "health needs" within Lord Woolf's definition. The Complaints Officer for Social Services, after studying "Coughlan", conceded that his authority was in danger of acting "UltraVires" and has forced the H.A. to agree a refund to both patient and social services.

B, with the same condition, had been told to pay Nursing Home fees. After "Coughlan", his support group suggested he seek advice. After a year's evasion, Social Services insisted that the Health Authority take over the fees, which they did 9 months ago. The Council say that a refund is nothing to do with them, as this is entirely a matter for the Health Authority. The H.A. are still seeking advice.

C (now 60) has been totally disabled for 10 years. She is currently under two separate consultants. Without telling her what he was doing a Consultant ruled that she no longer needed "specialised" care". The Power of Attorney, who knew nothing of this "assessment" by the consultant until recently, now argues that this "test" was specifically ruled unlawful by "Coughlan" and complains his area was still using the unlawful circular on which it was based until recently. Social Services paid the early Nursing Home fees but wrote to the PoA directing the sale of Mrs B's home or they would take a charge on it. The Minister then advised Social Services to take legal advice on "Coughlan". They didn't and Mrs B's house was sold. The PoA refunded Social Services. On reading a Magazine article, the PoA contacted Social Services and the Health Authority. The Primary Care Trust replied promising to investigate. Despite further letters, nothing more was heard until the Council wrote after 3 months to say that the HA had decided and the Council agreed that Mrs C was not entitled to free care from the Health Service. The PoA asked the Council for documents, which were forwarded. The PoA complained that there was no record of any formal proceedings whatever or any sign that the "Coughlan" Case had been considered. Who had taken the decision? Where are the minutes of the meeting etc? The council referred to the GP's report and said, "That is your decision". The PoA did not know that this assessment had taken place. The Doctor had in fact heavily underlined details of Mrs B's disabilities. When the PoA visited the GP, she phoned the Council while the PoA was there to say forcefully (a) she was not the decision maker and (b) she regarded Mrs C as highly disabled. She later countersigned the PoA's note in hand of the meeting. The PoA still has no idea what happened between the GP's visit to Mrs C and the Council's letter two months later. The Health Trust never told Mrs C of its decision and it is not known who took it. The PoA asked the Trust for all N.H.S. documents and for a hearing before an "Independent Tribunal". After another delay of 3 months they wrote to say that the matter is "so complex" that they could not yet reply. They did then offer to send documents, but none have been received. However, the PoA did obtain from the Council their joint briefing with the HA to Doctor's for assessments (a briefing not given to the G.P. in this case). It does emphasise the financial implications for patients and says the decision must be taken by a consultant in consultation with the family. Twice their own rules had been disobeyed. Mrs C has just be assessed in the "top band" for nursing care but her PoA argued that the assessment shows that she is entitled to totally free care. The Nursing Home increased the fees by £55.

Suddenly, on 13th March, 2002 an officer of the Health Trust phoned the Nursing Home to say that all the fees would be paid by the Trust; on 21st March a different official wrote to say the wrong procedure had been followed and no decision had been taken. Mrs C became very distressed. However, the new criteria in the area now include the words "Individuals who do not have the care needs described may still be entitled to full NHS funded care where the overall scale of the individual's needs is such that they should be regarded wholly as the responsibility of the Health Authority." The PoA has made further submissions under "Coughlan". In April, 2002, the PCT admit liability and gave a partial refund to 26th Feb, 2002. A 14 day notice demanding a full refund or a Tribunal under the new Court Protocol has been served (29th April, 2002) and solicitors for the PCT have acknowledged they have to respond.

D, totally disabled by the degeneration of the nervous control system of the limbs and needing frequent changes to his drug prescriptions, was told by a Social Worker at an informal meeting of junior staff that he would have to move to a nursing home at his own expense. He expects to pay £25000 a year. His support group suggested he sought advice. The family obtained the Consultant's report, which confirmed major disabilities. The health trust has conceded a further joint assessment with Social Services whose "Cabinet Member" member has asked his legal team to investigate the risk of acting "ultra vires".

E has been in a nursing home for several years. When a social worker said that no financial help was available, the family refused to allow Social Services to intervene. After reading a magazine article, they asserted that the N.H.S. should be paying and demanded a review. After several months, a consultant ruled that Mr E. did not need to return to hospital but could stay in a Nursing Home. The family objected that this was not the question they had raised and asked for an "Independent Tribunal" under "Salesi v Italy", to rule if Mr E was entitled to "free continuing care" from the N.H.S. They had contemplated refusing to pay, telling the Nursing Home to invoice the NHS, but in view of the hardship it would cause the home they decided not to. The Health Board agreed to call in an outside Consultant, who was probably startled to receive from the family a summary of "Coughlan".

F, aged 96, exhausted all her assets on Nursing Home fees. As Social Services had exhausted their budget, they "ordered" the PoA, a relative, to pay out of her own resources. After a major row, Social Services have now refunded over £5000

G, aged 86, in hospital because of a coronary, after some months suddenly started to recover. Without her family being told, she signed a "financial agreement" with Social Services without realising that this meant she had to pay for home help. As there had been discussion with the physiotherapist, of which Social Services were unaware, that Mrs G might stay with a relative elsewhere, the family complained (a) that it was unlawful for the Hospital to call in Social Services at all without the written consent obtained by the Health Trust from the patient. (b) that no signature should be obtained by anybody without advice from the family and (c) that the Health trust should have made available to the family a summary of "Coughlan" and the local "eligibility criteria". The family intend to repudiate the signature as unlawfully obtained if any attempt is made to force the sale of Mrs G's home.

The family of Mrs H, totally disabled, had the good fortune to consult her support group before she was transferred from hospital and flatly refused to pay, referring the consultant to "Coughlan".

I, a Hospice Manager, travelled 30 miles to his County Town to make it plain that he would go on local T.V. to say that his well-known charity was being deprived of funds because both the Health Trust and Social Services were refusing to pay a patient's fees. Social Services then agreed to pay for a patient who the Council's officers say is a Health Trust responsibility. Mr I complained to his Community Health Council about the difficulties caused to his Charity by frequent three-way disputes between, the Health Authority, Social Services and the families.

J, totally disabled, in a wheelchair, young, previously unemployed and without family, was transferred by the Health Trust not to Social Services but to the District Council as "homeless". With no information as to his condition and not knowing he was in a wheelchair they put him in a bed-and-breakfast. Fortunately, a neighbour knew enough to get an emergency legal aid certificate!

K, an East Sussex resident with three disabled elderly asked a verbal question by written notice at the County Council meeting. Social Services replied- *"The County Council has concerns about the Health Authority's interpretation of its legal obligations in relation to the provision of continuing health care and it has been actively seeking to persuade the Health Authority to adopt a more helpful position, which we are advised would be more appropriate."* In short, they admit to breaking the law!

Appendix III– Elligibility Criteria Analysis

Key Elements of Criteria - By reference to covered conditions and other factors	Comments on lawfulness with reference to Coughlan
• *Complex needs, regular specialist input or therapy eg artificial feeding* • *No mobility and intense nursing care need based on dependancy*	Coughlan does not refer to 'complex needs' although frequency, intensity, specialism and continuity are all isues that can be taken into account
• *Complex or intense nursing/clinical care* • *Degenerating or unstable conditions requiring 24 hot day attention* • *Specialist palliative care at home* • *Specialist programmes of health related interventions*	This appears far too restrictive to pass the quantity or quality tests, athough the latter category of 'interventions' is unspecified.
• *Complex and intensive care with high level of dependency and 24 hour surveillance* • *Unpredictable progressive conditions likely to require immediate intervention of specilast staff.*	This criteria limits eligibility to the most bare lifesustaining functions rather than looking at any broader health needs; it is likely to be too restrictive to pass either the quantity or quality tests
• *feeding, mobility dependence, 2-4 hourly nursing attention re intake/output, communication and capacity loss*	These are too restrictive, and much narrower than the broad health needs category under Coughlan
• *constant attention of a qualified bitsem specilaist equipment to maintain life, high dependence on nursing care, pgv state*	These are by definition health needs under both the quantity and quality tests.
• *lists health input functions for hands on care arranged and funded by the NHS 'unless agreement has been reached between health and social services that another worker will carry out the task with appropriate advice from a health professional'*	It is clear from Coughlan that these type of 'agreements' have a very dubious legal basis.
• *4 bands based on mobility, continence, feeding and tissue vulnerability. Only band 1 qualifies for full NHS funding*	These are likely to be too tightly drawn, for example band 2 involves catheta care and enaemas, dressing ulsers, and assisted feeding to avoid choking and inhalation – all clearly nursing functions.
• *Based on 96 circular and containing a general policy statement that 'health care provided by general nurses in nursing homes is funded by Social Services'*	This is clearly outdated and unlawful; one of the elements of Coughlan was that the setting should be disregarded
• *Has 3 classes – health care, joint care, and social care – all personal care is placed in the latter.*	Nothwthstanding the fact that *Coughlan* casts doubt on whether there can be any intermediary 'joint care' category, the latter two categories include forms of medical surveilance and administratiion – clearly health related needs
• *4 bands – involves 2 or 3 of the following* *B1.mechanical ventillation, double incontinence, total imobility, multiple drug therapy, pvs* *B3. single incontinence, inability to feed, limited mobility, open wounds stable drug regime*	Under this criteria only band 1 qualifies unambigiously for full NHS funding; this is remarkably restrictive given that these are the only the most serious palliative cases where it is the patient's basic lifesigns rather than their health needs that are being supported.
• *Palliative care if less than 4 weeks to live, physical dependence and degenerative diseaes, barthel index score below 5*	Palliitave care is by definition health care and doesn't need to be a qualification for long term or continuing care
• *Acute rehab, eg strokes, deteriorating conditions requiring palliative care,*	The focus on rehabilitation is more likely to be Coughlan compliant

people wo require expensive specialist health care equipment	
• *4 bands – 1 ventilation, pvs etc, 2 inability to walk or eat and frequent/double inncontinence, 3 wounds, drug regimes and limited mobility.*	Again this authority adopts a 'four bands' approach with not much between them, except that band one is close to legal and clinical definitions of death and this is the only band which unambigoulsy qualifies for full NHS funding!
• *pvs, double incontinence, artificial feeding, technical interventions or require supervision at least weekly from a specialist nurse.*	Limited set of criteria; somewhat narrower than Coughlan
• *Division between 'basic' and 'specialist' nursing tasks as fundiing key*	It was precisely this division which Coughlan questioned.
• *2 of the following – frequent, complex and intesive care from trained nurses throughout 24 hrs, high level of dependency requiring 24 hr surveilance, unpredictable pogressive conditions requiring intervention at least once a week.*	This level is essentially intensive care which is a far narrower than the Coughlan Case definition;
• *Immobility, feeding by gastromony, ulcers covering 50% of the lower leg, tracheotomy changes, convulsions, insulin dependence, brittle parkinsons, unmangeable dementia.*	These are the sort of disabilities which one could resaonably expect to be covered by the Coughlan case
• *Bands 1-6 from routine assistance to round the clock interventions.*	Again the bands look at 'level' of need rather than catering for individual cases applying the quantity and quality tests

Appendix IV:The legal framework

Understanding the context of this problem involves and detailed examination of the legal framework. Health and Social Services have a complex statutory framework; this is partly because the legislative regimes have developed separately although much has been consolidated in the Health and Social Care Act 2001 which provides for joint assessment procedures. The body of legislation makes it clear that there are separate responsibilities; however increasingly these distinctions are blurred in practice. The following legislation is key:

- **National Assistance Act 1948**
  Section 21 Subject to and in accordance with the provisions of this Part of this Act, a local authority may, with the approval of the Secretary of State, and to such extent as he may direct shall, make arrangements for providing -(a) residential accommodation for persons aged eighteen or over who by reason of age, illness, disability or any other circumstances are in need of care and attention which is not otherwise available to them.

- ***National Health Service Act 1977***
  Consolidates local authority powers to provide for after care and preventative services.

- ***Chronically Sick and Disabled Persons Act***
  Places a duty on local authorities to meet social care needs of persons defined as disabled under the National Assistance Act

- ***Health Act 1999***
  This of legislation set the scene for pooled budgets and joint commissioning of services, commonly referred to as 'Health Act Flexibilities'
  - Section 29 extends the powers of Health Authorities to transfer money to local authorities so that they can fund any local authority health-related function. The powers are also applied to Primary Care Trusts, which, like Health Authorities must be satisfied that the purpose of the transfer is related to NHS functions or the health of individuals and (under the old legislation) that such a transfer is to fund services to improve the health of the local population more effectively than equivalent expenditure in the NHS.
  - Section 31 allows the NHS and local authorities to pool resources and to delegate health and health-related functions from one party to another (in the form of lead commissioning or integrated provision). The arrangements relate to prescribed functions and must be likely to lead to an improvement in the way in which the relevant functions are exercised. They leave existing charging arrangements in place. Examples of health authority functions included in Section 31 partnership arrangements include hospital accommodation, medical, dental, nursing and ambulance services and various facilities, including rehabilitation services and services intended to avoid admission to hospital.

- ***Health and Social Care Act 2001***
  Removes local authorities' powers to provide or arrange nursing care by a registered nurse. Nursing care is defined as "services by a registered nurse and involving a) the provision of care, or b) the planning, supervision or delegation of the provision of

care, other than any services which, having regard to their nature and the circumstances in which they are provided, do not need to be provided by a registered nurse". This provision is not concerned with all nursing per se, but merely with paying for the nursing services provided by a "Registered Nurse".

Glossary of Terms

Guidance*:* Circulars issued by the Department of Health to Health Authorities and Local Councils to provide information and instructions on Government Policy and statutory obligations, they are usually called HSCs and LACs. Although the Department of Health cannot dictate to public authorities how they allocate sources, in practice Guidance is used influence

Eligibility criteria: Local policies to ration access to specialist medical, nursing and personal social services; service managers and professionals must apply these policies to particular cases

Intermediate Care**:** has specific outcomes for rehabilitation, reablement or recuperation, and is provided for a time-limited period, normally up to six weeks;

Palliative Care**:** A general term to describe care for the dying

Self-funder Someone who, up to 1 October 2001, has paid all of their nursing home fees themselves from their own resources, perhaps through a council or a third party and receives no financial assistance from a local council. Also included in this definition is the small number of people who, previously through a mixture of different social security benefits from the DWP (but not those in receipt of higher levels of income support) are able to pay their fees, even though a council may top these up. There are also a small number of people placed by social services both before and after 1 October 2001 where social services pay only *part* of the cost of the care by a registered nurse. This is the common description of situations where the individual contributes as a result of a financial assessment.

***Assessment* -** a process where the needs of an individual are identified and their impact on independence, daily functioning and quality of life is evaluated.

Continuing care - (or 'long term care') is a general term that describes the care which people need over an extended period of time, as the result of disability, accident or illness to address physical or mental health needs.

***Registered Nursing Care Contribution (RNCC)* -** a tool developed by the Department of Health to determine the care by a registered nurse required by someone who is resident in a nursing home or has been assessed as requiring care in a nursing home. Determination of care by a registered nurse is a process carried out by an NHS registered nurse at the same time as or following a health and social care assessment using the Department of Health tool for Registered Nursing Care Contribution.

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