Dilnot Commission Call for Evidence
Contribution from the ADASS Continuing Care Reference Group

Summary

- NHS Continuing Healthcare (NHS CHC) is a significant aspect of the current arrangements for funding care and support to which the Commission needs to give consideration.
- Just over 51,000 people are recorded as receiving NHS CHC at present and this number is likely to grow.
- Those in receipt of NHS CHC are, by definition, people with high levels of need. The estimated cost of meeting these needs in the current financial year is over £2bn.
- Given the high cost typically involved in meeting the needs of those eligible or on the fringes of eligibility for NHS CHC, decisions regarding entitlement frequently have big financial implications for the individuals involved.
- It is recognised that CHC funded provision will overall (i.e. on an aggregated basis) be more expensive to the public purse than that provided to a similar group of individuals via 'social care'. However we would urge the commission to consider carefully any potential consequences in its recommendations for social care that could impact on CHC entitlement or further confuse its application.
- People view the NHS (and in this context therefore CHC) as a safety net for their high level and often end-of-life care needs.
- In the context of a complete review of the current system, consideration should be given to removing the need to decide what is ongoing 'healthcare' and what is 'social care'
- There are big inconsistencies in the current system. There is clear evidence that, despite having a National Framework and a single set of criteria for NHS CHC, individuals are still far more likely to be deemed eligible for NHS CHC in some PCT areas than in others.
- The law in this area is confusing and contentious, particularly in relation to the limits of local authority responsibility.
- The current system is extremely complicated and time-consuming. Many professionals struggle to understand the system, let alone members of the public.
- In designing new arrangements for funding care, there is a need to recognise the costs of administering the current regime.
- If NHS CHC is to remain and some form of insurance arrangement is introduced, there will be a need to give greater clarity as to when the NHS can be expected to fund an individual's ongoing care.

1. Background

1.1 The dividing line between care that local authorities can lawfully provide and care that the NHS should provide is governed by complex statute and case law. Local Authorities cannot lawfully purchase/provide or charge for the care of people who have ongoing nursing/healthcare needs above a certain level. The NHS is required to fully fund the care of individuals who have a 'primary health need' and are therefore eligible for NHS Continuing Healthcare (NHS

CHC). Directions require that people with nursing/healthcare needs above the limits of local authority responsibility are deemed eligible for NHS CHC.

1.2 ADASS and the LGA have been actively involved in the issue of NHS CHC for several years and since 2006 have had a national Continuing Care Reference Group. This has representation from all ADASS regions in England. The Reference Group works with the DH, with LAs and with other national stakeholders with the aim of achieving the fair, transparent and consistent application of the NHS CHC criteria throughout England. Through this group ADASS has worked increasingly closely with the DH, including jointly preparing national practice guidance (published in 2010) which has been widely welcomed by statutory and independent sector organisations.

1.3 The ADASS Continuing Care Reference Group welcomes the opportunity to respond to the Call for Evidence by the Commission on Funding of Care and Support. It is surprised that NHS CHC gets no mention in the Call for Evidence document, since it believes this to be significant aspect of the complex system by which care and support is currently funded.

2. <u>The Relevance of NHS Continuing Healthcare</u>

2.1 Since the early 1990s eligibility for NHS CHC has been a source of confusion, controversy, ombudsman investigations, litigation, media attention, and ministerial concern. Historically there were different criteria for NHS CHC in each health authority area of the country. At least some of these criteria were not fit for purpose, indeed unlawful. In 2007 a National Framework was introduced which provided a single national process for determining eligibility and did much to improve fairness and consistency across England. In 2009 the Framework and the associated tools were updated. The *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care July 2009 (revised)* took effect from 1st October 2009 and was accompanied by updated Directions. Under the Framework PCTs, SHAs and local authorities have clear statutory responsibilities. The proposals outlined in the 2010 white paper '*Equity and Excellence: Liberating the NHS'* will require the NHS statutory functions to be assigned to different organisations/bodies once PCTs and SHAs are abolished. The ADASS Continuing Care Reference Group is working with the DH to help shape how the transition of responsibilities is managed. Indeed, there is an urgent need for the risks and challenges inherent in NHS CHC to be fully understood both in terms of the future funding of care and in terms of the changing architecture of the NHS.

2.2 The current overall cost of meeting the needs of people eligible for NHS CHC is estimated to be in excess of £2bn a year (source: National Funded Care Benchmarking Analysis Q2 2010-11).

2.3 DH figures (Q2 2010-11) indicate that at present just over 51,000 people are in receipt of NHS CHC. This figure represents a 'snapshot' count on a given day. All of these people have very significant healthcare needs, and many are near to the end of their lives. Whilst the system is much fairer than before the Framework was introduced there are still wide variations between PCT areas,

ranging from more than 20 people eligible per 10,000 population to less than 3 people per 10,000.

2.4 As an area of public policy NHS CHC is unique in that:

- it governs the dividing line between health and social care provision
- it is fundamentally about citizens' rights
- it affects adults of any age with a wide range of disabilities and clinical conditions
- it directly affects some of the most vulnerable people in our society
- it carries very significant financial risks for the organisations involved
- it requires close partnership working between local authorities and the NHS, particularly if care is to be provided in a cost-effective and personalised manner
- it can only be fairly delivered through a national approach to eligibility, with clear governance and monitoring arrangements

2.5 The current government has given no indication that NHS CHC is to be abolished. This being the case, ADASS believes the future arrangements for its delivery and governance must:

- promote greater consistency in decision making across the country, achieving similar outcomes on eligibility for people with similar needs
- provide clarity on governance, commissioning, assessment and care/case management responsibilities
- encourage partnership working across health and social care organisations in order to:
    - achieve the best use of limited resources
    - minimise disruption for individuals who move between health and social care responsibilities, and also for those making the transition from child to adult services
    - make best use of expertise and specialist skills within partner organisations
    - maximise 'personalisation' of care
- provide mechanisms for pooling financial risks, particularly for 'low volume high cost' care arrangements
- keep decision making close to the individual and to the health and social care practitioners supporting them
- facilitate linkages with other policy areas (e.g. End of Life Care)

3. Responses to the Consultation Questions

Question 1:
Do you agree with the Commission's description of the main opportunities and challenges facing the future funding of care and support?

3.1 Whilst agreeing with the overall description of the main opportunities and challenges facing the future funding of care and support, ADASS believes that NHS CHC requires specific consideration. The statement '*people with assets over £23,000 receive no state support and need to fund their own care'* requires qualification. Where an individual has a 'primary health need' and is

therefore eligible for NHS continuing healthcare, the NHS is responsible for providing all of that individual's assessed needs – including accommodation, if that is part of the overall need.

3.2 Around 51,000 people at any given time currently receive 'free' NHS care, irrespective of their financial situation, either in some form of care home or in their own home. This figure has risen from around 31,000 people in March 2007, and there is every indication that the figure will continue to rise as more people survive for longer with more complex, intense or unpredictable healthcare/nursing needs.

3.3 Whilst the number of people in receipt of NHS CHC at any given time is relatively small, the cost of meeting their care needs is high. For the 2010-11 financial year this cost is expected to be in excess of £2bn (source: National Funded Care Benchmarking Analysis Q2 2010-11).

3.4 For years local authorities have been funding the care of people who arguably should (in law) have received fully funded NHS care. Local authorities are rightly concerned to ensure that the eligibility criteria for NHS CHC are applied correctly. Meanwhile primary care trusts have seen the cost of providing NHS CHC rise dramatically at a time when all agencies are under financial pressure. Clearly there are huge financial incentives for individuals, backed by lawyers, to argue that someone is eligible for NHS CHC. Consequently there are many disputes between LAs and PCTs and between individuals and PCTs. In the current system there is a real danger that those who 'shout loudest' or who have legal representation are more likely to win the argument that they are eligible for NHS CHC than those who are not in a position to argue their case so strongly. Sadly, the eligibility process is becoming more litigious and adversarial.

Question 2:
Do you agree with the Commission's description of the strengths of the current funding system, and its potential shortcomings? Do you think there are any gaps?

3.5 We broadly agree with the Commission's assessment of the current system, with the need to maintain a 'safety net', the need to support personalisation, to keep a focus on prevention, to promote partnership, and to support carers.

3.6 It is correct that many people face very high care costs under the current system, which is why NHS CHC is a very significant factor that needs to be considered.

3.7 In terms of value for money, there is a need to understand better the cost of administering and policing the current divide between means tested social care and free ongoing NHS care. The process of determining eligibility for NHS CHC requires a great deal of paperwork to be completed, multi-disciplinary meetings, PCT verification arrangements, dispute resolution panels, and Independent Review Panels. Whilst there are currently no figures for the cost of running this eligibility system there is no doubt that it is

substantial, both for the NHS and for Local Authorities. These costs are not about providing care but simply about deciding who should fund the care in the first place. For many reasons it is always going to be difficult, time-consuming and expensive to work out what is 'healthcare' and what is 'social care', particularly for individuals with high levels of need.

3.8 The Commission is right to point to the complexity of the current system. Many professionals, let alone members of the public, struggle to understand what makes someone eligible for NHS CHC. The law is in this area is obscure and confusing. ADASS has made representations to the Law Commission as part of the Review of Adult Social Care Law in the hope that the statutory scheme governing the divide between 'free' NHS care and means tested social care can be clarified. However, the current government has so far given no indication that the law is likely to change in this respect and we understand that the Law Commission is unlikely to be able to provide detailed recommendations to clarify the lawful limits of local authority responsibility with regard to providing ongoing care.

Question 3:
Given the problem we have articulated what are your suggestions for how the funding system should be reformed? How would these suggestions perform against our criteria that any system should be sustainable and resilient, fair, offer value for money, be easy to use and understand and offer choice? Please also take into account the impact that your suggestions will have on different groups.

3.9 In the context of a complete overhaul of the system for funding care, consideration should be given to amending the legislative scheme in order to remove the need to distinguish between continuing care that is the responsibility of the NHS (i.e. NHS CHC) and continuing care that is not. The costs of maintaining this distinction are too high. Instead there may be merit in revisiting the recommendations of the Royal Commission on Long-Term Care which, for the purposes of dividing funding responsibility, proposed a distinction between living costs, housing costs and personal care, where the latter incorporated elements of social care and health care. It should then be possible to develop new arrangements which ensure that the NHS, local authorities and individuals share the costs of care in a fair and transparent way.

3.10 We agree that it is currently very difficult to price the risks involved in care and support, and would argue that this is exacerbated by the confusion and inconsistencies around NHS CHC. This inconsistency and confusion over the circumstances in which the NHS will fully fund someone's care will become a major issue if some form of insurance based model is proposed for the future funding of care. Those calculating financial risks for insurance purposes will rightly demand greater clarity than exists at present over the circumstances in which the NHS is responsible for fully meeting an individuals assessed needs, otherwise it will be impossible to accurately calculate the insurance risk for any given individual.

3.11 It is clear that greater resources will need to be devoted to care and support in the future. Our hope is that by either clarifying or eliminating the distinction between ongoing 'health care' and ongoing 'social care' these increased resources can be utilised in the most effective way for the benefit of patients and service users.

On behalf of the ADASS Continuing Care Reference Group

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