

Commentary and Advice for Local Authorities on

The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care

Association of Directors of Adult Social Services (ADASS)
and the Local Government Association (LGA)

October 2007

Introduction

This document has been prepared by the ADASS Reference Group on Continuing Care, in consultation with the LGA and has been approved by the ADASS Executive and the LGA.

- i. ADASS and the LGA welcome The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (referred to here as 'the Framework') as a significant step towards addressing the considerable difficulties, inconsistencies and lack of fairness that currently exist in relation to 'continuing care'. We also welcome the recognition that an increased number of people will be eligible for fully (or part) funded NHS care as a result of the introduction of the Framework, and that the need for additional funding for the NHS has been identified.
- ii. ADASS and LGA welcome the Department of Health (DH) emphasis on the need for a consistent approach to assessment and eligibility and urge Local Authorities (LAs), similarly, to strive for consistency within their own organisation, with neighbouring LAs and with local partner agencies. It is important for LAs to have an understanding about what they can lawfully provide and the appropriate use of the Decision Support Tool (DST) will be helpful in this regard.
- iii. Alongside the DH, ADASS and the LGA are keen to ensure that the Framework is not open to local interpretation in a way that continues to exclude some people who should be eligible to receive full (or part) NHS funding from doing so, or results in people with similar needs having different continuing healthcare eligibility outcomes because of where they live.
- iv. It is the ADASS and LGA view that the Framework and associated tools require further clarification to ensure that they are inclusive enough and achieve the intended consistency of eligibility for NHS funded care. We are also concerned that additional funding for the NHS, identified in the Impact Assessment of the Framework, may not be sufficient to meet the additional costs that will fall to PCTs and will not be explicitly targeted for this purpose. However **our primary objective at this point is to ensure the Framework's consistency of application nationally**, particularly given the huge disparity in provision of fully funded NHS Continuing Healthcare (CHC) across the country so far. To this end ADASS and the LGA will continue to work closely with the DH to ensure that the existing national disparity regarding funding entitlement is eliminated once the new Framework comes into operation in October 2007.
- v. To achieve the desired equity of access to NHS funded services it is important that LAs provide a consistent approach to social care

- assessments and eligibility, and do not fund, or charge for, services unlawfully. In particular LAs are encouraged to review any existing joint funding arrangements with Primary Care Trusts (PCTs) to ensure these are lawful.
- vi. ADASS and the LGA have been working closely with the DH for many months on the policy issues surrounding NHS Continuing Healthcare. We have decided not to issue either separate guidance or a different decision support tool than that produced by the DH, but instead to provide commentary and advice in relation to the Framework. The intention is to assist LAs in working closely with NHS partners, and to help ensure that LAs act within their legal powers and obligations.
 - vii. ADASS and LGA have drawn upon legal (counsel) opinion given in respect of our earlier draft documents in preparing the advice set out below. **We recommend that Local Authorities (LAs) adopt this advice and ensure that they are working within their legal powers in seeking to achieve consistency on a national basis and ensuring that people receive (free) NHS care when entitled to it.** The advice should be used to support partnership discussions when developing local processes and protocols. This commentary and advice may need to be revised in due course if the DH review and amend their current documentation.
 - viii. This ADASS/LGA advice should be read in conjunction with the 'The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care' published by the Department of Health on 26th June 2007, and the relevant Directions published on 30th August 2007. It should also be read alongside the current versions (at this point those issued in September 2007) of the associated 'Decision-Support Tool for NHS Continuing Healthcare' (DST), 'Fast Track Pathway Tool for NHS Continuing Healthcare' (Fast Track Tool), 'NHS Continuing Healthcare Checklist' (Checklist). The sections in this advice correspond to those in the Framework and reference is made to the relevant paragraph numbers in that document.
 - ix. ADASS strongly urges its branches to actively engage with SHA and PCT partners in implementing, and subsequently monitoring, the Framework. Any LA that does not currently have a named lead for NHS Continuing Healthcare is advised to identify someone to take this role. There should be a local network of LA leads established, based around SHA boundaries to discuss local issues and ensure consistent LA communication with the SHA
 - x. This commentary and advice should not be seen as an alternative to The Framework and Directions. It is a complementary document that aims to

bring further clarity and consistency from an LA perspective and as such should be a useful aid to partnership working.

Key Messages

The document's detailed commentary contains important advice for LAs in relation to this difficult and complex area of policy. A number of key issues can be distilled from the new framework and this advice including:

a) Major Changes:

- a significant increase nationally in the number of people receiving full NHS Continuing Healthcare Funding
- a significant increase in the number of people whose care and support is funded jointly by the LA and PCT.
- joint funding may be appropriate in residential or nursing homes for people not eligible for NHS Continuing Healthcare
- LAs have powers/duties to fund some additional community care needs where someone is eligible for full NHS funding and is living in their own home, albeit that in such situations the NHS remains responsible for funding/providing all health and personal care services.

b) Local Procedural Issues:

LAs will need to take a full and active role in shaping local policy and practice in relation to 'continuing care', in order to ensure that the LA is acting within the law and that no one is incorrectly denied NHS funding. This includes:

- setting up processes to check and, where appropriate, challenge decisions (before they are finalised) that appear to deny NHS funding to individuals who should be eligible for it.
- setting up a robust dispute resolution process between the LA and the PCT.

LAs are strongly advised to have a named lead officer for NHS CHC, and to establish an SHA wide network of LA leads to work collaboratively amongst themselves and with the PCT/SHA.

LA staff as well as NHS staff need to be familiar with the Checklist, the Decision Support Tool (DST) and the main elements of the National Framework, and should receive appropriate training.

c) Practice Issues:

- Professional judgement is essential when using the Checklist and DST. Some individuals may need a full continuing care assessment even if they do not cross the Checklist threshold, and some may be eligible for NHS Continuing Healthcare funding even though they do not appear to cross the DST threshold.
- Any individual who 'crosses' the Checklist threshold but is ultimately deemed not to be eligible for NHS Continuing Healthcare is still likely to have their care jointly funded/provided by the LA and PCT.
- Where a person's primary need is a health need, the NHS is responsible for providing/funding all their health and personal care needs, including accommodation if this is part of the overall need. A Primary Health Need (PHN) may be indicated by any one (or more) of the key characteristics of nature, intensity, complexity or unpredictability of need. 'Intensity' includes 'continuity of need' which may on its own indicate a PHN.
- The correct use of the DST is essential to ensuring a consistent approach to assessing eligibility. However inconsistency may continue if LAs or PCTs adopt different views on the combination of high/moderate (etc.) needs that would normally indicate a PHN. As one **guideline** it is suggested that anyone found to have the following combination of needs:
 - two or more high needs (or need above high), AND at the same time
 - three or more moderate needs (or needs above moderate)
 should *normally* be considered to be beyond the scope of LA provision (see para. 5 h) below).

This guideline is based on an ADASS review of cases that were fully NHS funded or had clear evidence that they had needs that were beyond the power of the LA to meet. The guideline should **not** be used prescriptively but rather, when someone has this combination of needs, LAs should look to the PCT for clear evidence why the person does not have a PHN before they (the LA) consider full or part funding any care or support needs. Every case must be assessed and decided on its facts.

- Where full NHS funding is correctly denied some of the person's care needs may still be beyond the reasonable limits of sole LA funding, and therefore joint funding arrangements need to be considered.
- In a care home setting, ADASS and LGA expect that for a some people the NHS element of any joint funding may need to go beyond what used to be called the Registered Nursing Care Contribution (RNCC) but is to

become the single rate 'NHS-funded Nursing Care payment'. Joint funding by the NHS should not be limited to situations where the individual is in a 'nursing home' setting.

- Local Authority Adult Social Services Departments should not take a rigid line in having no involvement at all where someone is deemed eligible for NHS Continuing Healthcare or where the LA is not currently involved in funding. There may well be sound reasons for a joint assessment or joint review of the individual's needs or the provision of additional LA funded community care or professional services.
- Where someone is in receipt of NHS Continuing Healthcare funding but is living at home, the LA may nevertheless have responsibilities to assess for and provide some support. The NHS will, however, be responsible for case management and for meeting all of the individual's health care, personal care and associated social care needs (see para. 1 f below).
- Neither the PCT nor the LA should unilaterally withdraw from funding an existing package, or additional services, without appropriate reassessment, identification of the body responsible for funding and alternative funding being put in place.

Section 1. 'The National Framework'.

(Paragraphs 1 to 15 of the Framework)

- 1 a) ADASS and the LGA wish to emphasise that the National Framework and associated directions apply to LAs as well as PCTs. There is a need for LAs to be consistent in their approach to applying Fair Access to Care Services (FACS) eligibility criteria and to understand the limits of their responsibilities. Health and Local Authority staff need to understand each other's role and it is essential that the boundaries between local authority and NHS responsibilities are identified as clearly as possible so that both agencies can make consistent and lawful decisions.
- 1 b) We welcome the recognition that the RNCC (or NHS-funded Nursing Care payment) is only one of a number of models for joint funding arrangements in situations where someone has continuing care needs but is correctly deemed ineligible for full NHS Continuing Healthcare funding. We outline in our advice additional joint funding models for this cohort of people which we hope will promote consistent and lawful decision making by both LAs & PCTs by ensuring that individuals are not charged for care that should be provided to them free. (See paras.1 e), f), g) below)

- 1 c) A guiding legal principle for LAs (and for PCTs) is that, where someone is in a care home setting, the LA can only lawfully fund/provide general nursing services which are 'merely incidental or ancillary to the provision of the accommodation' and 'of a nature which it can be expected that an authority whose primary responsibility is to provide social services can be expected to provide'. See paragraphs 21 to 29 of the Framework.
- 1 d) ADASS/LGA have an expectation that, where someone does not meet the criteria for full NHS funding but has a high level of health needs and interventions not provided by a registered nurse, PCTs will joint fund packages of care in any care home, not just in those designated as 'care homes providing nursing'. The PCT contribution will represent health or nursing services provided by nurses, auxiliaries, care workers or carers.
- 1 e) People in care homes providing nursing may require additional funding from PCTs above the 'NHS-funded Nursing Care payment' (previously RNCC) where care not requiring registered nursing is nevertheless not of a nature that the LA can be expected to provide because their care relates directly to addressing their health needs.
- 1 f) Where someone is deemed eligible for fully funded NHS Continuing Healthcare but chooses to live in their own home in order to enjoy a greater level of independence, the expectation in the Framework, and of ADASS and the LGA, is that the PCT would remain financially responsible for all health and personal care services and associated social care services to support essential activities of daily living for that person e.g. equipment provision, routine and incontinence laundry, daily domestic tasks such as food preparation, shopping, washing up, bed-making, etc. (including additional support needs for the individual whilst the carer has a break). However, people who choose to live in their own home may have additional community care needs which may be appropriate for the LA to fund subject to their local eligibility criteria (FACS) and charging policy e.g. property adaptation, support with essential parenting activities, support to access leisure or other community facilities, carer services that may include additional general domestic support, or indeed any appropriate service that is specifically required to enable the carer to maintain his/her caring responsibilities.
- 1 g) ADASS and the LGA welcome the introduction of a single band for NHS-funded Nursing Care (£101 from 1 October 2007). However, in some areas and for some residents this funding will not cover the full cost of registered nursing time and therefore negotiations will need to take place between the LA and the PCT regarding funding contributions in which it must not be assumed that the LA will simply pick up the difference in cost. Please see paragraph 2 h) below.

- 1 h) The expectation of both ADASS/LGA and DH is that a significant number of people (currently receiving medium or low band RNCC) will be awarded the increased funding to meet their registered nurse needs as a result of the introduction of the single band. This increase is as a result of a policy change not an increase in a person's needs or care home costs. Therefore there will be no justification for an increase in the care home fee but rather there should be a reapportionment of the contributions of the PCT and LA (or resident if self-funding) towards the current fee level. ADASS/LGA recommend close working between PCTs and LAs to ensure that care home fees are not unjustifiably inflated as a result of the introduction of the single band.

Section 2. 'Legal Framework' *(Paragraphs 16 to 22 of the Framework).*

- 2 a) ADASS and the LGA remind LAs that it is unlawful for them to provide/purchase or charge for care which should be the responsibility of the NHS under Continuing Healthcare Criteria. Therefore it is essential that LA staff are clear about the types of situation that must be referred to the relevant PCT for funding consideration. (N.B. There may be situations where it is necessary for the LA to fund care on a temporary basis, without prejudice, pending the resolution of a funding dispute with the PCT to ensure that current needs are met, see paragraphs 2 b) and 9 a) below)
- 2 b) If a situation occurs where the professional judgement of the LA is that there is clear evidence the person has a Primary Health Need (PHN) and should therefore be fully funded by the NHS, but the PCT declines to fully fund, the LA should not simply accept this decision and agree to fund the placement by default, and charge the individual accordingly. It should pursue the matter, making use of local dispute resolution procedures where appropriate. Whilst such cases are being resolved the individual concerned must receive the care that s/he needs and the LA and PCT must agree interim funding arrangements. Where the LA is charging a client contribution in a situation which appears to be a clear case for full NHS funding, legal advice to ADASS suggests that the charges should still be collected but be set aside in an interest bearing account in order to facilitate full restitution should the case be finally deemed a full NHS responsibility.
- 2 c) In order to have a consistent and lawful approach by LAs regarding referrals for NHS Continuing Healthcare, LAs must ensure that relevant staff are familiar with the 'NHS Continuing Healthcare Checklist' and that all situations meeting the threshold for referral identified in paragraph 7 of the Checklist are referred for consideration of NHS Continuing Healthcare.

When considering which staff require training, LAs are reminded that Continuing Healthcare and the Framework apply equally to people with functional or organic mental health problems or a learning disability, as well as to disabled people or people with a sensory impairment or a long-term health condition.

- 2 d) LAs are reminded that eligibility for NHS Continuing Healthcare must be considered first, before any consideration of RNCC/ NHS-funded Nursing Care Payment. Therefore, by definition, any RNCC determination should also be accompanied by a rationale as to why the person does not have a primary health need (PHN) and is not eligible for NHS CHC funding or why an NHS CHC assessment was not completed.
- 2 e) Section 49 of the Health and Social Care Act 2001, which introduced the 'NHS Funded Nursing Care' arrangements, prohibited local authorities from providing/purchasing nursing care from a registered nurse. This was implemented after the *Coughlan* Judgment and had the effect of further reducing the power of local authorities to provide or fund care in a care home providing nursing care (by removing their power to provide nursing care from a registered nurse). Registered Nursing Care is defined in section 49 as "any services provided by a registered nurse, involving provision of care and the planning, supervision or delegation of care." These restrictions and 'Free Nursing Care'/RNCC/NHS Funded Nursing Care have no relevance to the assessment or eligibility of an individual for NHS Continuing Healthcare, and therefore the assessment for NHS Continuing Healthcare must be undertaken first.
- 2 f) The view of ADASS and the LGA is that there is still a lack of clarity in the Framework as to who funds care not requiring registered nursing which is not 'of a nature which it can be expected that an authority whose primary responsibility is to provide social services can be expected to provide'- e.g. in a specialist residential home for people with particular health conditions such as epilepsy, Prader-Willi Syndrome etc., (where the person has been assessed as not eligible for fully funded NHS care) Some of the health needs that are met by care assistants or auxiliary nurses in a care home (with or without nursing), or by carers, care workers or auxiliary nurses in a person's own home will frequently be of a nature that local authorities cannot lawfully be expected to provide.
- 2 g) The ADASS and LGA position is that the RNCC/NHS-funded Nursing Care payment only represents a *contribution* to the cost of nursing care and does not necessarily cover the full cost of registered nurse care or any of the costs for other health related support provided by unregistered nurses / care assistants which is not of a nature social services can be expected to provide. Therefore LAs need to work with PCTs to agree how

the additional health related costs are to be met. There should be no expectation by PCTs or LAs that the LA will simply absorb these costs.

- 2 h) We acknowledge that accommodation and social care in a 'nursing home' generally costs more than the same care in a home without nursing due to higher staff ratios, qualified staff, etc. Therefore we suggest that for nursing home placements LAs should consider negotiating (if they have not already done so) an approach with their PCT to cover these additional costs and the costs of nursing/health care that is not of a nature that an LA can lawfully provide (where they are assessed to be present). LAs may wish to take/agree a pragmatic approach. This could be based on the principle of sharing any additional costs, for example by the LA paying either:
- up to their usual residential care rates plus 50% of the fee differential between residential care and the actual cost of the placement after RNCC/ NHS-funded Nursing Care payment has been deducted, or
 - the usual LA residential rates plus 20%

An alternative but more complex approach would be to negotiate differential costs on a case-by-case basis.

- 2 i) For all care home placements (with or without nursing) joint funding will be appropriate where the individual has health needs that are met by auxiliary nurses, care workers or carers, and which are not of a nature the LA can lawfully meet. The same principle applies to people living in their own home. (See also paras. 1e), f) and g).)

For care homes without nursing, and people living in their own home, the use of a 24 hour diary is recommended as the best method of identifying the nature and intensity of specific care/support interventions and determining whether they are primarily health or nursing tasks or those that are of a nature that an LA can reasonably be expected to provide.

Section 3. 'Primary Health Need'

(Paragraphs 23 to 29 of the Framework).

- 3 a) ADASS and the LGA welcome the recognition that PCTs and LAs need to work closely together in applying the Primary Health Need (PHN) test on the one hand, and the 'Incidental and Ancillary' (I&A) and 'Nature of Social Services' (NSS) tests on the other, to ensure that there is no gap in provision for patients/service users.

'Primary Health Need' is not defined in the Framework. In the *Grogan* judgment, the Judge emphasised that where the phrase is used it must be taken to mean not just 'health needs', but needs on a holistic basis, including medical, nursing and social care. Therefore, someone with a PHN will inevitably also have some social care needs that the PCT must fund as part of their care provision.

Whilst it could be argued logically that '*primary*' means 51% or above, it does not necessarily follow that 49% or less should inevitably be deemed '*incidental*' or '*ancillary*'. The Oxford Dictionary gives a meaning of "*ancillary*" as "providing necessary support to the primary activities or operation of an organisation or institution" and of "*incidental*" as "accompanying but not a major part of something" and "liable to happen as a consequence of an activity". The words convey the meaning of something that is a part, but not a major part, of what is provided. Indeed the *Coughlan* Judgement emphasised this point by using the phrase '*merely incidental or ancillary*'.

- 3 b) Individuals will have a range of needs and it is important to be clear about the balance and interaction of these needs in deciding where funding responsibility lies.
- 3 c) The I&A and NSS tests are the correct ones to apply in determining the lawful limits of local authority responsibility and even then the *Coughlan* judgment clearly indicated that LAs can only lawfully provide a low level of general nursing services (and since 2001 cannot provide any *registered* nursing at all).

With the passage of time the nature of health and social care tasks can evolve, however the Directions of 1993 (LAC (93) 10) remain in force. These Directions relate to the responsibilities of LAs to provide residential accommodation and welfare services. They emphasise the 'incidental' and 'ancillary' nature of the nursing care that LAs may lawfully provide in relation to someone provided with accommodation under Section 21 of the 1948 National Assistance Act. They also, along with Section 2(1) of the Chronically Sick and Disabled Persons Act 1970(CSDPA), give an indication of the nature and type of welfare services that local authorities have a duty or power to provide which include: social work services; advice; support; practical assistance in the home; assistance with equipment and home adaptations; visiting and sitting services; provision of meals; facilities for occupational, social, cultural and recreational activities outside the home; assistance to take advantage of educational facilities; assistance in finding accommodation (e.g. a care home) etc. It can be seen, therefore, that when deciding whether services are of a nature that an LA can be expected provide, it is necessary to consider whether the

services in question are focused on social care and general welfare needs rather than health or nursing care needs.

- 3 d) In considering who funds nursing care the Court of Appeal in *Coughlan* (para 43) stated that it was 'important that any eligibility criteria should be drawn up with particular care. They need to identify at least two categories of persons who, although receiving nursing care while in a nursing home, are still entitled to receive the care at the expense of the NHS. First, there are those who, because of the scale of their health needs, should be regarded as wholly the responsibility of a health authority. Secondly, there are those whose nursing services in general can be regarded as being the responsibility of the local authority, but whose additional requirements are the responsibility of the NHS.'
- 3 e) There will be situations where overall the person's health and nursing needs are incidental and ancillary but some of those needs are not of a nature that Social Services could be expected to provide. In these circumstances a jointly funded arrangement between the NHS and LA is likely to be both appropriate and lawful. As a result of the introduction of this framework and our own legal advice ADASS and the LGA expect there to be an increase in the number of people receiving joint funding between the LA and NHS, particularly in situations where the LA would previously have been expected to fully fund the placement or support package.
- 3 f) If, however, an individual is in a care home placement and, taken as a whole, the health and nursing needs (general or registered) required are more than I&A or NSS then LAs cannot contract, fund or charge for the placement as a social services package.
- 3 g) There is a clear need for assessors from NHS and LAs to understand each other's eligibility criteria (i.e. FACS and the National Framework), legal guidelines and assessment and commissioning processes.
- 3 h) ADASS and the LGA have had concerns that many continuing healthcare assessments appear to focus on the characteristics of 'complexity' and 'unpredictability' without giving sufficient weight to those of 'intensity' and 'nature'. We welcome in particular the acknowledgement and emphasis by the DH (both here and elsewhere in the framework) of 'continuity of care' being an important factor in determining eligibility for CHC and also the emphasis that a person may be assessed to have a PHN on the basis of *only one* of the key characteristics of, nature, intensity (continuity), complexity or unpredictability. LAs should be mindful of this guidance when making their own assessments or reviewing PCTs' assessments.

In order to gain a complete picture of someone's needs, including the intensity and nature of those needs, we strongly recommend that a 24-hour diary of needs and interventions be compiled to form part of the assessment documentation. This should be a standard part of the community care assessment process when considering NHS CHC.

- 3 i) ADASS and the LGA support the government's aim (through the End of Life Care Programme and through the imminent End of Life Care Strategy) to improve the quality of care at the end of life for all people and enable more people to live and die in the place of their choice. We also recognise the difficulties with setting rigid time limits in relation to full NHS Continuing Healthcare funding for end of life care and appreciate that the current wording of the DST and Fast Track Tool is intended to be inclusive rather than prescriptive. Whilst we understand that the DH anticipates that the DST and Fast Track tool between them should ensure that people with a prognosis that they will die within 12 weeks of the assessment will receive NHS funding, there remains a concern that this will not prove to be the case in practice, notwithstanding that the DST and the Fast Track Tool prompt the assessor to be mindful of prognosis, potential deterioration and future needs.

However, ADASS and the LGA remain of the view that to ensure fairness, equity and consistency, some guideline on timeframe is helpful and necessary and believe that NHS CHC funding should always be available, irrespective of the outcome of the DST assessment, to people who are found to have a terminal illness or rapidly deteriorating condition, and a prognosis that they are likely to die within 12 weeks, and where there is either:

- a 'step change' in their condition triggering the need for an acute hospital admission, or
- an immediate or imminent (i.e. within 12 weeks) need for a new placement or care/support package, or
- an immediate or imminent need for a significant change or increase in existing provision

We advise that LAs should usually expect all people who meet these criteria to receive NHS CHC funding, and PCT decisions that deny these individuals NHS funding in the last weeks of their life should be challenged. Agreements about interim care and funding arrangements must be reached quickly in order to ensure that the individual receives a service that is not disrupted by unseemly disputes at this crucial time. Where it is clear that someone is reaching the end of their life but the above criteria do not apply, then, if appropriate, their needs should be assessed in the normal way using the Checklist and DST.

Section 4. 'Core Values and Principles'

(Paragraphs 30 to 43 of the Framework).

- 4 a) ADASS and the LGA support the core values and principles outlined in the National Framework and in particular welcome the emphasis on a person-centred approach. We encourage LA and PCT staff to work closely together to ensure that individuals are treated with dignity and respect throughout.
- 4 b) The provision of advocacy services should be encouraged and supported for individuals dealing with statutory bodies over their continuing care needs, and over the issue of who funds their care. A variety of national voluntary organisations already provide this support, including The Citizens Advice Bureau and The Alzheimer's Society. Complaints Advocacy is also available for NHS patients through ICAS (Independent Complaints Advocacy Service) funded in each SHA area by the DH. LAs are encouraged to consider how local advocacy schemes can be used to support individuals and families in these circumstances. In some circumstances complaints advocacy will form part of the Independent Mental Capacity Advocate (IMCA) role.
- 4 c) We welcome the clarification that 'managed' health needs *still remain health needs* and are to be considered and given due weight in any decision about eligibility for NHS Continuing Healthcare. This is an issue that has caused confusion in the past for both LAs and PCTs.
- 4 d) Where someone has capacity to consent but refuses to consent to an assessment for CHC or provision of NHS funded care e.g. because of fear of losing Direct Payments, we advise that the LA must make a judgement whether that person still has needs that the LA is responsible for meeting and if not ultimately it may have to give reasonable notice of their intention to withdraw funding and service provision for all or part of the support package. Individuals do not have a right to demand that an LA provides services that they have assessed are not their lawful responsibility to provide or continue to provide.
- 4 e) ADASS and the LGA welcome the clear requirement that neither the PCT nor the LA should unilaterally withdraw from funding an existing package without appropriate reassessment, identification of the body responsible for funding and alternative funding being put in place. LAs must be mindful of this and ensure that a robust disputes resolution process is in place to avoid undue delay in decision-making by either party. Interim, 'without prejudice', funding may be necessary to ensure that a person's care needs are not compromised pending the resolution of a dispute.

Section 5 'Eligibility Considerations'

(Paragraphs 44 to 63 of the Framework).

- 5 a) Whilst ADASS and the LGA welcome the process outlined to fast track eligibility for CHC for those needing terminal care, we still have some concern that the wording of the DST will not avoid disputes regarding people in the last weeks of their lives. This is why we propose a guideline timeframe of prognosis of death within 12 weeks, coupled with a terminal illness or rapidly deteriorating condition (see above, para. 3 i).
- 5 b) We support the introduction of the Checklist and urge LAs to incorporate this into LA assessment procedures so that relevant assessment and care management staff are familiar with this tool. Whilst the Checklist is intended to have a low threshold to ensure that everyone who should be is considered for NHS Continuing Healthcare, we would stress the point made in the Framework that there may well be circumstances where full consideration for NHS Continuing Healthcare is necessary even though the individual does not appear to meet the indicated threshold. The expectation is that any reasonable request for full assessment for continuing healthcare will be responded to positively. We also take the view that anyone who crosses the threshold set in the Checklist is likely to have some health or nursing needs which are not 'incidental or ancillary' or are 'not of a nature that Social Services can provide'. Therefore anyone who crosses the Checklist threshold who is ultimately deemed not to be eligible for NHS Continuing Healthcare is likely to have their care jointly funded by the LA and the PCT, and that the PCT element of the joint funding may need to go beyond RNCC/ NHS-funded Nursing Care payment.
- 5 c) It is very important for staff completing the Checklist 'screening tool' to have had training, not just in how to use the Checklist but also on the contents of the National Framework and the use of the Decision Support Tool. It is recommended that LAs, in conjunction with PCTs, establish an ongoing programme of training to meet this need for all relevant staff. We suggest that the fact that the person completing the Checklist has had training is noted at the end of the Checklist next to their signature.
- 5 d) ADASS and the LGA agree that it is important for the consideration of eligibility for NHS Continuing Healthcare to occur at the correct time, after there has been a realistic opportunity for rehabilitation to take place and welcome the clarification that it remains the responsibility of the PCT to fund appropriate care and rehabilitation services in the interim. Where people are receiving rehabilitation services in their own home or in a care home, which is currently funded by the LA, the LA will usually have responsibility for funding (or continuing to fund) essential care and accommodation services. This advice does not preclude formal joint

working/funding arrangements that have been put in place between LAs and PCTs.

- 5 e) We agree that it is the responsibility of the PCT to identify the co-ordinator(s) for the process of full consideration of CHC, and for clarity we believe that role should normally be carried out by NHS staff or employees of the PCT as the full CHC assessment is the responsibility of the PCT. LA staff should, however, fully support the process with any relevant information and assessment materials that they have. Where the LA is otherwise likely to be responsible for funding all or part of a support package, we recommend that arrangements should be in place for the LA to understand, check and (where appropriate) challenge decisions of ineligibility for NHS Continuing Healthcare before they are finalised and communicated to the patient/family concerned. Such arrangements should include mechanisms for agreeing any joint funding where it is agreed that there is not entitlement to NHS Continuing Healthcare.
- 5 f) Whilst there is not an expectation by ADASS and the LGA of LA involvement in every NHS CHC assessment, there is an expectation of a positive response to all referrals for joint or individual assessments where there is a statutory duty under s47 of the NHS and Community Care Act 1990 to carry out an assessment. Individuals should not be denied access to a community care assessment or the advice and support of a LA Care Manager on the grounds of their financial circumstances e.g. because they are privately funding their care home fees or home-based support package. They should not in any situation be denied access to an assessment for CHC by reference to their financial circumstances, which are irrelevant to health care services for the purposes of this guidance.
- 5 g) We recognise that professional judgement is important in any assessment process but would strongly advise that national guidelines on eligibility thresholds should normally be adhered to, unless there are clear reasons for not doing so. If eligibility guidelines are not followed in a particular case then the onus is on the assessors and decision-makers to record their justifications for this.
- 5 h) There is concern that paragraph 17 of the Decision Support Tool (as published in September 2007) is vague and too open to local interpretation, leaving it possible for PCTs to effectively set very different thresholds for NHS CHC across the country, thereby perpetuating the 'postcode lottery'. Paragraph 17 states:
'If there is:
- *one domain recorded as severe, together with needs in **a number** of other domains, or*
 - ***a number** of domains with high and/or moderate needs,*
- This can also indicate a primary health need.'*

There are clearly a number of combinations of high and moderate needs that could indicate a primary health need. For example, as one guideline we suggest that anyone found to have:

- a. two or more high needs (or need above high), AND at the same time
 - b. three or more moderate needs (or needs above moderate)
- should *normally* be considered to be beyond the scope of LA provision, and if not considered to have a PHN the reason for this should be clearly evidenced by the PCT.

The guideline should **not** be used prescriptively but rather, when someone has this combination of needs, LAs should look to the PCT for clear evidence why the person does not have a PHN before they (the LA) consider full or part funding any care or support needs. Every case must be assessed and decided on its facts. There may well be situations where the individual does not appear to meet the threshold indicated in the DST yet it is correctly concluded that their primary need is a health need and that they should therefore be eligible for NHS Continuing Healthcare funding. For example it may be that the individual has a range of relatively low level needs which add up to a requirement for intensive or continuous general nursing and/or healthcare of a volume which cannot be considered incidental and ancillary to their need for accommodation. Staff are reminded that the DST includes an additional 'domain' entitled 'other significant care needs to be taken into consideration' and this section may be used to explain that an application is being made on the basis of continuity/intensity of need.

In the light of the guideline above, unless the PCT considers they have a Primary Health Need, an individual could be assessed to have needs between what the LA can lawfully fund and what the NHS decides to fund. The outcome of any challenge to such an assessment may result in the NHS accepting they have a PHN and are therefore eligible for NHS CHC or there may be a joint funding agreement put in place. Where there is a joint funding arrangement put in place, LA funding should be limited to what it can lawfully fund. Joint funding on an arbitrary basis should not be used as a convenient alternative to making a lawful decision in complex cases. It should be stressed that a careful consideration of all the relevant factors is necessary in all cases before determining eligibility for NHS continuing healthcare.

- 5 i) ADASS and the LGA recognise the difficulties in extrapolating from the limited information publicly available on those cases that have been decided in the court or adjudicated by the Health Service Ombudsman. However, these cases give clear indication of where the correct line between LA and NHS responsibility lies in those particular circumstances.

For ease of reference we provide a summary of three relevant cases as an additional appendix to this Framework (see annex F below). ADASS and LGA advise that where an individual has genuinely similar needs to those outlined in these cases then the same eligibility decision (for NHS CHC) should be the outcome of the assessment. *This will be the case irrespective of the outcome of the DST assessment, although the expectation is that the correct application of the Framework and DST should confirm their eligibility.* The reason for the decision should be recorded on the final page of the DST.

- 5 j) ADASS and the LGA are in full agreement with the DH on the need to ensure that no-one is denied NHS Continuing Healthcare on the grounds of budgetary considerations and recommend that not just finance officers but also NHS CHC budget holders should not be part of decision-making panels for individual cases where they do not also have a professional clinical role in the assessment and decision-making process. Whereas eligibility decisions should be made without regard to budget considerations, decisions about how to meet those eligible needs do not preclude the involvement of those holding budgetary responsibility – for either health or social care bodies.
- 5 k) LAs must work in close partnership with PCTs to inform decisions about eligibility in accordance with the relevant Directions published on 30/8/07. These require PCTs (so far as is reasonably practicable) to consult with the relevant social services authority before making a decision about a person's eligibility for NHS Continuing Healthcare, and require the relevant social services authority (so far as is reasonably practicable) to provide advice and assistance to the Primary Care Trust, which has consulted it.

Section 6. 'Links to Other Policies'

(Paragraphs 64 to 71 of the Framework) '.

- 6 a) Individuals subject to Section 2 or Section 3 of the Mental Health Act 1983 (MHA) are the responsibility of the NHS by virtue of their compulsory detention for NHS care, whereas if under this Act someone is subject to Section 17 leave, then the provisions of Section 117 are triggered. Section 117 is a discrete duty under the MHA and there is no legal link between this and NHS Continuing Healthcare. ADASS and LGA would remind LAs of the guidance that they should have an agreement in place with their local PCT regarding the apportioning of funding for s117 services. The responsibility for the provision of s117 services lies jointly with LAs and the NHS, there is no specific guidance on how the costs should be shared and different LAs/PCTs have different arrangements in place, or none. Some LAs consider funding on a case-by-case basis, others use the local NHS

Continuing Healthcare criteria as an indicator and others look for an equitable 50:50 share of costs.

- 6 b) ADASS and the LGA would remind LAs that the Mental Capacity Act 2005 (MCA) comes into full effect from 1st October 2007 and this affects policy and practice in a number of ways which are relevant to Continuing NHS Healthcare. Under this Act there is a need to fully involve individuals in the process relating to decisions that affect them, whether or not they have the mental capacity to make the decision themselves. In addition, LAs and PCTs must have regard to the MCA code of practice including in relation to assessing capacity, making 'best interest' decisions, arranging for Independent Mental Capacity Advocates and understanding of the role of relatives with Lasting Power of Attorney status. It is beyond the scope of this document to provide detailed analysis on this subject and LAs are encouraged to take legal/professional advice as necessary.
- 6 c) ADASS and the LGA support the emphasis on timely reviews for younger people in advance of the transition to adult services, and encourage LAs to work closely with PCTs on this.

Section 7. 'Care Planning and Provision'

(Paragraphs 72 to 81 of the Framework).

- 7 a) ADASS and the LGA have concerns about the lack of clarity in the National Framework regarding LA provision to people who are eligible for NHS Continuing Healthcare but are living in their own home. (See para. 1 f) above).
- 7 b) We agree that the responsibility for 'case management' of individuals subject to Fully Funded NHS Continuing Healthcare rests with the NHS, and we underline that the LA is not responsible for undertaking care planning, for commissioning or funding the necessary care, nor is the LA responsible for ongoing monitoring or subsequent adjustments to care arrangements. However, Local Authority Adult Social Services Departments should not take a rigid line in having no involvement at all where someone is deemed eligible for NHS Continuing Healthcare or where the LA is not currently involved in funding. There may well be situations where there is benefit in jointly assessing or reviewing individual cases (e.g. where the individual's needs have changed and they may soon no longer be entitled to Fully Funded NHS Continuing Healthcare). In addition there are some support needs that it may be appropriate for the Local Authority to assist with. For example local authorities may decide to provide: assistance with accessing benefit advice; information regarding housing or charitable support; provision of information/signposting;

providing independent Mental Capacity Advocacy Service (IMCA); acting as Guardian under the Mental Health Act; provision of 'safeguarding' services under Adult Protection Procedures; support in managing people's finances where they lack capacity; Occupational Therapy involvement in Disabled Facilities Grant (DFG) applications; advice and information to carers. (See also para. 1 e), f) and g).)

This advice does not preclude formal joint working arrangements that have been put in place between LAs and PCTs.

- 7 c) ADASS and the LGA are disappointed that the Government has decided not to extend Direct Payments and/or Individual Budgets to NHS Continuing Healthcare. We are concerned about the detrimental consequences for people who lose the control afforded by Direct Payments because their healthcare cannot be lawfully funded by the local authority. However we would recommend that LAs work with PCTs to share knowledge and expertise and to encourage them to be responsive to individuals who want greater independence and control over their support packages, if possible by replicating personalised support packages where a successful Direct Payment arrangement was previously in place. LAs should seek their own legal advice before entering into arrangements that might be construed as unlawful use of Direct Payments legislation to support someone with NHS CHC needs.
- 7 d) We support the clarification of ongoing PCT responsibility for relevant non-registered healthcare services where someone is not deemed eligible for NHS Continuing Healthcare. As previously noted, the ADASS and LGA position is that that RNCC/ NHS-funded Nursing Care payment only represents a contribution to the cost of registered nursing care and may not cover the costs of health related support provided by nurses / care assistants which is not of a nature social services can be expected to provide. Similarly, the fact that someone in their own home (or in a care home) has health or nursing needs that do not have to be addressed by a qualified nurse does not necessarily mean that the tasks involved should fall to the LA or the individual to undertake or fund. If a registered nurse has lawfully delegated a task to a willing and able carer or care worker, then this does not absolve the NHS of responsibility for monitoring the health needs and support of the person or funding this task should that become necessary in the future.

Section 8. 'Review'

(Paragraphs 82 to 88 of the Framework).

- 8 a) ADASS and the LGA fully support the guidance that neither the NHS nor LAs should unilaterally withdraw from an existing funding arrangement without a joint reassessment of the individual and without first consulting one another and the individual about the proposed change of arrangement. As noted above, where someone has fully funded NHS Continuing Healthcare there may well be situations where there is benefit in LAs jointly reviewing individual cases, particularly where the individual's needs have changed and they may soon no longer be entitled to full NHS funding. We recommend that this guidance be brought to the attention of all contracts and commissioning officers so that this point is not lost in day-to-day continuing administration of existing packages and so it can be shown to opposite numbers in PCTs.

Section 9. 'Dispute Resolution'

(Paragraphs 89 to 98 of the Framework).

- 9 a) ADASS and the LGA welcome the requirement to have a dispute resolution process between LAs & PCTs in relation to NHS Continuing Healthcare decisions. We strongly encourage each LA to have a named lead officer for NHS CHC, for them to establish an SHA wide network of LA leads and for them to work collaboratively amongst themselves and with the PCT/SHA to establish a disputes resolution process to deal with unresolved LA/PCT differences regarding RNCC/ NHS-funded Nursing Care payment and NHS CHC decisions. An effective dispute resolution process will be timely and person-centred. There should be clear timescales for disputes to be discussed at different stages and clear arrangements for interim funding, without prejudice, pending the outcome of the dispute.

Section 10. 'Governance'

(Paragraphs 99 to 102 of the Framework).

- 10 a) Given the continued potential for widely differing practice across PCTs in relation to this area of policy, we welcome the requirement for regular standard reporting on the numbers receiving NHS Continuing Healthcare. We will continue to work with the DH to monitor progress and would welcome feedback from individual LAs on the effectiveness of the new arrangements.

END

Additional Annex F

Summary of Key Court/Ombudsman Cases

The three following case summaries have been adapted from guidance issued within a number of LAs. ADASS and LGA consider that the additional detail provided should be helpful to LAs in understanding the needs and implications of the cases concerned.

F1. Pamela Coughlan – Pen Picture of Clinical, Nursing and Care needs

- F1.1 Pamela Coughlan was injured in a road traffic accident in 1971 and as result became tetraplegic (spinal injury) and wheelchair dependent. She retained some (very limited) use of her hands with which she could manoeuvre her electric wheelchair and write (with a pen strapped to her hand). She remained completely mentally aware, could access the Internet, converse freely and represent her views articulately. She had no cognitive impairment or behaviour that could be described as challenging.
- F1.2 Pamela Coughlan was paralysed in the lower part of her body, with no movement in her legs, and limited movement in her upper torso. She required hoisting for all transfers however once transferred into a wheelchair she has a reasonable amount of independence. She required repositioning approximately 8 times per day to maintain skin integrity. She did not require a regular programme of active or passive physiotherapy or exercise, although being assisted to stand twice per week assisted with maintaining appropriate organ positions and strengthening her bones.
- F1.3 She wore a corset during the daytime to keep her chest upright without which she would have had breathing difficulties. There were no night care issues regarding her breathing.
- F1.4 She was doubly incontinent; needing intermittent catheterisation, every 3 hours as this proved the most effective way of keeping dry. She required manual evacuation of her bowels every second night.
- F1.5 Because of her injury she was unable to maintain her core body temperature, which was unstable and variable, and consequentially, because of excessive perspiration, she required changes of clothes and the corset up to three times a day. Pamela was able to tell when she was too hot or too cold and therefore proactive monitoring was not required regarding this aspect of her care.
- F1.6 Pamela Coughlan was dependent on others for all aspects of her personal care and daily living activities. She could eat independently using a spoon

strapped to her hand provided that the food is cut up for her. Someone needed to hold a cup whilst she was drinking as her hand would spasm if she touched a hot cup.

- F1.7 Clinically and from a nursing perspective she was stable with predictable needs some of which presented with medium risks e.g. regarding fainting if air flow was inhibited (managed by corset), spasm provoked by heat (e.g. hot cup), autonomic dysreflexia (very high blood pressure) as a result of pain or injury below the spinal injury site (T5/T6).
- F1.8 All of her medication was routinely prescribed and administered by mouth; Senokot, Docusate, Calcium, Iron. Once her condition stabilised she did not require an allocated consultant nor require any interventions from 'specialist' healthcare professionals.

The court found that Pamela Coughlan's needs "were primarily health needs for which the Health Authority is, as a matter of law, responsible".

- F1.9 Pamela Coughlan's healthcare needs and her need for registered nurse care were neither complex nor unpredictable. However the court took the view that a) the quality and quantity (nature and intensity) of her health needs and interventions were such that she had predominantly healthcare needs and b) her need for registered or unregistered nurse care was more than incidental or ancillary to her accommodation needs and was not of a nature that a Local Authority could reasonably provide (i.e. they were not social care needs).

F2 Mrs N - Wigan and Bolton Ombudsman Case

- F2.1 Mrs N, had a history of strokes, as a result of which she had no speech or comprehension. She was unable to swallow and required feeding by a PEG tube. She was cared for in a nursing home. She had poor sitting balance and was nursed mainly in bed. She was unable to weight bear. Mrs N was incontinent and had a catheter in place. She required assistance with her bowels every 3 to 4 days. Her skin required monitoring and she needed assistance with all care. She tolerated the feeding regime well and the PEG presented no problems. She was generally very pleasant and often smiling. She did not appear to have any insight or recognise people around her.
- F2.2 The Health Services Commissioner found that:

"It is clear from the information I have seen about Mrs N's condition that she was extremely dependent and required a high level of physical care; like Miss Coughlan she was almost completely immobile; and she was

doubly incontinent. I have seen no evidence that she had breathing difficulties as Miss Coughlan had; but she required PEG feeding which Miss Coughlan did not. She was unable to communicate verbally. I cannot see that any authority could reasonably conclude that her need for nursing care was merely incidental or ancillary to the provision of her accommodation or of a nature one could expect social services to provide. It seems clear to me that she, like Miss Coughlan, needed services of a wholly different kind. If the Health Authority had had a reasonable policy, and applied it appropriately, they would have provided NHS care for Mrs N”.

F3 Malcolm Pointon – Ombudsman Case

- F3.1 Mr Pointon was 63 at the time of the Ombudsman judgement. He had Alzheimer’s disease. He was doubly incontinent, was unable to feed himself, could not speak, could not understand instructions, had poor visual perception, needed constant supervision as he was a risk to himself, needed frequent reassurance and needed assistance with all aspects of personal care
- F3.2 The Ombudsman found that DH guidance had not been properly followed as the assessment tools used were focussed on physical care and not psychological needs. Mrs Pointon was giving highly personalised care with a high level of skill. This nursing care was equal to, if not superior than, that which Mr Pointon would have received on a dementia ward. The report criticises the belief that nursing care can only be provided by qualified nurses.
- F3.3 The Ombudsman found that “the PCT assessed Mr Pointon against the wrong criteria, once again focusing on physical needs and also failing to recognise that the standard of care provided by Mrs Pointon was equal to that a nurse could provide. I uphold the complaint.”
- F3.4 The Ombudsman also recommended that the PCT consider whether any retrospective payments should be made to Mr Pointon.

END