King's Fund

NHS Continuing Care: Health Committee - New Inquiry

Evidence from the King's Fund

Summary of paper

The King's Fund has received feedback from the public and from practitioners who have serious concerns about NHS continuing care. There is confusion over who is eligible for free NHS continuing care and concern about the diversion of considerable resources to assessing and reviewing individual situations. Many people comment on the inequity between those receiving highly expensive services under continuing care criteria as against those people with high dependency needs who need primarily 'personal' as against 'health' care and receive much lower funded packages of care. This paper argues that whilst national criteria and guidance might support a more consistent application of eligibility criteria, current policy on continuing care does not fit well with other moves to provide better, person-centred integrated care for people with long term needs. A more radical review is needed of the funding of long term care and the wider policy framework to support people with continuing care needs.

Introduction

1. The King's Fund is an independent charitable organisation working to improve health and social care through research, policy analysis, development work, grant making and leadership development. The evidence submitted on NHS continuing care is drawn from our current policy and development work. This includes the King's Fund Care Services Inquiry into care markets for older people in London[1]; and research and policy analysis concerning the management of long term conditions[2], integrated care for people with complex needs[3] and partnership and whole systems working[4].

2. The following evidence, firstly, highlights feedback we have received from the public, older people and their families, voluntary organisations and PCT commissioners about their experience of the current system for reviewing and assessing people with continuing care needs. Secondly, we consider the scope for improving implementation of the current system through a national framework. Thirdly, in the light of other Government policies relating to people with continuing care needs we comment on some of the underlying difficulties of current policy on funding NHS continuing care. We refer here to the Social Care Review to be carried out by Sir Derek Wanless, commissioned by the King's Fund.

Impact of reviewing past funding decisions and current system

3. Evidence submitted to our Care Services Inquiry during 2004, including new research into commissioning care services for older people in London, indicates widespread dissatisfaction about implementation of policy on NHS continuing care. The four main areas of concern, which reflect findings in the recent review of continuing health care[5], are:

---

[1] Robinson J Care Services Inquiry Interim Report 2004 Kings Fund
[2] Dixon J et al Managing Chronic Disease What can we learn from the US experience? 2004 Kings Fund
[3] Banks P Policy Framework for Integrated Care for Older People Developed by the Carmen network 2004 Kings Fund
[4] Banks P Partnerships Under Pressure A commentary on progress in partnership working between NHS and local government 2002 Kings Fund
[5] Henwood M Continuing Health Care: Review, revision and restitution Summary of an independent research review Department of Health 2004

- **Public confusion and distress:** because it is not clear who is eligible for free NHS continuing care and people's raised expectations of free care may be dashed following a review of their original assessment. For example, some people expect everyone with Alzheimers Disease to be eligible for free NHS care, whilst the criteria only apply to those people with dementia who have particularly challenging behaviour. Even more confusing to the public is the notion that as the person's condition changes, and their behaviour is no longer challenging and unpredictable, they may no longer be eligible for NHS continuing care.

- **Inequity**: as the costs of providing NHS continuing care in a person's home may be far in excess of levels paid by the local authority for older people with high dependency needs but who do not have continuing health needs as defined under current criteria. We have heard from one London PCT, for example, of individual frail older people being cared for at home, with essentially a 'hospital at home' service, at costs in excess of £250,000 per annum (over £4,800 a week) under NHS continuing care. This compares with the average gross weekly expenditure per person of supporting older people in residential and nursing care and providing intensive homecare of £443 (Performance assessment framework results for social services 2003-04).

- **Resource pressures** on the local health economy where PCTs have to meet very high costs to support some people with particularly complex and challenging needs at home. Some describe their continuing care budget as 'spiralling out of control' where they are meeting people's preferences for care at home and find even one or two people with very expensive individual packages, as quoted above, can put considerable pressure on budgets. There are also substantial staff resources needed to implement the current system; this includes undertaking lengthy reviews, following up complaints, holding panels, carrying out assessments and clarifying accountabilities.

- **Stress and frustration for staff who are implementing the current system** which they describe as 'a bureaucratic nightmare' and 'the biggest mess we have had to live with'.[6]

The merits and challenges for a national framework for continuing care

4. People responsible for implementing policy on continuing care at a local level have called for a nationally consistent approach in their feedback to us. Some argue that nationally agreed eligibility criteria with support to implement these at a local level could go a long way to improve the current confusion and varied practice. A national framework would offer clear statements about who is eligible and clarity about how assessments are made. This would make the system more transparent to the public and ensure a more consistent approach across the country.

5. However, we foresee considerable challenges to making this work. Establishing clear criteria in itself will not be easy when there has long been dispute (and the production of frequent guidance) over what constitutes personal as against health care. The impact on practice of standardised assessment tools and guidance is also questionable when local interpretation, custom and practice can be as, if not more, influential. There are dangers that attempts to make this process consistent, fair and transparent will lead to an overly bureaucratic and 'tick box' assessment. This approach runs counter to evidence about best practice in assessments with people in stressful and difficult situations. The assessor needs to carefully build up a picture of the complex and often unique interplay of a person's needs which do not always fit neatly into predetermined categories. The diverse interpretations we have heard about translating local authority eligibility criteria under Fair Access to Care, indicate some of the problems inherent in interpretation of criteria in the area of severe and complex needs. It will therefore be important to carefully monitor the implementation of a national framework for NHS continuing care.

---

[6] Banks P Commissioning care services for older people: a study of achievements and challenges in London -to be published as a working paper for the final report of the Care Services Inquiry Kings Fund 2005

6. Even more problematic is the public perception of fairness. It is likely to continue to be difficult for many people to accept that the way in which one person experiences an illness or condition will make the difference as to whether they get free care or pay for care. For example, a person who has challenging unpredictable behaviour as a result of Alzheimers disease may qualify for free care, whilst someone in the latter stages of the disease and who is in a stable condition may not be eligible.

Coherence with other policies

7. Current policy to support people with long term conditions and older people with complex needs acknowledges integrated approaches are needed to weave together services to meet people's holistic needs. There are a range of examples which demonstrate moves away from previously compartmentalised and fragmented approaches. These include:

- new integrated health and social care teams
- single assessments which coordinate assessments from a range of health and social care professionals
- flexible 24-hour support attached to housing facilities
- pro-active ways of coordinating health and social care for older people and people with long term conditions through case management.

The Health Act 1999 has supported these developments by enabling budgets to be pooled and other flexibilities used by local authorities and PCTs to jointly commission and provide services. Reimbursement policy and special funding from government have provided incentives for a range of joint service developments in the community. This has recognised the interdependence of health and social care services, particularly where appropriate care services in the community can alleviate the use of acute health care.

8. However, uncertainty about funding and debates about who should pay for care continue to present challenges to the development of integrated care for people with complex and long term needs. Our Care Services Inquiry has heard claims and counter claims about the under-funding of care and support for older people. It appears the modest size of pooled budgets for older peoples services in most areas reflects financial constraints on both the NHS and local authorities and make it difficult to develop some of the integrated services needed. We have also heard different views about who should pay for social care and what the balance should be between the use of public monies and individuals' own income and assets. These controversies highlight the unresolved problems of a system of funding long term care which is built on the distinction between health care (which is free and financed through general taxation) and social care (which is means tested). Problems relating to the NHS funding of long term or continuing care are a reflection of these longstanding problems.

9. Issues around the funding of long term care remain unresolved since the Government rejected the main recommendation of the Royal Commission on Long Term Care (1999) that personal care should be paid for out of general taxation. In failing to accept the Commission's proposals, the government has persisted in a policy that is unfair and cannot be resolved through minor adjustments. Recognising major reform may be costly the King's Fund has commissioned Sir Derek Wanless to undertake a review into the funding of social care, focusing in the first instance on older people. The terms of reference are:

- To examine the demographic, economic, social, health and other relevant trends over the next 20 years that are likely to affect the demand for and nature of social care for older people (aged 65 and over) in England
- In the light of this, to identify the financial and other resources required to ensure that older people who need social care are able to secure comprehensive, high quality care that reflects the preferences of individuals receiving care
- To consider how such social care might be funded bearing in mind the King's Fund commitment to social justice
- To report by the Spring of 2006

This review will also explore funding and related issues at the interface between health and social care.

10. The evidence from the Wanless review of funding social care (and any evaluation of implementation of a national framework on NHS continuing care) could form the basis for a more fundamental review of the funding of people needing long term care, including those meeting the current criteria for free NHS continuing care. We would suggest a review which addresses these underlying problems will, in the long term, provide a more satisfactory solution to the current difficulties with NHS continuing care.

Penny Banks
Fellow in Health and Social Care

King's Fund
11-13 Cavendish Square
London WIG OAN

020 7307 2682
p.banks@kingsfund.org.uk

18 February 2005