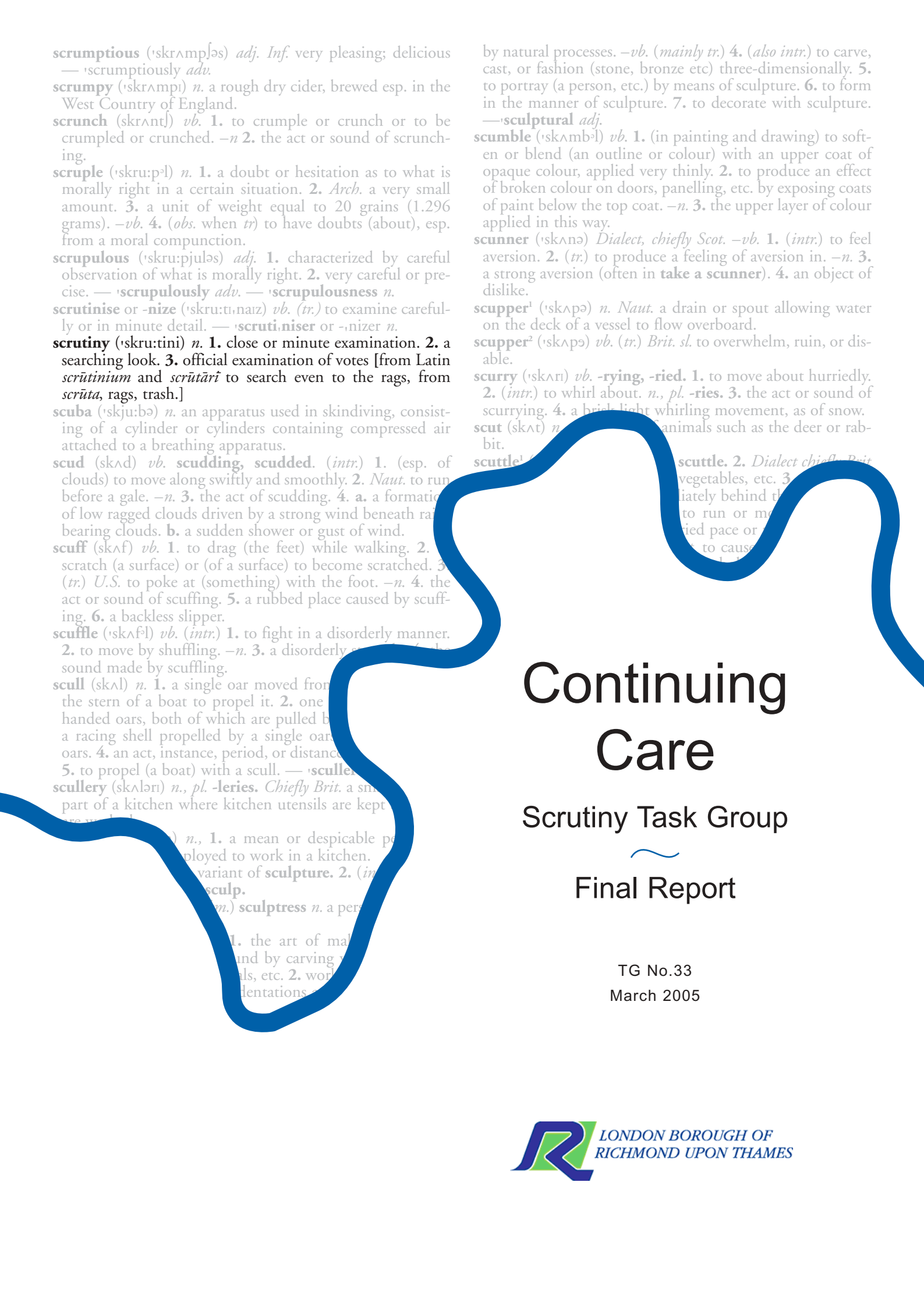

Continuing Care

Scrutiny Task Group

Final Report

TG No.33

March 2005

LONDON BOROUGH OF RICHMOND UPON THAMES

CONTENTS

FOREWORD

From the Chairmen of the Health and Social Care & Housing Overview & Scrutiny Committees

Cllr Nicki Urquhart

Chairman, Health O&S Committee

Cllr Sue Jones

Chairman, Social Care and Housing O&S Committee

It gives us great pleasure to introduce this report. Continuing Care is an issue that affects or will affect many of us – either as users, carers, friends or relatives of users – at some time. When this time comes, users and carers are invariably faced with the dual demands of dealing with difficult health and social care needs while negotiating their way through the system in order to receive the care to meet those needs. Their case often comes to an Assessment Panel when these needs are most acute and when there has recently been a change for the worse in the person's health.

There are pressures on everyone involved and it is a great challenge to make sure that there is a system in place which is based on the five principles of fairness, transparency, consistency, robustness and also compassion.

We very much appreciate the time and effort that has been put in to this piece of work by the Members of the Task Group together with the professionals, voluntary sector representatives and carers who have to deal with the issue on a daily basis. Your work will help ensure that those five watchwords do underpin the whole system of Continuing Care for our residents. Many thanks to all of you.

Councillor Nicki Urquhart
Councillor Sue Jones

Chairmen of the Health and Social Care & Housing O&S Committees

INTRODUCTION

There are many families and individuals in our Borough who will at some time be faced with the prospect of a loved one becoming seriously ill, or having a bad accident, or being born with, or developing in later life a disability which means that they need long term health care and social care. The life changing decisions that have to be made in these circumstances have both social and financial implications for those individuals and their families; for the Health Service, Social Services and, in the case of children, the Education Service; and for our partners in the voluntary sector who strive to offer help and support to the individuals themselves and to those people who care for them.

The aim of this Task Group was to look at the criteria against which decisions about Continuing Care services for people are made; the procedures that are followed; and in particular the impact on the individuals and their families. We wanted to understand how the system was working in Richmond upon Thames and how the individuals and their families who were going through it, often for many years, felt about it.

Thanks to the willing participation of my Task Group members, the many staff from both the statutory and voluntary services who have taken part, and the contributions of individual families who have and continue to be involved in Continuing Care, we have been able to produce a report which I hope illuminates both the good work that is being done and the need for further improvements.

Amongst the many statutory directions and government guidance in this area, we have kept in mind throughout the “Supporting People with Long Term Conditions – an NHS and Social Care Model to support local innovation and integration” objectives of improving care and improving lives. This includes ensuring that individuals and their carers are fully involved in the decision-making processes which affect their lives, and the provision of services which are based on properly assessed needs and offer real choice. Our recommendations are made in this spirit.

I would like to thank everyone who helped with our work and I commend our recommendations to you. If you have any comments on this report, I would love to hear from you.

Councillor Denise Carr

Chairman of the Continuing Care Scrutiny Task Group

EXECUTIVE SUMMARY

1. The Task Group looked in detail at the draft All Adults Continuing Care Agreement for the South West London Strategic Health Authority (SHA) area covering criteria and procedures for meeting Continuing Care needs and made a number of recommendations to the SHA which have been incorporated in to the revised version of the document due to be signed off on 1 March 2005.

2. In addition, there are four main areas in which the Task Group has made further recommendations relating to the implementation of the Continuing Care assessment process in the London Borough of Richmond upon Thames. These are:
   - Continuing Care Assessment Panel processes
   - User/carer involvement and support
   - Provision of information
   - Training for all staff and voluntary sector groups involved.

3. The focus of all the recommendations is on ensuring that the users and carers have the best possible support at a difficult and stressful time. It is in this spirit that the recommendations have been made.

4. The Group believes that the Continuing Care Assessment Panels must have a clear user/carer focus with attendance at all panels if desired, properly resourced administrative support and good accompanying documentation/information material.

5. In order to achieve a good, consistent service there needs to be training for all staff and voluntary sector groups involved in the process. It is important that users/carers receive the correct information – crucially not to have information that is later contradicted at the Assessment Panel.

6. The Continuing Care team at the PCT will greatly improve the services offered but there still needs to be clear commitment to ensure that users/carers only have a single point of contact as they cannot be expected to be their own Care Managers.

7. In the interests of empowering the users/carers as much as possible there needs to be a written integrated care plan in all cases. There is also the need to ensure that all carers separate assessments of their needs.

8. There has been great value added to the work of this Task Group through the close involvement of representatives of the Voluntary Sector. The Group would encourage the strengthening of ties and links between the voluntary sector and Overview and Scrutiny. The appointment of a Community Co-ordinating Officer would assist this.

9. The Task Group recommends that the Overview and Scrutiny Committees return to this topic in 6-9 months time in order to review progress on the implementation of the agreed recommendations.

10. The recommendations of the Task Group will be fed in to the Strategic Health Authority Board meeting in April to approve the Continuing Care criteria and procedures; the House of Commons Health Committee inquiry on NHS Continuing Care; and the Department of Health's work on a National Framework for Continuing Care.

PART I – ROLE AND FUNCTION OF THE TASK GROUP

ESTABLISHING THE TASK GROUP

11. At the meetings of the Health O&S Committee (on 8 September 2004) and the Social Care and Housing Overview and Scrutiny (O&S) Committee (on 9 September 2004) Members requested officer support for a Scrutiny Task Group on Continuing Care. This was agreed by the O&S Co-ordinating Group on 13 September 2004.

12. Members were aware that there had not been any political input thus far into the whole Continuing Care criteria and process. It is a topic which had been in the national media in recent months. Most of this was regarding cases where users had funded care which would, under the criteria now in operation after court judgements etc., have been funded by the NHS. At the initial meeting on 22 November 2004, the Group established the following terms of reference:

    The aim of this Review is to feed in to and comment on the work currently being co-ordinated by the Strategic Health Authority (SHA) with the other 5 local authorities and the Primary Care Trusts (PCTs) in the SHA area[1] on the criteria for fully-funded NHS Continuing Care, paying attention to this from the perspective of the client and his/her carers and family.

13. Members also said they would like to undertake a review of the functioning of the Continuing Care Assessment Panels for the different client groups in the Borough.

14. It was agreed that the Group needed to work to tight timescales if it was to produce a report and have an input into the All Adults Continuing Care criteria which the SHA wanted to have agreed in March. Within this timescale the Group wished to take as holistic an approach as possible. The Continuing Care process depends on joint working between several agencies – mainly the Council's Social Services and the PCT – and the Group wanted to reassure themselves that the whole system – from the criteria to the work of the Assessment Panels, and the service provided to users and their carers by the Council's Social Services and the NHS – was led by the guiding principles of fairness, transparency, consistency and compassion.

[1] The South West London Strategic Health Authority covers the 6 London Boroughs of Croydon, Kingston, Merton, Richmond upon Thames, Sutton and Wandsworth, and the 5 PCTs of Croydon, Richmond and Twickenham, Kingston, Wandsworth, Sutton and Merton.

TASK GROUP MEMBERSHIP

Cllr Denise Carr – TG Chairman

Cllr Virginia Morris

Margaret Dangoor (Co-opted Member)

Rhoda Frazer (Richmond Age Concern)

Kathy Sheldon (Co-opted Member)

15. We would like to thank the staff and individuals who met with us and attended our meetings. Please see the list on page 35 of the many individuals who gave up their precious time to assist us. Special thanks go to Simon Stockton, the consultant for the local authorities on the revised Continuing Care criteria for his help and useful suggestions and to Jonathan Hill-Brown, the Scrutiny Support Officer, for his hard work in assisting the Group. The Task Group greatly appreciated the support from senior management in LBRuT Social Services, the Richmond and Twickenham PCT and the SWLSHA and for the way in which they engaged with our work. We are also grateful to colleagues in the Royal Borough of Kingston who came to share their knowledge and experience with us. Finally, thank you to the representatives from the voluntary sector and, above all, the users and carers, for whom this work is about.

PART II – BACKGROUND

ADULTS CRITERIA (AGE 18 AND OVER)

16. The Health & Social Care Act 2001 provided the framework for requiring Strategic Health Authorities to, over time, align the fully-funded NHS Continuing Care criteria and practices across the PCTs and boroughs within their areas and produce a single set of criteria for each SHA. Following consultation during 2002, the South West London Strategic Health Authority (SWLSHA) produced this in March 2003, and followed it up with operational guidance[2] in August 2003, covering Older People, Younger Adults with Physical Disabilities, Older People with Mental Health Problems and Patients requiring Palliative Care. These documents were signed at officer level by all the parties (though they had been reported to both the Richmond and Twickenham Primary Care Trust (RTPCT) Board (7.10.03) and London Borough of Richmond upon Thames' (LBRuT) Social Care and Housing O&S Committee (10.9.03) for information). LBRuT Social Services led the negotiations on behalf of the 6 constituent boroughs (Croydon, Kingston, Merton, Richmond upon Thames, Sutton and Wandsworth), but not all the boroughs were happy to sign up. Accordingly, the criteria and guidance were used for over a year on this basis, with some staff training, monitoring and review being carried out.

17. Specific directions to draw up criteria for fully-funded NHS Continuing Care (level 1) for all adults were issued by the Department of Health in February 2004[3]. The previous work on the 2003 criteria was built upon, reviews of the Continuing Care criteria and procedures for the other client groups (Cognitive Impairment, Learning Disability, Mental Health) were progressed, and a review of level 2 (jointly funded by Health and Social Services) cases was commenced. The revised Operational Guidance covering All Adults in respect of level 1 criteria and, for level 2, Older People, Younger Adults with Physical Disabilities, Older People with Mental Health Problems and Adults requiring Palliative Care, were then produced in December 2004. Further guidance is being worked on for level 2 for adults with Cognitive Impairment, Learning Disability and Mental Illness. Local policies apply for these clients in the interim. Similarly, for level 3 (funded by Social Services), the guidance only covers the same client groups as for level 2, with further work being done on the other groups.

18. The new guidance and criteria for All Adults is due to be signed off in March. A review is scheduled for July 2006.

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[2] This joint policy was an agreement between the South West London SHA, the 5 PCTs and the 6 London Boroughs. Please follow this link to view: http://cabnet.richmond.gov.uk/Published/C00000169/M00000983/AI00005148/$SSH10Sep03ContinuingCareAppendix.doc.pdf

[3] National Health Service Act 1977, The Continuing Care (National Health Service Responsibilities) Directions 2004. (They came into force 27 February 2004.). http://www.dh.gov.uk/assetRoot/04/07/46/90/04074690.PDF

CONTINUING CARE REFERENCE GROUP

19. This Group was set up in Spring 2004 to oversee the review of the criteria. It is chaired by the Strategic Health Authority and includes representation from the 6 local authorities and 5 PCTs. The policies of 15 other SHAs were reviewed and descriptors for fully-funded NHS Continuing Care criteria were developed and tested. These led to the criteria set out in the December 2004 document referred to above (see para 17).

RETROSPECTIVE REVIEWS AND RESTITUTION

20. Eligibility criteria for Continuing Care were first introduced in 1995, but were subject to numerous challenges, in particular in the 1999 Coughlan[4] case. Following thousands of complaints, the Health Ombudsman, issued a report in February 2003 which required PCTs to review previous cases going back to 1996 which had not been granted NHS funding. These were reviewed under revised, Coughlan-compliant criteria and all were required to be fully investigated by the PCT, heard at local panel and then at an appeal stage locally before being referred to the Ombudsman for final determination if required.

21. As at 9 November 2004, 29 reviews had been carried out by the local PCT panel of which 3 had been awarded restitution and 23 had been forwarded on to the SWLSHA panel. Of these, the PCT decision had been upheld in 17 cases and 4 had been referred to the Ombudsman. Some cases had taken up to nine months to determine, but only a few still remained outstanding. The PCT had been granted ring-fenced funds of £127,214 to cover restitution costs.

OMBUDSMAN'S FOLLOW-UP REPORT – THE MOVE TO NATIONAL CRITERIA

22. In December 2004, Ann Abraham, the Health Service Ombudsman for England, published her "NHS Funding for Long Term Care – Follow up report"[5]. Based on the evidence gathered from almost 4,000 complaints since the publication of the first report in February 2003[6], it recommended the creation of national minimum eligibility criteria and highlighted the need for a national set of assessment tools and the right skills and capacity at local level to help patients to get the funding to which they were entitled and to make the system transparent, consistent and fair. The Government has fully accepted the report's recommendations and the Department of Health has commissioned a National Framework to implement

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[4] In July 1999, the Court of Appeal gave a crucial judgment (R v. North and East Devon Health Authority ex parte Coughlan) relating to funding for continuing care. This considered the issue of whether nursing care for a chronically ill patient might lawfully be provided by a local authority as a social service (in which case the patient paid according to their means) or whether it was required by law to be provided free of charge as part of the NHS. The judgment said that whether it was unlawful to transfer responsibility for the patient's general nursing care to the local authority depended, generally, on whether the nursing services were:

(i) merely incidental or ancillary to the provision of the accommodation which a local authority is under a duty to provide and
(ii) of a nature which it could be expected that an authority whose primary responsibility is to provide social services could be expected to provide.

[5] http://www.ombudsman.org.uk/hsc/document/care04/care04.pdf
[6] http://www.ombudsman.org.uk/hsc/document/care03/care03.pdf

them. (Please see Appendix B on page 35 for a fuller list of key dates regarding progress towards the establishment of Continuing Care criteria.)

CHILDREN

23. Though not a statutory requirement, the SWLSHA, PCTs and boroughs have also been looking at the procedures for Continuing Care for children and have drawn up a set of Level 1 criteria for children with physical health needs resulting from an accident, illness or disability. The criteria will be implemented in shadow form in parallel with implementation of the All Adults criteria from April 2005. It is also intended to extend the criteria to include children with learning disability and mental health needs.

24. However, the SWLSHA and PCTs have yet to agree funding responsibility for level 1 and legal advice is being sought on the respective responsibilities of Health, Social Services and Education. For now, although the criteria help to clarify thinking on what the NHS funded level 1 for children should be, Health, Social Services and Education still have to agree between themselves how the costs of a care package will be split between them. A Tripartite Panel for Children is being piloted in this Borough, with representation from the three service areas.

WHAT IS CONTINUING CARE?

25. "Continuing Care" means care provided over an extended period of time following an assessment of need to a person aged 18 or over to meet physical or mental health needs which have arisen as a result of disability, accident or illness.

26. "NHS Continuing Care" (level 1) is fully funded by the NHS and may be provided in an NHS Continuing Care facility, or by placement in a nursing home or by a package of care purchased and provided in the client's own home. All care in this case is funded by the NHS.

27. Level 2 Continuing Care comprises services from both the NHS and Social Services which may be specifically purchased or, more commonly with regard to the NHS, provided through existing core primary and community care services.

28. Level 3 Continuing Care comprises care purchased or provided only by Social Services (though the client still makes use of the core NHS primary and community services available to everyone).

29. NHS funded care is free at the point of delivery, but local authorities have powers to charge users on a means-tested basis for Continuing Care funded by Social Services. Residential Care is covered by national rules (Charging for Residential Accommodation Guide – CRAG produced by the Department of Health); other charges, e.g. for home care, are discretionary. In Richmond upon Thames the Social Services and Housing Finance team carry out the financial assessments of people going into residential care and would give advice on any benefit entitlements. In addition the "Richmond Community Partnership", a partnership between the Pension Service (part of the Department of Work and Pensions), Age Concern Richmond upon Thames and LBRuT Social Services provides a benefits advice service to everyone over the age of 60.

30. It must also be pointed out that Continuing Care is about a spectrum of care and the totality of a user's needs. In other words, the focus is on the provision of appropriate care in a suitable setting and moving away from the traditional view that NHS care simply covers hospital or nursing care. It should be noted that anyone assessed as needing level 3 Continuing Care would still receive the usual NHS services, GP etc.

31. Provision of Continuing Care should be made following a multidisciplinary assessment and determination of health and other care needs and is undertaken in line with the Single Assessment Process (SAP) for Older People. Patients with complex needs often require services from a range of providers and these should be developed jointly between the NHS responsible commissioner and the responsible local authority, so that the individual receives a co-ordinated package of care designed to meet their needs. Such care can be provided in a range of settings – care homes, patients' homes, hospitals or hospices. Assessments and provision of care should be made in full consultation with the person, their carers and relatives and should take into account user/carer choice about the service they wish to receive.[7]

32. There is a duty on the PCT and the local authority to carry out an assessment of need in accordance with the criteria set by the SHA for fully-funded NHS Continuing Care. Everyone is entitled to an assessment. The PCT is required to advise the person assessed of the outcome of the assessment and, if the person is not satisfied, he/she can request a review of the decision not to provide NHS funded continuing care, which should take place within 14 days. This is the first of a four-stage appeals escalation process:

Step 1	**PCT Review Panel**. This should take place within 14 days. Anyone who is dissatisfied about the procedure followed by the PCT, or the application of the criteria, and whose case cannot be resolved informally, may apply for review under the next stage.
Step 2	**SHA Independent Review Panel**. If the complainant is unhappy with the response to the complaint, they should be advised that they can request an independent review from the Healthcare Commission.
Step 3	**Independent Review from Healthcare Commissioner**. If they remain dissatisfied following a review, or if a review is refused, they can then approach the Health Service Ombudsman.
Step 4	Review by **Health Service Ombudsman**

[7] The Commission for Social Care Inspection is the Government agency responsible for the registration and inspection of care homes. Lists of registered homes (along with inspection reports) can be obtained from their website: http://www.csci.org.uk/ or directly from their regional office for this area:
41-47 Hartfield Road, Wimbledon, SW19 3RG, Tel: 020 8254 4950

IMPORTANCE OF THE ISSUE

33. The issue of criteria for Continuing Care is important in the first instance for the users and carers, both in terms of the care received and, depending on the level of care awarded, the financial contribution from their own pocket to fund it. As one member of the Task Group put it, the outcome of a 30 minute hearing at the Assessment Panel could determine whether or not the family home has to be sold or not.

34. It is important for the Council to get it right for its residents and that they receive the best possible care. The assessment system for those in need of Continuing Care must be fair, transparent, consistent, robust and compassionate. The Council also has the wider responsibility towards all its taxpayers to ensure that the system is fair and does not expose the Council to costs which should properly be payable by the NHS. Above all, it must be compliant with the various legal judgements such as the Coughlan case, as well as with the recommendations of the Health Ombudsman and the requirements of the Department of Health.

35. The decision-making processes for Continuing Care have often been unclear for users, carers and staff in terms of the availability of and eligibility for Continuing Care, and how the system works. This puts many users and their carers at a serious disadvantage.

36. The absence of national criteria, as well as large numbers of appeals, have highlighted confusion about funding responsibilities between different PCTs, Social Services of different authorities and LEAs, and have added to the difficulties at a local level. Staff told the Task Group that the Responsible Commissioner[8] guidance has now made their work easier but that there are still problems in agreeing responsibility for clients previously assessed and placed.

37. In addition, the whole issue of Social Services, and its importance for Overview and Scrutiny Members, was highlighted in the results of the residents' budget focus groups. These consultation exercises were facilitated by professional pollsters on behalf of the Council in connection with the budget setting. Over the last 3 years, social care provision for the elderly has consistently been cited as one of the top priority areas for investment by the Council. It was ranked second in order of importance by participants at the focus meeting for the 2005/6 budget.[9] It is also of interest to note that there was broad agreement from participants of all age groups that those who could afford to should pay towards the cost of social care.

[8] "Establishing the Responsible Commissioner" – Guidance for PCTs on commissioning responsibilities was issued in October 2003 by the Department of Health. This clarifies that the PCT responsible for the GP with whom a patient is registered will be responsible for the NHS care costs.
http://www.richmond.gov.uk/councillors/Documents/Task%20Groups/Continuing_Care/Responsible_Commisioner_guidelines_published_2003.pdf

[9] http://cabnet.richmond.gov.uk/Published/C00000170/M00001234/AI00007438/$MLTFS20058budcons.doc.pdf

PART III – INFORMATION GATHERED

ALL ADULTS CONTINUING CARE CRITERIA AND OPERATIONAL GUIDANCE (DEC 2004)

38. The Task Group recognised and was impressed by the hard work that had gone into the production of the updated guidance. The document introduced a welcome degree of clarity and definition based on the work of the Continuing Care Reference Group (see para 19 above) which had looked at best practice in other SHAs and involved wide consultation within the SWLSHA. The emphasis on consultation with and involvement of users and carers; on training for all staff involved either in assessments or the panel decisions; on good documentation and record keeping; and on the importance of monitoring were welcomed. The suggested proformas in the attached appendices were considered helpful and the pen picture examples were clear and comprehensive.

39. The Group also found the original glossy leaflet produced specifically for the public by the SHA in March 2004 to be clear and helpful, though now it was out of date and required reissuing.

40. The Task Group felt that the Joint Commissioning Boards had an important role to play in developing criteria and guidance of this kind and in monitoring its implementation. It was reported that the JCBs were currently being consulted on this issue.

41. The Task Group considered that it was not practicable given the time pressures to question the detailed clinical definitions in the criteria which were primarily for use by professionals. Rather, the Group saw its role as being to examine the clarity and user-friendliness of the document for clients, carers, families, staff and advocacy groups. The Group went through the document in some detail and made a series of recommendations, most of which have been accepted by the SHA. The full list of suggested changes, along with the SHA response can be found at Appendix C on page 38.

ADULTS CONTINUING CARE ASSESSMENT PANELS IN LONDON BOROUGH OF RICHMOND UPON THAMES

42. In Richmond upon Thames there are three Continuing Care Assessment Panels for adults.

    1) Adults (all people over 65 and 18-65 year olds with a physical disability)

    2) Adults with a Learning Disability (aged 18-65)

    3) Adults with Mental Health problems (aged 18-65)

    (Please see the list on page 15 for details on all of these Panels.)

43. The Task Group was impressed by the co-operative working between Health and Social Services and the low level of disagreements and appeals. However, there seemed to be a lack of leaflets and documentation for users/carers and therefore a great reliance on the Care Manager to inform and support them through the procedures.

SUMMARY OF ADULT CONTINUING CARE ASSESSMENT PANELS IN LBRUT

ASSESSMENT PANEL:	Adults (aged 18-65 with physical disabilities + all over 65 excluding PLD)	Mental Health (aged 18-65)	People with Learning Disabilities (aged 18+)
Terms of Reference	Not yet drawn up (though its work is based on best practice guidance)	Not yet drawn up (though its work is based on best practice guidance)	Not yet drawn up (though its work is based on best practice guidance)
Regularity of meetings	Fortnightly on Wednesday afternoons	Monthly	Monthly
Meeting venue	Barnes Hospital	Richmond Royal – Normansfield Room	Teddington Clinic
Panel Chair(s)	Jointly chaired by Jane Clark (LBRuT Social Services) and Jane Nicoli-Jones (RTPCT)	Neil Doverty, Borough Director within South West London and St. George's Mental Health NHS Trust until 10.2.05. Adult Service Manager in the interim whilst new Trust management structure is put in place.	Nicky Rayner (Community and Commissioning Manager - PLD) and Beverley James (PCT Joint Commissioning Manager - PLD) both sit on the Funding Panel (also called the Placements Panel). They take it in turn to chair the meetings.
Panel Membership	Non-voting regular panel members: Consultant psychiatrist or senior MH nurse, 2 Consultants Physicians, Specialist nurse from Kingston Hospital (sometimes attends)	Panel membership: Aarti Joshi (Joint Commissioning Manager – Mental Health) + 4 Community Mental Health Team Managers – lead Social Worker, LBR finance manager, LBR housing representative, Psychiatric Consultant, MH Service Manager, Kingston Lane Manager	Non-voting members: Eva Ruka (Clinical Psychologist, Challenging Needs Service), Jonathan Rhodan (Social Services Finance), Karen Roxburgh (Manager of PLD Care Management Team), Panel administrator (currently no fixed appointment)
Further expert advice	Further experts as appropriate, although it is sometimes difficult to get doctors released for the afternoon.	Several other experienced Adult Support Workers/Care Managers and other specialist practitioners as required. (Multidisciplinary expertise)	There is the lack of general nursing advice to the Panel. At the moment informal advice is sought from Jane Nicoli-Jones, nurse and co-chair of the Adults Continuing Care Assessment Panel.
User/carer attendance	No, but can make written submission.	No.	No. There is not the same interest from LD carers to attend the meetings of the panel as they generally do not have any savings. Therefore there is not the same

ASSESSMENT PANEL:	Adults (aged 18-65 with physical disabilities + all over 65 excluding PLD)	Mental Health (aged 18-65)	People with Learning Disabilities (aged 18+)
			financial implications for them as there are for older people who face having to spend their savings and pensions to pay for care if they are not awarded fully-funded NHS Continuing Care. However, it was pointed out to the Task Group that some have trust funds.
Number of cases per session	10-12 Continuing Care cases (75% normally qualify as level 1)	Panel covers Continuing Care + domiciliary and bed & breakfast. 2-3 new cases to each panel + pre-advice of upcoming cases and regular case reviews.	Panel covers all LD cases including respite and domiciliary care. On average, only 2-3 cases per month are for level 1 fully-funded NHS Continuing Care.
Administration	Panel is administered by Linda Woodley at the PCT. Papers issued to the joint chairs, including all specialist reports, 1 day in advance. (Decisions are documented by the administrator.)	Panel is administered by Linda Woodley at the PCT.	Insufficient resources for regular administrative support.
Case presentation	Cases are presented by a care manager following a full multi-disciplinary health and social care assessment.	Cases are presented by a care manager, or Team Leader.	Cases are presented by a care manager.
Decisions	Takes decisions on Level 1. Level 2 cases referred to the Residential and Nursing Panel (also called the Funding Panel – also chaired by Jane Clark to ensure consistency).	This panel decides on both level of care and the care package itself, as Aarti Joshi, the Joint Commissioning Manager also sits on the panel.	This panel decides on both level of care and the care package itself, as budget holders from Health and Social Services are panel members.
Communicating the decision	3 copies of letters are sent to care managers (who are responsible for advising clients/carers). Information on appeals is also included with the letter.	It is at the discretion of care managers to communicate the decision to the user/carers in the most appropriate way.	The Panel also relies on advice from the care managers as to what form notification of the panel's decision should take. Some can be overwhelmed by a formal letter. Care managers keep care providers informed.

ASSESSMENT PANEL:	Adults (aged 18-65 with physical disabilities + all over 65 excluding PLD)	Mental Health (aged 18-65)	People with Learning Disabilities (aged 18+)
Care Plan	Separate from the panel decision, a care plan is drawn up in conjunction with the user/carer by the appropriate agency. If care is to be provided at home, a copy of the plan is sent to the PCT as well as to the family/carer. There is a Performance Indicator on issuing of Care Plans.	It is at the discretion of care managers to communicate the decision to the user/carers in the most appropriate way.	See box above
Case review	Initially after 3 months, thereafter annually (minimum requirement), unless there is a change of circumstance. A review can also be requested at any stage. (Users/carers are informed of this possibility.) It is Government guidance that every review is an assessment. Eligibility should be considered against the criteria every time a case is reviewed. Reviews currently come before the panel, though in future they will be the responsibility of the Continuing Care team based at the PCT.	Initially at 6 months, then annually as a minimum, unless indicated otherwise.	Reviews are normally carried out annually (unless the Panel sets a specific review date requiring earlier review). Not all reviews for Continuing Care come to the panel, though sometimes it is made a condition of the original approval for funding.
Placements	Beds for Continuing Care are currently commissioned in NHS Community Hospitals. No contract monitoring resource at the PCT at present. Over the long-term the PCT would like to move away from these beds to allow more flexibility about where care is provided. PCT is happy for Social Services to arrange the service and bill the PCT accordingly.	The aim is to place clients within existing Borough facilities, thus reducing out of Borough placements.	There a number of block-funded residential schemes within the Borough - spot placements are also made both within and outside the Borough when block-funded schemes are either full or unable to meet the needs of a client.
Training	Training is being undertaken for all staff involved in Continuing Care, including and West Mid and Kingston Hospitals.	Staff involved will be included in the training programme for RTPCT/LBRuT	Staff involved will be included in the training programme for RTPCT/LBRuT.

CONTINUING CARE ASSESSMENT PANEL SET-UP IN ROYAL BOROUGH OF KINGSTON

44. The Task Group was given a presentation by Simon Cole, the Principal Placements Manager at the Royal Borough of Kingston (RBK). They have 4 main panels and a Special Contractual Panel to deal with any contentious funding issues with the PCT:

    - Older People's Services Panel
    - Accommodation Panel (comprises representatives from RBK Community Care Services, SWL and St. George's Mental Health NHS Trust and RBK Housing Services.
    - Panel for people with drug and alcohol problems
    - Children's Panel
    - Special Contractual Panel

45. The Group was very impressed by the range and quality of the documentation and information about the Continuing Care Panels and procedures available to the public.

46. It was also noted that users/carers were encouraged and enabled to attend and take part in the panel meetings. Staff felt that their attendance had many positives benefits. It gave the panel decision-makers a better understanding of the care needs and views of the users and carers. Users and carers could see that a fair and balanced decision had been reached.

DATA ON MONITORING AND APPEALS FROM THE PCT

47. Please see the table below for numbers of level 1 and 2 cases for Continuing Care April 2002 – Sept 2004. These cases cover the client groups under the SWLSHA Continuing Care criteria and guidance from 2003[10]. The information in the table below comes from the Continuing Care audit carried out by the Richmond and Twickenham PCT.

	Level 1	**Level 2**
April 2002 – March 2003	44	112
April 2003 – March 2004	54	47
April 2004 – Sept 2004*	50	16

* only covers first 6 months of accounting year.

48. Financial data was difficult to obtain as the current system of Continuing Care is a relatively new area. Until now, there has not been separate monitoring of Continuing Care cases as opposed to e.g. other placements, care packages etc. The most readily available figures are those for level 1 fully-funded NHS Continuing Care for Older People, Young People with Disability and the Elderly Mentally Ill. As can be seen at Appendix E, the Richmond and Twickenham PCT spent nearly £3m on these client groups in the financial year 2003/4. For other budgets, Adult Mental Health, level 2 cases etc., no figures were readily available. Just to give an idea of some of the sums involved for one of these groups, please see the figures below for PLD cases. This shows that around £9m. is currently being spent annually on PLD Continuing Care by the PCT (or what would be Continuing Care under the new criteria):

Section 28a[11] (spending via Social Services)	£6m
Further cases paid for by PCT	£2m
The amount of funding for Continuing Care received by Social Services from PCT for level 2 cases	£724,000

[10] Older People, Younger Adults with a physical disability, EMI, patients requiring palliative care.

[11] This refers to the section of the NHS Act which enables NHS bodies to transfer money to LA's for LA's to use to commission services on behalf of the NHS.

CHILDREN'S CONTINUING CARE

49. Members of the Task Group met with Simon Carlton (RTPCT Children's Continuing Care Co-ordinator) and with Mair Hutchings (Social Services Manager, Children & Families). The findings for the situation in Richmond upon Thames were that:

- there was a PCT leaflet for parents regarding Continuing Care, but it needed updating;
- joint assessments for children under 5 were being piloted, resulting in a Family Support Plan, for which tripartite funding was then agreed by the officers;
- separate assessments were carried out by Health, Social Services and Education for older children;
- draft SHA criteria were being used to assess level 1 cases, but funding of cases with complex health needs was then split three ways (PCT/Social Services/Education);
- a Tripartite Panel (chaired by Carol Keys-Shaw, RTPCT Associate Director for Children) had been going for 6 months. It met monthly and the membership includes a principal manager from Social Services (Children & Families), the Service Manager for Disabled Children, the head of Special Educational Needs, an Assistant Director of Education and the LEA Social Inclusion Officer. Other health staff or officers attended as required. Papers were normally tabled;
- Terms of Reference were being drawn up;
- cases were presented by the Children's Continuing Care Co-ordinator or other professionals as appropriate;
- parents did not attend but their views were represented by the Co-ordinator;
- Care Plans were agreed in principle, but there were different ones for the 3 services (though the move is towards a single Care Plan);
- funding was negotiated between the 3 potential funders;
- Continuing Care services/places were hard to find;
- cases were reviewed after 3 months, then annually;
- a Service Co-ordinator was the point of contact for the parents and advice;
- feedback from parents was invited, but no clear information about complaints procedures was provided;
- the Project for Children with Special Needs could offer support to parents.

50. The Task Group also held a meeting on 26.1.05 to look at the draft Children's Continuing Care Criteria. (Please also see para 23.) There were a number of points that the Group commented on and passed on to the SWLSHA. They can be found attached at App D.

51. The Children's Continuing Care criteria and guidance are at a very early stage, but the Task Group would like to make the following suggestions:

Suggestions regarding the Children Continuing Care process:

1. The documentation should make specific reference to parents and their role as carers.
2. There should be joint assessments and an integrated Care Plan.
3. Reviews should be held every 6 months as a minimum.
4. A range of services should be developed to meet assessed needs.
5. Better information and support should be provided for families.

In view of the establishment of the Project Board to look at the implementation of the Children Act 2004 and "Every Child Matters" in our Borough (including a Director of Children's Services leading to a Children's Trust by 2006), it is suggested that the three Overview and Scrutiny Committees of Education, Health and Social Care consider at what point they could best make timely input into this.

MEETINGS WITH CARERS

52. Cllr Carr conducted a telephone interview with Mrs M whose husband had suffered severe spinal injury following an accident and required level 1 fully-funded NHS Continuing Care. (Please see App F for a write-up.)

53. Cllrs Carr and Morris, together with Jonathan Hill-Brown, met with Mrs V, whose husband had recently been assessed for level 1 fully-funded NHS Continuing Care, following a crisis in his medical condition. (Please see App G for a write-up.)

PART IV – RECOMMENDATIONS

ALL ADULTS CRITERIA DOCUMENT

54. The Task Group was pleased that the SHA responded positively to many of the suggestions for changes in the All Adults criteria that were proposed by the Task Group. On a couple of the suggestions that were rejected the Group would like to expand on the reasoning behind them.

55. The Task Group's recommendation that all assessment reports should be typed rather than hand-written is, the Group accepts, a difficult one. Staff in hospitals or elsewhere do not always have access to a computer, nor the confidence in using one. With time often a critical factor, delays in obtaining documentation for assessment panel decisions should be avoided wherever possible. The Group made this recommendation more to highlight the need for users/carers to be involved – including their right to see any documentation relating to their case, which could be severely hindered by the very poor legibility of papers such as those in the anonymised cases shown to the Group. The point is therefore more about the approach and attitude of professionals at all stages of the process than about the specifics of the form of assessment documentation. It must be stressed that the Group was very impressed by the commitment of all the professionals regarding the issue of user/carer involvement.

56. Training as mentioned in the criteria and operational guidance: At the risk of appearing pedantic, the Group would still favour training which gave all staff an understanding not only of the specific elements of their part in the process but also the bigger picture. The evidence that the Group gathered from users, advocacy groups and officers was that the most important single factor leading to user/carer frustration was when indications of the outcome of the assessment panel were given by staff prior to the decision being made – and which turned out to be inaccurate.

Recommendation 1: *That in this Borough staff training ensures staff have a good understanding of the overall procedures as well as their specific role within the whole process.*

57. Member sign-off: The Task Group felt that there had been a lack of councillor involvement in the development of the Continuing Care criteria and guidance. (Though the LBRuT Social Care and Housing O&S Committee in LBRuT did see the 2003 SHA Continuing Care criteria and operational guidance.) Given the importance of these criteria, in both financial and care terms to the residents and the Council, the Group considers that the criteria document should be approved and signed off by either the Cabinet or the Cabinet Member for Social Services and Housing rather than the Director of Social Services and Housing.

Recommendation 2: *That the All Adults Continuing Care criteria and guidance be approved and signed off by either the Cabinet or the Cabinet Member for Social Services and Housing.*

ASSESSMENT PANELS

58. The Assessment Panels for Continuing Care in this Borough are relatively new (or at least the use of existing panels to assess clients against Continuing Care criteria). This has led to the specific constellation of the assessment panels in this Borough. The Group was very impressed by the more joined-up approach that is in operation at RB Kingston. While not favouring this model over the model which is gradually developing in LBRuT, there are some examples of best practice that could be adopted. These are: 1) Terms of Reference for each panel; 2) good administrative support/single manager for the panel process (this does not refer to the Chair(s) of the panels); 3) timely despatch of documentation prior to a panel meeting; 4) standardised assessment reports, decision papers and panel minutes; 5) fund-holders sitting on the assessment panel; 6) ensuring that all necessary professional/clinical advice is available to the panels as they need it. These elements are crucial if the aims of transparency and consistency are to be achieved. Good administration and record keeping are prerequisites of effective strategic planning and robust financial monitoring.

Recommendation 3: *That for all Continuing Care Assessment Panels for Adults in the Borough there be: 1) Terms of Reference for each panel; 2) good administrative support/single manager for the panel process; 3) timely despatch of documentation prior to a panel meeting; 4) standardised assessment reports, decision papers and panel minutes; 5) fund-holders sitting on the Panel; 6) attendance of all necessary professional/clinical advice as required.*

59. The Group has heard how frustrating the Continuing Care assessment process can be for users and carers. The Group is satisfied that concerns about the provision of good quality written information and advice at all stages of the process are being addressed and welcomes the proposals to build in quality assurance mechanisms. The Group would also agree that it makes sense to give the new Continuing Care team at the PCT responsibility for collating all the data on user/carer satisfaction centrally.

60. The Group did not reach a conclusion about the desirability of having a layperson on the assessment panels. It accepts that it could be difficult to attract suitable candidates but would like to see this possibility considered when the next review of the panels' work is carried out. Laypeople already sit on other Social Services panels and the Group heard that they could provide an alternative perspective to professional viewpoints.

Recommendation 4: *That the possibility of having laypeople on the assessment panels be considered when the next review of the Panels' work is undertaken.*

USER AND CARER INVOLVEMENT, PERSPECTIVE AND SUPPORT

61. It is good practice that users and carers should be involved in the process as much as possible. This is clearly stated in the SHA operational guidance/All Adults criteria and the Group was told that it would also be covered in the local training. While the Group understands the concerns of officers and others about

the very occasional cases when the views of users and their carers may conflict and it may therefore be preferable for the carer not to attend the meeting, the Group is of the opinion that these cases are the exception rather than the rule. There are policies and procedures which exist to protect users in these circumstances[12].

62. It also recognises that this is a very traumatic time for users and carers and that many might be unwilling to make use of the option to attend or take part in the panel meeting. Nevertheless, users and carers should always be encouraged to participate and given the choice whether or not to do so. The Group heard that the approach of maximising user/carer involvement works well in the Royal Borough of Kingston and has many positive spin-offs. Not least, the Group heard that it can be a useful reminder for Panel members that there are individuals behind every piece of casework. Even the most empathic and conscientious professionals can lose sight of this at times.

63. Kingston have protocols in place for dealing with difficult situations at panels which might arise due to user/carer attendance and panel chairs are given appropriate training on how to deal with such circumstances. This said, there have been no cases where the protocol has had to be invoked and the Group feels there is no reason why it should not be the case in Richmond upon Thames. One of the carers that the Group spoke to said that this would have been the change she would most like to have seen in the way her husband's case was handled. The Group believes that the sense of empowerment through this close involvement and the humanising of what can be a very confusing and frightening bureaucratic procedure are benefits which outweigh any potential risks.

64. The Group noted the helpful approach in the leaflet produced by the Royal Borough of Kingston regarding the Older People's Placement Panel. This states that:

"Your Care Manager will go to the Panel to give details about your situation and highlight your needs. You are encouraged to come along and are welcome to bring someone with you – a friend, relative, carer or advocate."

65. Please see Appendix H for a copy of the Assessment Panel feedback form for users/carers.

Recommendation 5: *That users/carers be given the opportunity and encouragement to attend and take part in the Panel and that formalised quality assurance procedures are put in place to obtain user feedback.*

66. The Group is aware that the development of the whole Continuing Care system both at the PCT/Mental Health Trust and within Social Services is still in its early stages. Deficits regarding readily available information are recognised by all professionals the Group spoke to. It would like to stress the importance and welcome the creation of the Continuing Care team at the PCT. (Please see also para 59.) The suggestion of a website with all relevant information would clearly make good sense, along with printed information for those without internet access. (See also para 77.) Beyond this, the Group believes it imperative that all

[12] LBRuT Social Services has policies and procedures which have been drawn up in accordance with the Department of Health's guidelines document entitled "No Secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse" (June 2004)

users/carers have a single point of contact, i.e. one officer, whether this person is from health or Social Services to help and advise them and to liase with the other professionals. One case was cited where carers had had to make 15 phone calls to identify the professional responsible for one aspect of their relative's care. It places an intolerable burden on carers who already have many other worries to be expected to become their own care manager, as was the case with all the carers the Group spoke to.

Recommendation 6: *That for each case, a key worker[13], whether from Social Services or Health, be appointed to be the main contact for the user/carer and to liase with the other professionals involved on their behalf and ensure good communication between all parties.*

67. It was suggested to the Group that it was not always appropriate to give users/carers written confirmation of the Panel decision, and that this might better be done by the Care Manager verbally. However, the Group feels that, in the interest of maximising the understanding of the users/carers of the process and informing them about the appeals procedure, written confirmation should always be provided. Please also see paragraph 77 regarding leaflets for the public on Continuing Care.

Recommendation 7: *That written confirmation always be given to the users/carers of the Panel decision together with details of the appeals procedures.*

68. The Group was pleased that it was planned to give training to voluntary sector organisations such as the Richmond Carers Centre and Richmond Age Concern and consider this essential. Training will be the responsibility of the PCT and the Group welcomes the formalising of this in the Trust's Learning and Development Plan. There is still a lack of a clear policy to link in and use such organisations as advocacy support for users. This will doubtless improve with the setting up of the Continuing Care team. The Group would encourage the proposals to organise work-shadowing and to produce a newsletter to keep relevant parties well informed. Users/carers should always be made aware of the possibility of making use of independent advocacy support, alongside the support they might receive from their Care Manager.

Recommendation 8: *That the relevant voluntary sector organisations be given the necessary training in order to provide effective advocacy support and that users/carers are made aware of this potential support.*

[13] Definition of "key worker":
".... key worker refers to a named person who the client/carer approaches for advice about any problem related to the client. The key worker has the responsibility for communicating with professionals from their own and other services [...]."
(Taken from resource pack of the Key worker scheme for the disabled child. Produced by the Social policy research unit at York University. 2000. Suzanne Mukerjee, Patricia Sloper, Bryony Beresford and Peter Lund.)

SERVICE PROVISION

69. The Group was pleased to note that where NHS funded criteria are met, the PCT must provide the required level of service in a clinically safe way (Health & Social Care Act 2001); that delays must be kept to a minimum and user/carer choice should be respected. This will require a range of jointly commissioned services based on needs assessment and forward planning.

70. As stated elsewhere the Group welcomed the creation of a Continuing Care team at the PCT which will help solve many of the problems reported to the Task Group regarding information, support and planning. Besides its role in supporting users/carers, it will have an important strategic role. The Task Group welcomes the input that this team will be able to make in planning care and monitoring quality and costs.

71. At the session examining anonymised cases, the Group noticed the inconsistency in the provision of care plans following the Panel decision. The Group notes the relatively high levels (91% for 2nd quarter 2004/2005) of people receiving a statement of their needs and how they will be met. The forecast for 2004/5 overall is 96%.[14] However, this figure gives no indication of whether the care plan should have been updated. Neither of the carers the Group spoke to had a current care plan or understood they were entitled to one. A comprehensive care plan[15] including health and social care provision is essential if users and carers are to understand and be able to monitor the care received. The Group would encourage Health and Social Services to continue to undertake all efforts to ensure that all clients receive a care plan which is updated as necessary.

72. It was noted that self-funders should also be included in the Continuing Care assessment procedures and supported accordingly. The Group would strongly support the extension of the financial advice services offered by the Richmond Community Partnership from automatically covering just clients who receive Day Care or Home Care to include those in receipt of residential care or respite care as well.

73. The Group notes the low levels of carer assessments – an issue which Social Services management are aware of. The performance for the second quarter of 2004/2005 is 18.5%. (Performance Indicator D42: the number of informal carers receiving an assessment as a percentage of the total number of clients and carers receiving assessments. It has since been subsumed in to Performance Indicator C62.) It is clearly a figure which needs to be improved if carers are going to receive the service and support they are entitled to.

Recommendation 9: *That a written integrated care plan be provided to all users and updated as a matter of course. It should be agreed by them and also reflect the input of the carer.*

Recommendation 10: *That a separate carer's assessment be offered in all cases.*

[14] See the Performance Indicator D39 in the report to the Social Care and Housing O&S Committee 30.11.04 (Item 49): http://cabnet.richmond.gov.uk/Published/C00000169/M00001223/AI00007512/$Summaryofallindicators04052ndqtr.doc.pdf#page=6

[15] The importance of a detailed care plan should not be underestimated. One of the carers the Group spoke to had had great difficulty when the home care agency had sent along a member of their team to temporarily cover for a colleague who had an allergy to cats and so could not enter the client's house.

FUTURE CONSULTATION WITH THE VOLUNTARY SECTOR AND OVERVIEW AND SCRUTINY

74. The effectiveness of the criteria and the performance of the Continuing Care assessment panels is a key issue for Overview and Scrutiny. The Group believes that, in whatever form appropriate in this Borough (be it as this Task Group or within the business of the Health/Social Care and Housing O&S Committees) and across the boroughs in the SWLSHA, Overview and Scrutiny Members should review implementation of the All Adults agreement, and progress on level 2 and 3 for the other adult groups not covered in the All Adults agreement, in 6-9 months time.

75. Overview and Scrutiny should also consider when it is appropriate to return to the Continuing Care procedures for children.

Recommendation 11: *That Overview and Scrutiny in LBRuT and the other boroughs in the SWLSHA review, or be encouraged to review, the progress on implementing the All Adults Continuing Care criteria in 6-9 months' time.*

76. The Group is pleased that the various Joint Commissioning Boards were consulted on the All Adults level 1 criteria and operational guidance. It is understood that the relevant JCBs will be similarly consulted on the criteria for levels 2 and 3 for adults with Cognitive Impairment, Learning Disability and Mental Illness, and this is considered a very important way of engaging with users, carers and voluntary sector.

77. As noted above, the Group was impressed by the original leaflet on Continuing Care produced by the SWLSHA. This should now be updated and supplemented by a range of leaflets produced at Borough level detailing the assessment procedures, the options for appeal etc. similar to those in Royal Borough of Kingston. Both the users interviewed by the Task Group would have welcomed a Question and Answer type document to highlight the sorts of issues they should be considering e.g. care plan, carers assessment etc. The Group has been made aware of the Leaflet Groups at the PCT in checking public leaflets for clarity and user-friendliness. It would also welcome the participation of the JCBs in any review of information produced for the public.

Recommendation 12: *That the Joint Commissioning Boards review all leaflets produced specifically for the public for content and user-friendliness.*

RECOMMENDATIONS FOR THE NATIONAL REVIEW OF CONTINUING CARE

78. Pooled Budgets and Charging for Social Services. This matter needs to be resolved at a national level if pooled budgets and integrated working are to be truly effective. This is a recommendation the Group would like fed in to the national review of Continuing Care.

79. Clarity is needed at a national level for historical out-of-borough cases where funding responsibility has not been clarified by the Responsible Commissioner guidance.

Recommendation 13: *That the importance of resolving the issues of both pooled budgets and funding responsibility for out of borough cases be fed into the national review of Continuing Care.*

LINKS BETWEEN THE COUNCIL/OVERVIEW AND SCRUTINY AND THE VOLUNTARY SECTOR

80. One of the strengths of the work of this Task Group was the excellent input from representatives of the Voluntary Sector. Their involvement enabled the Group to go someway towards fulfilling its responsibility "to reflect and voice the concerns of the public and its communities"[16]. The suggestion came from the Voluntary Sector that great benefit could be derived from having a Community Co-ordinating Officer whose job it would be to advise the Borough's Voluntary Sector Community Group (part of the Borough's Health and Social Care joint commissioning system), as well as O&S Committees. In the first instance this would be most relevant to the Social Care & Housing and the Health O&S Committees, but would also be helpful for other O&S Committees in engaging members of the public in their work.

Recommendation 14: *That the Council appoint a Community Co-ordinating Officer to develop and support voluntary sector involvement with Overview and Scrutiny.*

[16] Part of the mission statement for Scrutiny in Richmond upon Thames agreed by the Overview and Scrutiny Co-ordinating Group and based on guidance from the Centre for Public Scrutiny

CONCLUSION

81. The Group recognises the important financial and organisational issues which flow from this review. Though much good work has been done, it is necessary to formalise the involvement of users and carers in the procedures in ways which ensure a better understanding, more meaningful involvement and better outcomes.

82. The recommendations cover Health, Social Services, Education and the voluntary sector. All have a role to play in delivering a fair, consistent, transparent and compassionate process and procedure.

83. We were delighted to receive compliments from the individual carers who contributed their experiences to our work. They were surprised and impressed that we were doing this piece of work and wanted to hear from them first hand. The value of service user involvement in the work of Overview and Scrutiny cannot be overestimated.

TABLE OF RECOMMENDATIONS

Rec. No.	Recommendation	Recommendation for:
1.	*That in this Borough staff training ensures staff have a good understanding of the overall procedures as well as their specific role within the whole process.*	*PCT and LBRuT*
2.	*That the All Adults Continuing Care criteria and guidance be approved and signed off by either the Cabinet or the Cabinet Member for Social Services and Housing.*	*LBRuT*
3.	*That for all Continuing Care Assessment Panels for Adults in the Borough there be: 1) Terms of Reference for each panel; 2) good administrative support/single manager for the panel process; 3) timely despatch of documentation prior to a panel meeting; 4) standardised assessment reports, decision papers and panel minutes; 5) fund-holders sitting on the Panel; 6) attendance of all necessary professional/clinical advice as required.*	*PCT and LBRuT*
4.	*That the possibility of having laypeople on the assessment panels be considered when the next review of the Panels' work is undertaken.*	*PCT and LBRuT*
5.	*That users/carers be given the opportunity and encouragement to attend and take part in the Panel and that formalised quality assurance procedures are put in place to obtain user feedback.*	*PCT and LBRuT*
6.	*That for each case, a key worker, whether from Social Services or Health, be appointed to be the main contact for the user/carer and to liase with the other professionals involved on their behalf and ensure good communication between all parties.*	*PCT and LBRuT*
7.	*That written confirmation always be given to the users/carers of the Panel decision together with details of the appeals procedures.*	*PCT and LBRuT*
8.	*That the relevant voluntary sector organisations be given the necessary training in order to provide effective advocacy support and that users/carers are made aware of this potential support.*	*PCT and LBRuT*
9.	*That a written integrated care plan be provided to all users and updated as a matter of course. It should be agreed by them and also reflect the input of the carer.*	*PCT and LBRuT*
10.	*That a separate carer's assessment be offered in all cases.*	*PCT and LBRuT*
11.	*That Overview and Scrutiny in LBRuT and the other boroughs in the SWLSHA review, or be encouraged to review, the progress on implementing the All Adults Continuing Care criteria in 6-9 months' time.*	*LBRuT O&S*
12.	*That the Joint Commissioning Boards review all leaflets produced specifically for the public for content and user-friendliness.*	*PCT and LBRuT*

Rec. No.	Recommendation	Recommendation for:
13.	*That the importance of resolving the issues of both pooled budgets and funding responsibility for out of borough cases be fed into the national review of Continuing Care.*	*LBRuT*
14.	*That the Council appoint a Community Co-ordinating Officer to develop and support voluntary sector involvement with Overview and Scrutiny.*	*LBRuT*

SELECTED READING

- Health Service Ombudsman's report on "NHS Funding for Long term Care" Feb 2003: http://www.ombudsman.org.uk/hsc/document/care03/care03.pdf
- Health Service Ombudsman's report on "NHS Funding for Long term Care – Follow up Report." Dec 2004: http://www.ombudsman.org.uk/hsc/document/care04/care04.pdf
- LBRuT 04/05 Budget Consultation – Sept 2003 – Detailed findings (http://cabnet.richmond.gov.uk/Published/C00000170/M00000968/AI00005400/$BudgetConsultationMORIrep20045.doc.pdf)
- LBRuT 05/06 Budget Consultation – October 2004 (http://cabnet.richmond.gov.uk/Published/C00000170/M00001234/AI00007438/$MLTFS20058budcons.doc.pdf)
- LBRuT Community Plan (http://www.richmond.gov.uk/depts/chiefexec/policy/communityplan0306/default.htm)
- DoH Directions requiring all SHAs in England to set All Adults Continuing Care criteria (came into force 27 Feb 2004): http://www.dh.gov.uk/assetRoot/04/07/46/90/04074690.PDF
- DoH Independent Review on SHA Progress on review of past Continuing Care judgements: http://www.richmond.gov.uk/councillors/Documents/Task%20Groups/Continuing_Care/DoH_Melanie_Henwood_Review.pdf
- Responsible Commissioner guidance – Issued by the DoH November 2003: http://www.richmond.gov.uk/councillors/Documents/Task%20Groups/Continuing_Care/Responsible_Commisioner_guidelines_published_2003.pdf

GLOSSARY OF TERMS

DoH or DH	Department of Health
EMI	Elderly Mentally Ill
GP	General Practitioner (local doctor)
JCB	Joint Commissioning Board. There are six JCBs in the Borough. They were set up by the Council and the PCT to provide a system for working with partners, voluntary sector groups, users and carers in the health and social care sector. The six JCBs are: ❑ Long-term Conditions and Disability ❑ Older People ❑ Children and Families ❑ People with a Learning Disability ❑ Mental Health ❑ Health Inequalities
LBRuT	London Borough Of Richmond Upon Thames
LEA	Local Education Authority
NHS	National Health Service
O&S	Overview and Scrutiny (Committee/s)
PCT	Primary Care Trust
PLD	People with Learning Disabilities
RB (Kingston)	Royal Borough of Kingston upon Thames
SAP	Single Assessment Process. This came into force in December 2004 and is designed to ensure that older people only undergo one assessment on their health and social care needs, and that this is then shared with all relevant agencies.
SENCO	Special Educational Needs Co-ordinator – a specially designated teacher in every school
SHA	Strategic Health Authority (responsible for the strategy for several PCTs)
SWLSHA	South West London Strategic Health Authority. It covers the 6 London Boroughs of Croydon, Kingston, Merton, Richmond upon Thames, Sutton and Wandsworth, and the 5 PCTs of Croydon, Richmond and Twickenham, Kingston, Wandsworth, Sutton and Merton.

APPENDICES

Appendix A	**Timetable of meetings**
Appendix B	**Key Dates in Development of Continuing Care Criteria**
Appendix C	**Suggested changes to the Continuing Care Criteria and Operational Guidance for All Adults for the South West London SHA**
Appendix D	**Comments on the draft Continuing Care criteria for children with a physical disability**
Appendix E	**Summary of Continuing Care provision (for SWLSHA)**
Appendix F	**Notes of telephone interview conducted by Cllr Carr with carer, Mrs M**
Appendix G	**Notes of interview conducted by Cllr Carr and Cllr Morris with carer, Mrs V**
Appendix H	**Copy of Assessment Panel feedback form for users/carers used by Royal Borough of Kingston**

Appendix A – Timetable of Meetings

Date	Who attended	Issues discussed
22.11.04, 6.30pm	Cllr Carr (Chairman), Cllr Morris, Margaret Dangoor, Cllr Ellis (LB Wandsworth), Rhoda Frazer (Richmond Age Concern), Kathy Sheldon, Jeff Jerome (LBRuT Director of Social Services and Housing), Simon Stockton (consultant for local authorities), Jim Rogan (LBRuT Assistant Director, Adult Services), Jonathan Hill-Brown (LBRuT, Scrutiny Support Officer).	Scoping meeting
16.12.04, 6pm	Cllr Carr (Chairman), Cllr Morris, Margaret Dangoor (TG Member), Jeff Jerome (LBRuT, Director of Social Services and Housing), Jim Rogan (LBRuT, Assistant Director Social Services – Adults), Simon Stockton (Consultant for local authority Social Services departments in the South West London Strategic Health Authority (SHA) area), Kendel Fairley (Consultant for the SHA), Jo Silcock (SHA Lead Manager – Continuing Care), Lesley Yeo (Richmond and Twickenham Primary Care Trust (PCT) Director of Clinical Services and Nursing), Liz Grove (Integrated Neurological Services), Jean Lewis (Richmond Carers Centre), Dr Angela Tomlins, Francis King, Jonathan Hill-Brown (LBRuT, Scrutiny Support Officer)	Presentation by Simon Stockton and Kendel Fairley (consultants for the local authorities and SHA respectively) on the criteria setting process.
12.1.05, 12.30pm	Cllr Carr, Nicky Rayner (LBRuT Community and Commissioning Manager - PLD) and Beverley James (PCT Joint Commissioning Manager - PLD), Jonathan Hill-Brown (LBRuT, Scrutiny Support Officer)	Work of the PLD Assessment Panel
13.1.05, 6pm	Cllr Carr, Margaret Dangoor, Kathy Sheldon, Simon Stockton, Jim Rogan, Frances King, Angela Tomlins (Alzheimers Society), Jean Lewis, (Richmond Carers Centre), Liz Grove (Integrated Neurological Services), Jonathan Hill-Brown (LBRuT, Scrutiny Support Officer)	Examination of All Adults Continuing Care criteria

18.1.05, 9am	Cllr Carr, Simon Carlton, Jonathan Hill-Brown (LBRuT Scrutiny Support Officer)	Fact-finding meeting with PCT Children's Continuing Care Co-ordinator
19.1.05, 2.30pm	Cllr Carr, Neil Doverty (Borough Director – South West London and St George's Mental Health NHS Trust) and Aarti Joshi (Joint Commissioning Manager – Mental Health), Jonathan Hill-Brown (LBRuT Scrutiny Support Officer)	Fact-finding meeting with Mental Health officers
19.1.05, 6pm	Cllr Carr, Cllr Morris, Kathy Sheldon, Jane Clark (Principal Manager – Adult Community Services), Simon Cole, Lydia Hansbury (Richmond Homes for Life Trust), Jeff Jerome, Francis King, Jean Lewis (Richmond Carers Centre), Jim Rogan, Jonathan Hill-Brown (LBRuT Scrutiny Support Officer)	Comparison of Continuing Care assessment panels in Richmond with RB Kingston
21.1.05, 11.30	Cllr Carr, Mair Hutchings (Service Manager – Disabled Children), Jonathan Hill-Brown (LBRuT, Scrutiny Support Officer)	Fact-finding meeting with LBRuT Service Manager, (Disabled Children)
24.1.05, morning	Cllr Carr, Cllr Morris, Jane Nicoli-Jones, Jonathan Hill-Brown	Examination of 7 anonymised cases which were assessed as needing level 1 fully-funded NHS Continuing Care
24.1.05, afternoon	Cllr Carr, Cllr Morris, Lesley Yeo, Jane Clark, Sandeep Patel, Jonathan Hill-Brown	Interview with Lesley Yeo and Jane Clark
26.1.05, 6pm	Cllr Carr, Margaret Dangoor, Jim Rogan, Simon Stockton, Mair Hutchings, Nicola Bradley (Chair, Users and Carers JCB), Jennie O'Connor (Project for Children with Special Needs), Jessica Saraga (Assistant Director LEA), Jonathan Hill-Brown	Discussion of draft Continuing Care criteria for children with a physical disability. Examination of 2 anonymised children's cases which were assessed as needing level 1 fully-funded NHS Continuing Care
8.2.05, 6pm	Cllr Carr, Margaret Dangoor, Jim Rogan, Simon Stockton, Lesley Yeo, Jane Clark, Liz Grove, Jean Lewis, Jonathan Hill-Brown (LBRuT Scrutiny Support Officer), Francis King, 2 members of the public	Discussion on the draft final report of the Task Group
11.2.05, 6pm	Cllr Carr, Cllr Morris, Mrs V (carer), Jonathan Hill-Brown	Interview with carer
22.2.05, 6pm	Cllr Carr, Margaret Dangoor, Rhoda Frazer, Kathy Sheldon, Simon Stockton, Lesley Yeo, Mair Hutchings, Mr and Mrs Williams, Jeff Jerome, Francis King, Jonathan Hill-Brown	Approval of the final report

Appendix B – Key Dates in Development of Continuing Care Criteria

1993	In the preparation for the introduction of the community care reforms in 1993 there was recognition of the need to control the withdrawal of the NHS from responsibility for continuing inpatient care that was apparently taking place in some parts of the country. Clarifying and agreeing arrangements for continuing health care were one of the 'eight key tasks' identified by the Department of Health in joint letters issued by the then NHS Executive, and the Social Services Inspectorate.
1994	Leeds Case: The Health Service Ombudsman published a report on this case entitled 'Failure to provide long term NHS care for a brain-damaged patient'
1995	Department of Health issues guidance in response which stated that the NHS was responsible for arranging and funding inpatient continuing care, on a short or long term basis for people in the following 3 categories: ❑ '…. where the complexity or intensity of their medical, nursing care or other care or the need for frequent not easily predictable interventions requires the regular (in the majority of cases this might be weekly or more frequent) supervision of a consultant, specialist nurse or other NHS member of the multidisciplinary team…. ❑ '…. who require routinely the use of specialist health care equipment or treatments which require the supervision of specialist NHS staff …. ❑ 'who have a rapidly degenerating or unstable condition which means that they will require specialist medical or nursing supervision.'
1996	Further DoH guidance was issued that referred to the danger of eligibility criteria being over-restrictive.
1999	In March 1999 a **Royal Commission on Long Term Care** reported. This had looked at a range of issues connected with funding of long term care for elderly people. It identified three principles behind its approach: ❑ Responsibility for provision now and in the future should be shared between the state and individuals - the aim was to find a decision affordable for both and one which people could understand and accept as fair and logical; ❑ Any new system of state support should be fair and equitable; ❑ Any new system of state support should be transparent in respect of the resources underpinning it, the entitlement of individuals under it and what it left to personal responsibility. One of the Royal Commission's main recommendations was that the costs of long-term care should be divided between living costs, housing costs and personal care. Personal care should be available after assessment, according to need and paid for from general taxation: the rest should be subject to a co-payment according to means. The Commission defined personal care as the care needs, often intimate, which give rise to the major additional costs of frailty or disability associated with old age. It was to include support from skilled professionals.

July 2000	Government response. It rejected the recommendation about personal care, but accepted an alternative proposal to make nursing care in nursing homes free to users, by providing NHS funding.
July 1999	Court of Appeal made its judgment in the Coughlan case relating to the funding of NHS care. It stated that the responsibility for funding depended on whether the nursing services were: ❑ Merely incidental or ancillary to the provision of the accommodation which a local authority is under duty to provide; or ❑ Of a nature which it could be expected that an authority whose primary responsibility is to provide social services could be expected to provide.
March 2001	The Department of Health issued a National Service Framework (NSF) for Older People. That referred to the provision of free nursing care in nursing homes, but did not include any guidance on NHS funding for the full costs of continuing care for older people.
June 2001	New DoH guidance on Continuing Care. It divided funding responsibility into 3 categories: ❑ **NHS responsibility:** Where all the nursing service is the NHS's responsibility because someone's primary need is for health care rather than accommodation; ❑ **Shared NHS/Social Services responsibility:** Where responsibility can be shared between the NHS and the council because nursing needs in general can be the responsibility of the council but the NHS is responsible for meeting other health care requirements; ❑ **Social services responsibility:** Where the totality of the nursing service can be the responsibility of the local council.
Oct 2001	NHS funding for nursing care in nursing homes (often referred to as 'free' nursing care). As of April 203, the NHS funds care for all care home residents by a **registered nurse** (but not by other staff) for people who would previously have funded the full cost of their care themselves. (In April 2002 the previous distinction between nursing and residential homes ended, and all are now known as care homes, with or without nursing care.) The amount of nursing care required (the Registered Nurse Care Contribution - RNCC) is assessed by an NHS nurse to determine which of three bands (levels) of nursing care is needed. Each band, high, medium and low, attracts a different level of NHS funding. The practice guide mentions specifically that the advent of free nursing care left responsibilities for continuing NHS health care (which it defined as being where service to meet the totality of the patient's care should be arranged and funded entirely by the NHS) unchanged.
Feb 2003	Publication of the Health Ombudsman's report on "NHS Funding for long term care". http://www.ombudsman.org.uk/hsc/document/care03/care03.pdf
2003	Following publication of this report on long term care in February 2003 by the Health Ombudsman, the Department of Health requested all Strategic Health Authorities to establish an integrated set of eligibility criteria for NHS continuing health care to operate across each territory, and to undertake a process of retrospective review of cases where people may have been denied continuing care. The Department of Health commissioned from Melanie Henwood an independent review of local progress with these tasks. All SHAs were originally required to complete this review process by the end of December 2003; this was later revised to a completion deadline of 31 March 2004.

Mid 2003	Agreement between PCTs and local authorities in South West SHA area on Continuing Care needs for: Older People; Younger Adults with a Physical Disability; Older People with Mental Health Problems; and Patients requiring Palliative Care.
Nov 2004	Agreement between PCTs and local authorities in South West SHA area on Continuing Care needs for:
9 Dec 2004	Publication of the independent review by Melanie Henwood. http://www.richmond.gov.uk/councillors/Documents/Task%20Groups/Continuing_Care/DoH_Melanie_Henwood_Review.pdf
16 Dec 2004	Publication of Health Service Ombudsman's report on "NHS Funding for Long term Care – Follow up Report." http://www.ombudsman.org.uk/hsc/document/care04/care04.pdf
Dec 2004	Single Assessment came into force.

Appendix C – Suggested changes to the Continuing Care Criteria and Operational Guidance for All Adults for the South West London SHA

Below are the changes discussed at meeting of the Task Group on Thursday 13 January 2005, 6.00pm in the Terrace Room, York House. The right-hand column shows the SHA response.

Note No.	Page and paragraph	Recommended Change	SHA response
1.	p.3	Replace "Royal Borough of Richmond upon Thames" with "London Borough of Richmond upon Thames"	Accepted
2.	p.8, 2nd bullet point	The phrase "where appropriate" should be removed. There is enough of a caveat provided by "as far as possible".	Accepted
3.	p.7, under "Principles of Guidance	A further bullet point should be added "That all relevant organisations within the voluntary sector be kept advised on progress regarding the development of eligibility criteria and their application, as well as on assessment procedures."	Accepted
4.	p. 8, final para	Replace with "The guidance will be made available to relevant organisations within the voluntary sector under it Compact agreements with the statutory sector – and to members of the public on request."	Accepted
5.	p.9, first para	Typo. Replace "individuals" with "individual's"	Accepted
6.	p.9, 2nd para	Add after first sentence "All participants in the process must undergo full training on the application of the criteria and the procedures."	Not Accepted Staff need to be trained on that aspect of the process for which they are responsible. It is not necessary for all staff to understand the full process.
7.	p.9, end of 2nd para	The page references need to be changed to "pages 24-25"	Accepted
8.	p.9, final para	Heading 1.2 (d) The heading should state "Single Assessment Process for older people" in order to make that clearer from the outset.	Accepted
9.	p.10, 1st para	Typo. Replace "experiences" with "experience"	Accepted
10.	p.10, 1st	Mention should be made of carers' needs	Accepted

Note No.	Page and paragraph	Recommended Change	SHA response
	para	and that they are entitled to a separate carer assessment.	
11.	p.10, Section E re. FACS	There should be a sentence saying that clients should expect to receive a care plan and that after review a new care plan will be provided.	Accepted
12.	p.12, para under 'Placements'	Reword for clarity. Replace "by involving the individual, carer/and or family to decide where the individual is to be placed which will best meet the individual's need." with "to involve the individual, carer/and or family in deciding which placement will best meet the individual's needs."	Accepted
13.	p.12, para on "Placements"	Insert "Mental" before "Health Trusts"	Not Accepted The text refers to all trusts and not just mental health trusts.
14.	p.13, definition of cognitive impairment	The definition of cognitive impairment should include a reference to functional skills – the inability to perform everyday tasks.	Not Accepted It is inappropiate to list just one outcome of the impairment.
15.	Ditto	Should the definition also be more specific about speech articulation as e.g. stroke victims often have perfect understanding but the inability to articulate?	Not accepted Speech is different to understanding which is dealt with in the next line.
16.	p. 13, definition of cognitive impairment	Replace "muddled" with "confused"	Accepted
17.	p.13, final para	Replace "spectrums" with "spectrum"	Accepted
18.	p.13, final para	After "aspergers syndrome" add "which would be covered by Mental Health"	Not Accepted The additional words do not help clarify the point of the paragraph.
19.	p.11-15, section 1.4	There should be a more consistent layout for all three categories: adults with mental illness, cognitive impairment and learning disability. There needs to be the same subcategories for each. For example, advocacy is only mentioned in relation to	Accepted for Advocacy. This will either be moved to another generic section or

Note No.	Page and paragraph	Recommended Change	SHA response
		PLD.	repeated.
20.	p.14	The paragraph on assessments on p.14 applies, for example, to all categories and should be placed above section 1.3	Not accepted This additional material designed to address the specific concerns of people with a learning disability.
21.	p.14	In addition, a further paragraph is required reading "All those assessed under the Continuing care criteria will be sent a care plan on the health and social care needs."	Accepted as an additional sentence added to third para of "Assessments".
22.	p. 15, first bullet point	Typo. Replace "individuals" with "individual's"	Accepted
23.	p. 15, second bullet point	Typo. Replace "individuals" with "individual's"	Accepted
24.	p.16, note 5 on palliative care	Is the 12 weeks appropriate when palliative care could last for 1-2 years?	Not accepted See separate para below table.
25.	p.24, section on training	The Group questioned whether the word "expectation" was strong enough when PCTs and Social Services departments will have to implement those criteria and procedures. It was felt that the wording of the paragraphs should be tightened up to make training a requirement rather than an option (even if *de facto* all staff will receive training). Similarly the PCT responsibility for cascading training should be made clear, and that there should be a rolling programme to carry this out. Mention of training for hospital staff should also be included.	Not accepted The document stresses that training is an important requirement for the successful delivery of the Continuing care policy.
26.	p.26/7	Only 2 categories are mentioned: Mental illness and PLD. There needs to be a paragraph on Adults with Cognitive Impairment.	Not accepted The addition of adults with a mental illness and people with a learning disability require special focus. All other adults are included within the generic

Note No.	Page and paragraph	Recommended Change	SHA response
			policy.
27.	p.26, final bullet point	There should be an addition to say that the review timetable should be attached to the papers sent to user/carer following panel assessment.	Accepted
28.	p.28, 1st para in section 2.4	"continuing care panels" should be capitalised.	Accepted
29.	p.28, final para	It should state that users and carers should normally be invited to attend the panel meetings if they wish. If they are not able to attend more flexibility should be allowed for forms of representation. Mention should be made that voice recordings may be used to present and that care managers can provide assistance in making written reports.	Not accepted The DH regulations do not have this a requirement. It is for local PCTs to agree local arrangements. The Operational Guidance makes very clear that patient representatives must have an opportunity to contribute to the assessment of the patient.
30.	p.29	Accessibility of information. It should be a requirement that all written communication should be typed rather than hand-written.	Not accepted It is good practice for everything to be typed but making it a requirement could lead to delays and loss of flexibility.
31.	p.31, 2nd para	Not only clinical suitability should be taken into account but also practical concerns, e.g. how far the placement is from the carers.	Not accepted The primary aim must be to first meet the clinical needs of a patient. It is good practice that patients are placed close to other family members, where

Note No.	Page and paragraph	Recommended Change	SHA response
			requested.
32.	p.34	The Appeals procedure and escalation is difficult to understand. It should be numbered. 4 points are suggested: 1. PCT Review Panel 2. SHA Independent Review Panel 3. Independent Review from Healthcare Commissioner 4. Health Service Ombudsman	Accepted
33.			
34.	General comments:		
35.		There should be the stated requirement to regularly review medication.	Not Accepted The policy does not address detailed clinical practice. The frequency of medication review must be decided by the clinician responsible for care.
36.	Throughout the document	Emphasis should be made at all relevant points throughout the document of the need for clear, plain language in ALL documentation relating to a case.	Accepted This is a complex subject and inevitably the Operational Guidance must be technically precise. However where possible clarity should be maintained. The public leaflet can be written in easier language.
37.		There should be Member sign-off for the agreement.	Accepted.

The Task Group very much welcomed the subsequent agreement on 25.2.04 of the SWLSHA regarding:

1) The addition of "functional" to the definition of "cognitive impairment".
2) The addition of "advocate" throughout the document.

Appendix D – Comments on the draft Continuing Care criteria for children with a physical disability

Below are the comments discussed at meeting of the Task Group on Wednesday 26 January 2005.

The Task Group appreciated being given the chance to look at the Continuing Care criteria for children while they are still in draft. The Group is aware that the criteria for children are not at as advanced a stage as those for adults, and only cover level 1 fully-funded NHS Continuing Care for children with a physical disability, but not for any other levels or need categories. It also recognises that the SHA is under no statutory obligation to produce criteria for children.

The Group notes the difficulties with these criteria as level 1 only indicates what NHS care input *might* cover. There is still a discussion about what the final contribution will actually be between NHS, Social Services and Education. It heard that legal advice is being sought on this point. Overall it welcomes the criteria as enabling the system and process for transition cases (i.e. for users moving from the children's to the adult's criteria) to be made clearer.

The Group just had some general comments to make:

- The Group found it strange that no mention was made of the parent(s) anywhere in the document when their role is clearly so central to their child. The Group felt they should not fall under the definition of 'suitably trained staff' but that separate mention should be made of parents who have been suitably trained. In general terms, clarity of what is meant by 'suitably trained staff' could help to ensure fair access to services for all families. (Please also see 4th bullet point.)
- The Task Group expressed the concern that, in borderline cases, parents/carers who did less for their child perversely received a better level of service/higher banding. There is a risk that those families who invest a great deal of time and money into the care of their child will be at a disadvantage to families with children with similar needs who do not make this investment.
- The Group hopes that mention of both parents and schools will be given greater prominence in the accompanying documentation to the final agreement.
- There should be consistency of language regarding 'qualified' nurses. There is currently reference to staff being 'qualified', 'suitably trained', 'specialist' or 'registered'.
- As for adults, the Task Group questions whether the 12 weeks referred to under criterion A5 are meaningful and whether this criterion would be more relevant if it referred simply to the need for palliative or terminal care.
- Criterion B5. The Task Group questioned whether the need for interventions 4 times in 24 hours was a meaningful definition for children because interactions would be much more frequent - whether in home-care or a residential setting.
- The regular reassessment of eligibility for children should, unlike for adults, be undertaken at least half-yearly.

Appendix E – Summary of Continuing Care provision (for SWLSHA area)

Total Expenditure (£) by PCTs on Level 1 Continuing Care

PCT	(All)

Expenditure (£)	Year	
Care Packages	2002/03	2003/04
Care Package at Ho	0	141,422
Continuing Care Pla	7,657,010	10,359,389
NHS CC Beds	3,654,282	3,824,591
Grand Total	11,311,292	14,325,402

Expenditure by PCT

Sum of Amount	Year	
PCT	2002/03	2003/04
Croydon	2,332,181	2,950,578
Kingston	3,174,529	3,610,399
Richmond	2,505,682	2,860,214
Sutton & Merton	1,229,440	2,369,591
Wandsworth	2,069,460	2,534,620
Grand Total	11,311,292	14,325,402

New Cases Accepted for Continuing Care

PCT	(All)

Activity (Patients)	Year		
Illness Group	2002/03	2003/04	2004/05
Circulatory	40	36	
Elderly Mentally Ill	50	69	16
Frail Elderly	33	83	34
Musculo-Sclerosis	11	13	
Other	51	92	3
Palliative	122	210	82
Vegetative state	4	2	
Grand Total	311	505	135

News Cases by PCT

Count of Year	Year		
PCT	2002/03	2003/04	2004/05
Croydon	166	213	
Kingston	41	80	
Richmond & T	44	54	49
Sutton & Merton	50	128	86
Wandsworth	10	30	
Grand Total	311	505	135

2004/05	
6 Months	
5 Months	

Population		
	Over 65	Over 85
Croydon	41,301	3,272
Kingston	17,462	2,685
Richmond	20,696	3,199
Sutton & Merton	46,973	6,578
Wandsworth	24,417	5,231

Expenditure / Population (k)		
2003/4	Over 65	Over 85
Croydon	71	902
Kingston	207	1345
Richmond	138	894
Sutton & Me	50	360
Wandsworth	104	485

New Cases / Population (k)		
	Over 65	Over 85
Croydon	5	65
Kingston	5	30
Richmond	3	17
Sutton & Me	3	19
Wandsworth	1	6

Appendix F – Notes of telephone interview conducted by Cllr Carr with carer, Mrs M, on 8.2.05

Mrs M had responded to our request for individuals to tell the Task Group of their experience of Continuing Care in the Borough.

Background

Mr M had had a serious car accident while the couple were on holiday in the Isle of Wight and had been in the Spinal Injuries Unit in Salisbury Hospital since 1 May 2004. He had spent five weeks in intensive care and then been transferred to the ward for rehabilitation. Mrs M had stayed at the hospital for seven weeks. Mr M is paralysed from the chest down due to damage to the spinal cord. Following a home visit at Christmas, Mr M is due to be discharged at the end of February. He was in good spirits and his natural positive personality and outlook on life, plus the support of the professional staff, his family and many valued friends, had been a big help in coming to terms with the accident and the resultant long term disability.

Helpfulness of Staff

Staff at Salisbury hospital had been very helpful and supportive. Mrs M had been involved in team meetings to set rehabilitation goals for Mr M (swimming, OT, physio etc.) and to co-ordinate his discharge. She had also been given a good book by the hospital on how to care for her husband. Counselling had been available to help cope with the stress. The Salisbury CAB visited the hospital regularly and was now supporting her with disability grants and benefits.

Similarly, staff in the borough had also been very helpful and had liased well with Salisbury, despite the distance (the hospital staff had also said how good the LBRuT was). The District Nurse from Teddington had been to visit Mr M in Salisbury on her own time and had advised on a suitable bed and nursing care – on his return home, a DN will visit every day. The OT had visited Mr and Mrs M's home and advised on adaptations, including a hoist, wet room etc. and advice had been offered to Mrs M on moving and handling for her husband (two people are needed to move Mr M). Staff at Queen Mary's Hospital, Roehampton, had advised on a shower wheelchair. She was also in touch with Mr M's Care Manager and access to both the Douglas Bader fitness centre at Roehampton and the Teddington hydrotherapy pool had been mentioned, but she didn't know how all this would work out yet.

A package of care had been put in place for Mr M's home visit at Christmas, including the option of Direct Payments and a member of staff from the Rowan Organisation was continuing to advise on this and had put her in touch with the Carers Centre.

Overall, Mrs M felt that there had been a drip feed of information for her and her husband. She had dealt with many staff and had been told that Mr M would get Level 1 continuing care funding but had not been involved in the Panel. So far no Care Plan had been received.

The Carer's Perspective:

Mrs M has found the whole experience very depressing. While Mr M had been in intensive care she had wanted every detail, hoping for the best prognosis, but some of the medical staff had been a bit brutal about the likely outcome, giving a worst-case scenario. The transition from intensive care to the ward had been a big change – like going from Harrods to Woolworth. She had then put the forms (financial assessments etc.) and other information she had been given aside for several months, as she hadn't wanted to think about the long-term realities. A move to a nearer hospital (Stanmore) had been suggested, but as Mr M was happy with the staff and treatment at Salisbury, it was agreed that he should stay there and Mrs M had been able to visit him regularly, once or twice a week.

As yet, no mention had been made of a separate Carer's Assessment for Mrs M but she was now more ready to face the practicalities of the new life before them and to focus on her husband's needs, her role and the support she will need to care for her husband and for herself in the years ahead.

Issues:

- Very good staff support, but many different staff to deal with
- Good verbal information on Continuing Care, but no written information on process or outcome or appeal mechanisms etc.
- Direct Payments offered and support given by the Rowan Organisation
- No Care Plan as yet
- No mention of a separate Carer's Assessment entitlement

Appendix G – Notes of interview conducted by Cllr Carr and Cllr Morris with carer, Mrs V, on 11.2.05

Attendance: Councillor Carr, Councillor Morris, Mrs V, Jonathan Hill-Brown

Mrs V is a carer whose husband has been assessed as needing level 1 fully-funded NHS Continuing Care. She received a letter from the Task Group which was sent by the PCT and agreed to be interviewed by Members of the Task Group.

Medical Condition of Mr V

The carer's husband, Mr V, has a series of medical problems which were originally caused by Normal Pressure Hydrocephalus and small strokes. These also led him to be doubly incontinent. He was unable to walk unaided, though he sometimes forgets his own frailty and suffers falls. He was given care at home until last year (care visits 4 times a day) when he suddenly became unable to swallow. It is likely that this was brought on by his diabetes and he is at risk of choking when swallowing. He was taken to Kingston Hospital where he had further complications: a chest infection, urinary tract infection and MRSA. He suffered serious weight loss until the stomach peg was put in. At times he can be very lucid in his thoughts, at other times very confused, disorientated and forgetful. The health professionals and Mrs V believe that it will not be possible for Mr V to return home, even though Mr V wishes to do this.

Mrs V has had 2 periods of respite care in the last year. Her husband was in the Ashmead Nursing Home for 2 weeks and, though he complained at the time, he seems to have favourable recollections his time there. Mrs V also went away for a weekend in July. On the night after she had left for a third period of respite care, her husband became ill and was admitted to hospital, where he has been since then.

Mrs V had much praise for Richmond upon Thames Social Services who have, over many years, been very helpful. She was very pleased with the main carer of the last few years for her husband. This carer is employed by an agency. However, the carers sent by the same agency to cover leave periods for the main carer had been very unsatisfactory. There had been instances when carers had turned up -4 hours after they were due, did not realise they had to bring the key held by the agency to let themselves in, had been unable to disconnect the catheter, had had very poor standards of personal hygiene, had been rude, or had been too small to lift and manhandle such a large man. Staff were clearly often unaware of the needs of Mr V before they arrived. Staff at LBRuT Social Services were made aware of these issues.

Mrs V had considered Direct Payments and received support in this from the Rowan Organisation. However, she eventually decided not to go ahead with it as the administration, signing of contracts etc was too daunting.

Assessment Panel and subsequent steps

Mrs V received a phone call to inform her of the outcome of the Continuing Care Assessment Panel. Originally there was talk of various options for a placement for her husband. It has since transpired that there is only really one option: a place at Roehampton Lodge at Barnes Hospital. Mrs V is concerned about this as the care

seems insufficient. There are 18 patients, many of whom are apparently stroke victims, and only one of them can speak. She is worried that her husband's condition will deteriorate if he does not get any interaction with others. There was also no physiotherapist and no occupational therapist. The doctor only came once a week and there was generally only one trained nurse at night (up to 3 sometimes during the day). Given the severity of her husband's medical needs, Mrs V is concerned this may not be a suitable placement.

Summary of other issues

- Care Manager was not at the discharge co-ordinator meeting. Praise for the work of the discharge co-ordinators.
- She would have liked to have been at the meeting of the Assessment Panel which decided her husband's banding for Continuing Care.
- She would also have liked to have seen the documentation relating to her husband's case.
- She had not received a carer's assessment and was not aware that she was entitled to one.
- No care plan has been provided since Dec 2003 and the option of care in other nursing homes has not been suggested.
- Mrs V was unaware that she could request a review of her husband's case.

Appendix H – Copy of Assessment Panel feedback form for users/carers used by Royal Borough of Kingston

Tell Us What You Think

Placements Panel Questionnaire

Royal Kingston

We are very keen to hear from you about how you think we are doing. We are also keen to listen to your ideas on how we could make things better. Please use this form to tell us about your experience at the Placements Panel meeting. If you would prefer to have the form filled out over the phone, or would like to speak to someone in confidence about your experience, please contact Kirstie Cochrane on 020 8547 6124.

About you

1. Are you a: user of our services ☐ friend ☐
   neighbour ☐ relative ☐

About what information you were given

2. Were you given a copy of 'The Mental Health Service User's Accommodation Panel'? (a leaflet that tells you about the panel, what to expect and how to get there).
   Yes ☐ No ☐
   If 'yes', was it useful? Yes ☐ No ☐
   If 'no', please tell us what information you would have found useful: .....
   .....
   .....

About the Panel meeting

3. Did the time / day of the Panel meeting suit you? Yes ☐ No ☐
4. Was the venue: Easy to find / accessible? Yes ☐ No ☐
   Comfortable? Yes ☐ No ☐
   If **'no'** to any of these questions, please tell us how you think we could do things better: .....
   .....
   .....
   .....
5. Were you made to feel welcome, for example, were you offered refreshments, introduced to the people on the panel? Yes ☐ No ☐
   If not, please tell us about this: .....
   .....
   .....

6. Did the Panel meeting start on time? Yes ☐ No ☐

   Please give details, including for example, if the meeting started late, was an explanation / apology given? .....

   .....

7. In your opinion, was there a full and thorough discussion of your situation? Yes☐ No☐

   If **'no'**, please tell us about this: .....

   .....

   .....

8. Do you feel you were listened to and able to have your say? Yes☐ No☐

   If **'no'**, please tell us about this: .....

   .....

9. If you could change one or two things about the way we run Panel Meetings, what would they be? .....

   .....

   .....

What are we going to do with your feedback?

Your comments will help us to check to make sure we are providing you with a service that suits your needs and to help us plan what changes we may need to consider in the future.

Every 3 months we will be looking at all the questionnaires that are returned to see what we can do to make improvements. If you would like to be sent a copy of my reports, please remember to fill out your details below:

I would like to receive a copy of our findings from the meeting: Yes☐ No☐

Name: .....

Address: .....

.....

.....

Tel No: ..... Mobile No: .....

Email address: .....

The best time to contact me is (please give day and time): .....

.....

Thank you for taking the time to fill out this questionnaire.

Please return the form in the prepaid envelope.