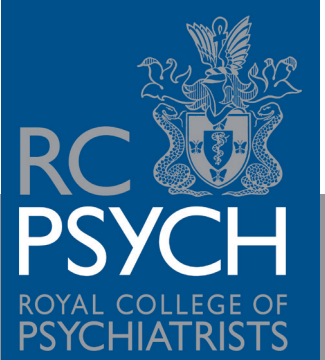


CR153



Links not boundaries:
service transitions for people
growing older with enduring
or relapsing mental illness

January 2009

Links not boundaries: service transitions for people growing older with enduring or relapsing mental illness

College Report CR153
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Royal College of Psychiatrists
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Contents

Working Group	4
Executive summary and recommendations	5
Introduction	8
Historical background	10
Survey of the implementation of CR110	12
A user's perspective	13
A carer's perspective	15
Service models	16
References	17
Appendix 1. Presenters at the Royal College of Psychiatrists seminar, 15 May 2006	18
Appendix 2. Participants in the Royal College of Psychiatrists seminar, 15 May 2006	20
Appendix 3. Service models presented at the seminar	21

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Executive summary and recommendations

This document updates the Council Report 110 *Caring for People who Enter Old Age with Enduring or Relapsing Mental Illness ('Graduates')* (Royal College of Psychiatrists, 2002). It has been produced by a working party including representatives from the Faculties of Old Age Psychiatry, General and Community Psychiatry, Rehabilitation Psychiatry, the Faculty of Old Age Psychiatry consumer group and a mental health nurse.

The report makes a series of recommendations aimed at improving the care of people who are growing old with enduring or relapsing mental illness and who face the possibility of moving between psychiatric services, most commonly from general and community (or rehabilitation) psychiatry to the psychiatry of old age.

The recommendations fall into six main areas:

- 1 the use of transition protocols
- 2 assessment
- 3 the process of transition
- 4 the care plan
- 5 monitoring
- 6 commissioning.

Making the transition between services can be a difficult and worrying time for users and their families. Organisations are advised to consider these recommendations, which have been produced after wide debate to which many people have contributed, and to review their policies and procedures to improve the experiences of families using their service.

RECOMMENDATIONS

TRANSITION PROTOCOLS

- 1 Services should have agreed transition protocols which lay out the criteria and process for considering transition between general and community, rehabilitation and old age psychiatry services, and which are used in response to a standardised and agreed trigger. The transition must be needs-led and not triggered by age.

- 2 Criteria for considering transition should be needs-led and set out clearly in the protocol.
- 3 The protocol must offer a clear but flexible framework for decisions, with clear focus on the needs of the individual and their family.
- 4 Protocols should be drawn up locally by a group including representatives of all three services (general and community, rehabilitation and old age psychiatry), users, carers, and local social services.
- 5 Protocols should clarify how local disagreements will be resolved and how lessons learnt from the transition process will be disseminated within local services, where it is appropriate to do so.

ASSESSMENT

- 6 The transition process should involve a comprehensive assessment of the individuals' needs, including needs related to their mental health, physical health, social and family circumstances and spiritual needs, and review of the current level of health and social care provision.
- 7 Assessment of need should be sensitive to sexuality, spirituality, and cultural and ethnic background, as elders from Black and minority ethnic communities may have particular difficulties in finding and accessing appropriate services. 'Count Me In' (Healthcare Commission, 2007) reported that around 10% of male and 6% of female in-patients aged over 50 years were from ethnic minority communities.

TRANSITION

- 8 There should be a joint case review/care programme approach (CPA) meeting involving mental health teams from both services as the forum for discussing and agreeing future care plans with both user and carer. Areas of disagreement should be identified and addressed. Available resources and options for treatment should be discussed.
- 9 It is best practice to consider transfer when a person's mental state is stable. It may be appropriate in some circumstances to transfer care of an acutely ill person, if their needs dictate it.
- 10 Copies of the protocol, clearly written in accessible language, should be available to all those involved in the transition process and especially to users and carers involved in that process.
- 11 Practitioners should ensure that users have information about advocacy services, and encourage the use of advocacy services when discussing these decisions, particularly where family members/carers are not involved.
- 12 The transition process should incorporate the users' views.
- 13 The transition process should incorporate the carers' views.

CARE PLAN

- 14 A written copy of the agreed care plan should then, with the service user's agreement, be shared with all relevant professionals, including their general practitioner and any supporting organisations, and copies made available to the user and carer (with the service user's agreement).
- 15 The care plan agreed should be designed to best meet identified needs within available resources. Any unmet needs, lack of resources or shortfall in available care provision should be noted. Transfer in the course of an in-patient episode may need to be considered, if the patient's needs are best met in a specific in-patient setting.

MONITORING

- 16 Information on the use of the protocol should be routinely collected.
- 17 The use of the protocol should be audited and reviewed regularly, and results made available to local planning and governance groups. The impact of these recommendations on services should also be monitored – for example, are there increased numbers of older people using general and community services as a result of needs-led transition policies?
- 18 Protocols need to be designed locally with attention to the principles set out above. It may also be helpful for services to share protocols and their experience with them. These principles could also usefully be applied to transitions driven by geographical relocations.

COMMISSIONING

- 19 Each service should make local Commissioners aware of the resource implications of needs-led transitions.
- 20 Commissioners should be aware that there is a group of people with complex needs who may be inappropriately placed in homes specialising in the care of people with dementia.

Introduction

Council Report 110 *Caring for People who Enter Old Age with Enduring or Relapsing Mental Illness ('Graduates')* (Royal College of Psychiatrists, 2002), was written by a group representing the Faculty of Old Age Psychiatry (Professor David Jolley), the Faculty of General and Community Psychiatry (Dr Nick Kosky) and the Section of Rehabilitation Psychiatry (Dr Frank Holloway), and recommended that:

- Each local health and social care economy should identify all 'graduates' (see p. 10).
- A full reassessment should be made of each individual's health and social care needs, and a care plan, designed to meet these needs within available resources, should be agreed.
- Progress towards improved care and improved health should be monitored by annual reviews.
- For people approaching the age of 65, their birthday should trigger a comprehensive review of their health and social care needs. Following this review, a care plan should be agreed and be subject to annual review.
- Medical responsibility will rest with a principal in general practice or a consultant psychiatrist, and maintenance of continuous review should be the responsibility of the case manager.

People who grow old with established mental illness experience the interface between the three specialist areas of general and community psychiatry, rehabilitation psychiatry and old age psychiatry. It can be difficult to decide how their needs are best met, although one of the overriding principles must be to ensure person-centred care (Department of Health, 2001). The Department of Health and Care Services Improvement Partnership (CSIP) stress in *Everybody's Business* (2005) that older people with mental health problems must not be allowed to fall between services. Some services have used achievement of the age of 65 as the trigger to initiate transfer of care from general and community psychiatry to old age psychiatry. The *National Service Framework for Older People* (Department of Health, 2001) highlighted the unacceptability of age discrimination, and the recent report from the UK Inquiry into Mental Health and Well-Being in Later Life (2006) notes that age had been used in the past to determine eligibility for services, commenting that 'chronological age is a poor indicator of biological, emotional, social or intellectual age'.

A recent Faculty of Old Age Psychiatry report (2006) identified the interface between general and community psychiatry and old age psychiatry as an important area with implications for service design. A working group

of the Royal College of Psychiatrists (2004) has identified some general principles:

- The service with the greatest expertise in relation to the care needs of an individual should take responsibility for their care.
- Continuity of care should take precedence over automatic referral to older adult services for physically well people without dementia over the age of 65 years.
- The age of 65 provides a useful service boundary for people presenting for the first time with a psychiatric disorder.
- Transfer of ongoing care should be made at a review meeting where necessary.
- Users should always receive the service which meets their needs best; sometimes the first assessment might be undertaken by one service, but ongoing care might be provided by the other.

This report addresses interface issues and considers how services might collaborate and interlink to ensure that people in this situation receive the best possible care. The background and case examples are taken from a Royal College of Psychiatrists' seminar held on 15 May 2006.

Historical background

The group of people referred to in CR110 as 'graduates' used to be cared for in the large asylums, but with the closures of large mental hospitals and the move to care in the community, they now reside predominantly in hostels or long-term care.

The majority of users of old age psychiatry services have two main diagnoses, dementias or depressive illnesses; the remaining minority have a range of conditions, including delirium, mixed disorders, paranoid states and alcohol and substance misuse. The diagnostic profile of people growing old in general psychiatry and rehabilitation psychiatry services is different, and is dominated by schizophrenia, unstable mood disorders, personality disorders and substance misuse.

PHYSICAL HEALTH

In people growing old with established mental illness, increased cardiovascular and respiratory disease and lifestyle issues (smoking, obesity, poor diet and lack of exercise) contribute to poor physical health. Those factors also influence the mental illness process and medication effects. This group also has a lower life expectancy in comparison with the general population (Harris & Barraclough, 1998).

MENTAL HEALTH

This group of people may have illnesses which have lost their acute features but left the person with a range of disabilities. Others still have active positive symptoms. They may also have developed new illnesses, both physical and mental and they may experience accumulating losses, including loss of family, friends, health, career and aspirations with a resulting need to adjust to their changed life circumstances.

The *National Service Framework for Mental Health* (Department of Health, 1999) brought much investment, linked to a service designed for adults of working age and characterised by the use of the CPA and provision of assertive outreach teams, home treatment teams and early intervention services. The *National Service Framework for Older People* (Department of Health, 2001) brought no additional money into older people's mental health services, nor has the recent Department of Health and CSIP (2005) policy document, *Everybody's Business*.

SPIRITUAL

It is harder for older people to attend their faith community meetings because of physical ill health and frailty. For this reason, the spiritual concerns of this group, especially as they face their mortality and that of family and friends, are poorly addressed.

SOCIAL CIRCUMSTANCES

This group is at risk of social isolation due to fewer sustained productive relationships and possibly loss of contact with their families. They are unlikely to have been in sustained employment, and may have spent many years in institutional care. They may have limited finances – there are some additional benefits available to older people, but many users have difficulty accessing them.

Survey of the implementation of CR110

A survey of the implementation of the previous report CR110 has been carried out (Bawn *et al*, 2007). Organisations providing mental health services were approached and nominated individuals who were asked about their knowledge of the report and how they dealt with possible moves between general and community psychiatry and old age psychiatry services. The survey revealed limited dissemination of the report – psychiatrists were aware of it, but there was limited awareness among managers and other groups. There was, however, strong support for the policy that services should be needs-led, not age-led. Two-thirds of responding services used a transition protocol to aid the process of considering a transfer between general and community and old age psychiatry services; however, most had been devised solely by mental health professionals. More advantages than disadvantages were identified by respondents and overall transition protocols were felt to be helpful, but there was little evidence of data collection regarding the use of protocols or the numbers of people making the transition between services. The authors concluded that a good practice protocol would have the following characteristics:

- be drawn up by a broad group which includes health and social care professionals, users and carers
- provide a clear but flexible framework for making decisions
- identify and address areas of disagreement
- be used in response to a standardised and agreed trigger – not triggered by users' age
- be based on assessment of user (and carer) need
- incorporate the user's views
- incorporate the carer's views (with the user's agreement)
- allow discussion of available resources and services
- identify unmet needs
- identify lack of resources
- involve routine collection of data, audit and review of the protocol's use.

A user's perspective

The Working Group was informed by a seminar held in May 2006. The user's and carer's perspective which follows has been developed from discussion and debate at the seminar.

Users of general and community and rehabilitation psychiatry services who are growing older raise a number of important questions:

- Will assessment during the transition be personalised and person-focused?
- Can they still influence their own treatment as they grow older?
- Will their physical health problems be addressed as well as their mental health problems?
- Will their lifestyle choices be respected?
- Will their life experience be respected?
- Will women have access to women's services, particularly where abuse is an issue?
- Are talking therapies accessible to older adults?
- Why should everything change at 65? The users are concerned about the emphasis on dementia in older adults' services, and whether their needs will be fully met.
- Will they transfer from the CPA to the single assessment process and what difference will this make?
- Is advocacy available if needed, both during the process of considering a service transition and in the new service, if a move is made?
- How will the needs of people with dual diagnoses be met in considering service transition?

Mind recently ran a campaign called 'Access all Ages' (<http://www.mind.org.uk/News+policy+and+campaigns/Campaigns/ages/>). As part of this campaign, a questionnaire was circulated to older service users. The results revealed a mixed picture, with practice varying considerably. Some learning points from this include:

- A key concern is reaching the age of 65 and facing a possible service transition with a change of personnel and with the single assessment process, potentially leading to a loss of a mental health focus. The quality and strength of relationships with keyworkers is not always appreciated.

- Social services are more stringent than health services about the rigid age cut-off of 65, and people may find that they are required to move day centre or other services, which can be very disruptive.
- Some people may want to transfer to old age psychiatry to access acute in-patient services for older adults, where the environment may be quieter and less distressing.
- There might be anxiety about stigma or quality of care in older adult services, which are often perceived to be less well-resourced than services for younger adults.
- Memory clinics are an area of older adult services which general and community and rehabilitation psychiatry services would like to access.
- Although flexibility is helpful, people find it difficult to understand service transitions when the transition criteria are unclear.
- There is a need for informed choice and quality services for all age groups.
- There is a question about the timing of service transition. Over half of service users are acutely ill at the point of transfer – is this an appropriate time to transfer care?

A carer's perspective

Carers may have no knowledge of how services are organised, despite a long history of caring. They may not know whether their relative is being treated by general and community psychiatry, rehabilitation psychiatry or old age psychiatry, and indeed may not care, so long as the needs of both the service user and carer are addressed. One of their main concerns is likely to be care coordination for relatives who have mental and physical health problems, and ensuring that, although a number of people may be involved in support and treatment, there is someone who is 'seeing the overall picture'.

What makes a difference to carers:

- honesty
- open communication between professionals and families/carers
- close communication and coordination between professionals
- continuity of care
- access to information and advice
- realism in offering support and treatment
- flexibility in service response and treatment planning
- informed choice.

Service models

At the seminar organised by the Working Group (15 May 2006), several different services gave presentations, sharing a range of experiences and ideas to stimulate debate and discussion. (The programme from the seminar is attached as Appendix 1 and the attendees who contributed to discussions are listed in Appendix 2; summaries from the presentations are set out in Appendix 3.)

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Appendix 1. Presenters at the Royal College of Psychiatrists seminar, 15 May 2006

10.00	Setting the scene Professor Susan Benbow, Chair of the Working Group and Morning Chair
10.10	The previous 'graduates' report and an audit of its impact on services Professor Dave Jolley, co-author of CR110
10.40	Discussant: Anne Bird, Associate Medical Director and member of General and Community Psychiatry Faculty Executive Committee
10.50	Discussion from the floor
11.00	User and carer perspectives Speakers from Users in Partnership and Carers in Partnership
11.30	Coffee
11.45	Local experiences of transition Susie Rabin and colleague, Mind
12.00	Discussant: Rowena Jones, Specialist Registrar
12.05	Discussion from the floor
12.15	Developing a transition protocol Andy Talbot, Consultant Psychiatrist for Older People/ Clinical Director, Mental Health Services for Older People, Humber Mental Health Teaching NHS Trust
12.30	Discussant: Lou Taylor, Principal Lecturer Postgraduate Studies, Faculty of Health and Social Care, Staffordshire University
12.35	Discussion from the floor
12.45	Lunch
13.45	Introduction by Afternoon Chair Dr Michele Hampson, link with General Adult and Community Faculty Executive Committee
14.00	The Shropshire Model Michael Hurt and Alison Marpole
14.15	Discussant: Elizabeth Collier, Lecturer and Mental Health Nurse, Salford
14.20	Discussion from the floor

- 14.30 'What can we learn from geriatric medicine?'
Duncan Forsyth, Consultant Geriatrician, Cambridge
- 14.45 'What can we learn from social services?'
Ruth Hicks, Middlesbrough Social Services
- 15.00 'What can we learn from transitions in the care home sector?'
Amanda Thompsell, Southwark Primary Care Trust
- 15.15 Discussant: Leon Rózewicz, Consultant Psychiatrist and Joint Associate Medical Director
- 15.20 Discussion from the floor
- 15.30 'Links not boundaries: planning the next Council Report'.
Susan Benbow and Michele Hampson
- 16.00 Close and depart

Appendix 2. Participants in the Royal College of Psychiatrists seminar, 15 May 2006

Dr Carmelo Aquilina
Heidi Baldwin
Professor Susan Benbow
Dr Sarah Black
Clive Bennett
Patricia Caplen
Elizabeth Collier
Dr D. Dasgupta
Duncan Forsyth
Gill Foster
Helen French
Dr Jane Garner
Dr Michele Hampson
Dr Jean Helling
Ruth Hicks
Dr John Hindle
Robert Howard
Michael Hurt
Professor David Jolley
Professor Paul Kingston
Rowena Jones
Dr Shakil Khawaja
Dr Sarah Lyle

Anton Manickam
Alison Marpole
Dr Jenny McCleery
Gillian McLean
Phil Minshull
Dr Shehram Moghul
Dr Adam Moliver
Dr Charles Morris
Kate Parnham
Dr Stephen Pearson
Dr Siobhan Pieroni
Dr Gill Pinner
Susie Rabin
Dr Anand N. Ramakrishnan
Dr Maeve Rea
Leon Rózewicz
Dr Moghul Shehram
Dr Ian Hugh Stout
Andy Talbot
Andrew Tarbuck
Louise Taylor
Dr Amanda Thompsell
Zoë Tovell

Appendix 3. Service models presented at the seminar

THE SHROPSHIRE MODEL

The Shropshire Model uses specialist nurse practitioners to manage the transition between general and community and old age psychiatry services. After referral from the care coordinator, the nurse practitioner assesses the notes/resources employed and risk, and then discusses the person with the general psychiatry team currently caring for them. A meeting is held with the person about to make the transition and the team caring for them, after which staff members from older adult services are introduced and a plan is worked out. A transfer date is then agreed and when everyone has been informed and has agreed, the transfer of care takes place. A comprehensive review of the person and their needs is in this way carried out over a period of about 12 months before transfer formally takes place.

CARE HOMES SUPPORT TEAM, DULWICH HOSPITAL, LAMBETH, LEWISHAM AND SOUTHWARK PRIMARY CARE TRUST

Key points from transitions in the care home sector include:

- fully involve the service user and carers in the decisions relating to the move
- give carers opportunity for involvement in the actual move
- the team involved in moving the person into the care home should give the home detailed initial written information regarding the new resident, including:
 - life history details/routines
 - indicators of relapse
 - when medication reviews are due
 - preferred activities
 - outside contact details
- raise any physical health issues (e.g. feet and dental)
- ensure drug regime is practical in the care home setting

- clear information on who to contact if problems arise
- ensure initial follow-up after transfer to the care home by staff who know the service user to deal with any sense of loss or concerns about the new environment
- formal meeting with senior care home staff prior to discharge from caseload to ensure information is known by staff and is in the care plan
- handover to another mental health team should be carried out by staff from both services meeting jointly in the home with the service user and carers
- involve the service user and carers in the decisions and in the transition plan
- identify what is different about the new care environment and what changes need to be made (e.g. in drug regime) to accommodate this
- try to involve the new general practitioner in handover meetings and ensure they are given full, timely, written information.

HUMBER MENTAL HEALTH TEACHING NATIONAL HEALTH SERVICE (NHS) TRUST TRANSITION PROTOCOL

At the Humber Mental Health Teaching NHS Trust a small working group of clinicians and managers developed a transfer protocol, in consultation with stakeholders. They defined the core business of an old age psychiatry service:

- to see people newly referred to mental health services at age 65 and over
- to see people who had been known to mental health services in the past but were discharged at least 6 months previously and now present with a new episode at age 65 and over
- to take over the care of people who meet the criteria to transfer to the care of old age psychiatry based on a change in their needs:
 - decline in physical health associated with age in a person with 'functional' mental health symptoms/diagnosis
 - sudden or severe decline in mental health, due to a superimposed organic condition
 - increase in social needs due to one of the above
 - development of a dementia alongside a psychotic illness or a learning disability
- access to appropriate younger adult mental health services to be maintained regardless of age.

Development of this transition protocol involved a time-limited implementation group, presentations to stakeholders, and planned monitoring with reviews of protocol operation.

ADDENBROOKES CRITERIA FOR THE DEPARTMENT OF MEDICINE FOR THE ELDERLY

If age can no longer define a service ('for older people'), then the service must define how it is special (different), that is:

- who needs it?
- what does it offer that other ('adult') services do not/cannot/will not do?

The juxtaposition between uni- and multi-pathology provides an obvious starting point for defining geriatric medicine as a specialty within general medicine. Thus geriatric medicine can define itself as non-organ-based adult medicine for the frail (usually older) vulnerable person. This inevitably moves the specialty from an age-related to a needs-related service, and was the basis for developing the following criteria:

- Ideally the following older patients ought to be admitted to the department of medicine for the elderly (DME) (if this is not possible, they should be referred for specialist opinion to a DME consultant):
 - likely to need rehabilitation and complex discharge planning owing to the complexity of their medical and social care needs
 - currently being followed up in a DME clinic
 - older patients with cognitive impairment (dementia or delirium) may need specialist input from either the DME or older people's liaison mental health service (e.g. as per Addenbrooke's guidelines on detecting and managing delirium), but dementia alone is not a reason for admission to a DME
 - the majority of patients requiring specialist DME input are 75 years old and over, however, age itself is **never** a reason for referring or not referring for DME specialist care.

MIDDLESBROUGH INTEGRATED MENTAL HEALTH SERVICES

Middlesbrough Integrated Mental Health Services are a partnership between Middlesbrough Council and Tees, Esk and Wear Valley NHS Trust. They have to interface with a wide variety of services, including community care teams, working-age adult services, acute hospital services, intermediate care, in-patient services, community services, primary care, secondary care, residential and nursing homes, and crisis resolution services. The following principles have been identified as important:

- partnership across agencies
- barred age discrimination
- needs-led service responses
- virtual teams
- carer support – key
- direct payments
- advocacy

- home-based services wherever possible
- focus on individual need
- supported by protocols and care pathways.

The key to any successful transition is good communication between the transferor and the transferee staff.

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