The PSSRU

The Personal Social Services Research Unit was established in 1974 and now has branches at three UK universities: the University of Kent, the London School of Economics and Political Science, and the University of Manchester.

Its mission is to conduct high quality research on social and health care to inform and influence policy, practice and theory.

An overview of our research programmes can be found on pages 30–36; contact details for the staff at the three PSSRU branches are on pages 38–39.

About this Bulletin

The PSSRU Bulletin is available to download free of charge from the PSSRU website

It records recent developments in the Unit, presents recent findings from each of our main programmes of work, and gives a concise overview of research projects and recent publications with contact information.

We welcome comments on this Bulletin or other aspects of our work.

Other PSSRU publications

A wide range of publications reports the PSSRU’s work. Some are mentioned in the articles which follow and listed in the section beginning on page 30.

The Unit website gives a complete listing, with many downloadable publications (including this Bulletin and previous issues), along with more information on current and completed research.

PSSRUList

To subscribe to this email list for announcements of publications, events and developments at the PSSRU, go to www.jiscmail.ac.uk/lists/pssrulist.html

PSSRU website
http://www.PSSRU.ac.uk/
Introduction

Welcome to issue 17 of the PSSRU Bulletin. The Bulletin provides a guide to the work undertaken by the PSSRU at the three branches – the University of Kent, London School of Economics and University of Manchester. PSSRU works to inform and address the major concerns of policy makers, managers and service providers in health and social care. Our particular foci of interest are social care for older people and the health and social care interface.

Our current work addresses and illuminates a number of the most important and innovative themes in health and social care, including areas identified in the implementation of the 2006 White Paper Our Health, Our Care, Our Say. Much of the work underway is outlined in pages 6 to 27 of the Bulletin. Amongst the articles and work described is information about the Single Assessment Process, self assessment, extra care housing, long-term conditions case management, direct payments, hospital discharge, dementia care and the funding of long term care, the development of new approaches to performance measurement and economics of mental health services. The material provides valuable evidence for policymakers and managers in local authorities, primary care trusts, mental health and acute trusts.

The Unit also has a number of exciting new projects summarised on pages 28–29 which address key concerns across health and social care. These include studies of preventive interventions (POPs), old age mental health care, the economics of early intervention, and carer outcomes. A summary of our current projects and associated publications can be found on pages 30–36.

Many staff in PSSRU have contributed to this edition of the Bulletin, but I should particularly like to thank Caroline Sutcliffe and Sue Tucker from the PSSRU at Manchester for their excellent work in editing and organising the material. Nick Brawn from Kent has again been responsible for the splendid work on design and setting the Bulletin for print.

Finally, it is a particular pleasure to highlight the important honour conferred upon Professor Bleddyn Davies, the founder of the PSSRU, by the American Public Health Association (APHA). He has been awarded the 2007 International Lifetime Achievement Award by the APHA in recognition for the range of work he has undertaken.

David Challis, PSSRU, University of Manchester, September 2007

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The PSSRU 2006–2007

New Research Grants
The PSSRU have recently been successful in the first round of the National Institute for Health Research (NIHR) Programme Grants for Applied Research. Programme Grants are prestigious awards of up to £2m over a period of three to five years, directed towards leading researchers who can demonstrate an impressive track-record of achievement in applied health research. Each programme comprises a series of related projects which form a coherent theme in an area of priority or need for the NHS.

PSSRU researchers at LSE will be contributing to the economic components of five programmes. One of these looks at supports and treatment for people with anorexia nervosa, another focuses on effective treatments for people with neurodevelopmental disorders and a third considers dementia services in the community. Staff from Manchester PSSRU will also be involved with the fourth programme, which will explore support at home for, and interventions to enhance the life of, people with dementia, whilst the fifth project, focussing on old age mental health services, is to be led by the Manchester branch.

The PSSRU in Manchester have also been awarded a grant from the NIHR Service Delivery and Organisation programme to investigate self care and case management in long-term conditions, and, in collaboration with colleagues from the Manchester Business School, obtained a grant from the Department of Health to explore the recruitment and retention of the care workforce for older people.

Along with Judith Torrington from Sheffield University, staff at the PSSRU at Kent are to develop an environmental assessment tool for use in older people’s extra care housing. They have also obtained funding for projects to investigate linking and matching in adoption, and models of multi-agency services for disabled young people and those with complex health needs.

House of Lords Select Committee on European Affairs report
Professor Martin Knapp recently acted as a specialist adviser to the House of Lords (Parliamentary) Select Committee inquiry on the European Commission’s green paper on a mental health strategy for Europe. The committee’s (substantial) report, Improving the Mental Health of the Population: Can the European Union Help? (2007) looked in detail at whether there is a role for the EU in improving the mental well-being of the European population and concluded that they could facilitate the exchange of information and best practice across Europe. The committee also suggested that enforcing anti-discrimination legislation relating to disability could significantly improve the position of people with mental health problems and that the EU should encourage those member states who do not have such legislation to introduce it.

Dementia UK
A major new study of the social and economic impact of dementia in the UK commissioned by the Alzheimer’s Society has received extensive media coverage. The report, undertaken by the PSSRU at the LSE and the Institute of Psychiatry at King’s College, London, shows that there are currently 700,000 people with dementia in the UK and that dementia costs the UK over £17 billion per year (see page 38).

Although dementia is one of the main causes of disability in later life, public funding for dementia research lags far behind that of other serious medical conditions and there are marked variations in the level of provision and expenditure across the UK. Among its recommendations, the study calls for increased funding for dementia research, the development of community services and a national debate on who pays for care.

MAP2030
The MAP2030 research group, an ESRC funded team at the LSE and other universities, is investigating the needs and resources of older people to 2030. The group held a very successful introductory seminar for stakeholders at the LSE in April at which participants discussed a range of potential policy scenarios for reform of the pensions and long-term care finance systems. Stakeholders included representatives of local and central government, voluntary organisations, interest groups and academia. It is hoped to hold more events on specific topics as the project progresses. Please visit our website at www.lse.ac.uk/collections/MAP2030/ for more information.

Conference presentations
In May 2007 David Challis and Jane Hughes from the PSSRU at Manchester ran a masterclass on care and case management at a conference organised by the Institute for Care and Welfare (NIZW) in Utrecht. This event focused on the Netherlands’ National Dementia Programme and was attended by a number of key policy makers.

In October David Challis was the keynote speaker at the Canadian Network for Care in the Community/Ontario Community Support Association in Toronto. This was related to a Canadian Institute for Health Research Grant which involves PSSRU work.

Prime Minister’s Standing Commission on Carers
Professor David Challis has been made a member of the recently convened Commission on Carers. The Commission recognises the importance of carers in the delivery of social care and is to examine the implications of demographic and other developments for carers, and in particular the New Deal for Carers.
Staff News

Bleddyn Davies

Bleddyn Davies, a long-time member of the American Public Health Association, was honoured as a recipient of the Gerontological Health Section’s International Lifetime Achievement Award in November 2007.

Bleddyn was Professor of Social Policy at the London School of Economics (LSE), Professor of Social Policy at the University of Kent, and Honorary Professor of Social Policy Research at the University of Manchester. He established the PSSRU in 1974, and remained as Director until retiring in 2003. He is now Emeritus Professor at LSE and Kent and Professorial Fellow at the Oxford University Institute of Ageing.

Among his honours, Bleddyn was awarded the OBE for services to social science and social policy. He is also an Academician of the Academy of the Social Sciences in the UK.

Bleddyn’s career, influence and achievements were celebrated in September 2002 when a day was held at the LSE to celebrate his work. The contributions from PSSRU colleagues, other academics, policy makers and managers were subsequently produced as a Festschrift.

Arrivals and departures …

We have been pleased to welcome a number of new staff to the PSSRU this year. New arrivals at the Manchester branch included Sue Davies, Kathryn Berzins and Helen Chester as Research Associates and Susan O’Shea and Jessica Abell as Research Assistants. Mark Wilberforce has also joined the branch as an honorary Research Fellow.

The Kent branch were very pleased to welcome back Julien Forder, who has been appointed Deputy Director and Professor of the Economics of Social Policy. Julien will divide his time between LSE and Kent. Working with Julien on the Quality Measurement Framework project is James Caiels, who joined us from the Centre for Public Health Research at the University of Chester. In January 2008, Nadia Brookes (currently at University Hospital Lewisham) will be moving to the PSSRU to work on a unit costs study for the National Offender Management Service. New staff on the Extra Care Housing project include local fieldworkers Rosemary Carlson, Marion Cole, Vicki Cook, Lynne Cullens, Lynda Hance, Chris Paige, Rebecca Smith, Bernard Styan, Zoe Poole, Janet Wistow and Julie Yazdanjoo. The Kent and LSE branches were also pleased to welcome visitors Dr Eric Latimer, from McGill, Canada (for one year) and Juan Cabasés, from the Universidad Publica de Navarra, Spain (for five months).

The LSE were pleased to appoint Jennifer Beecham as a Principal Research Fellow. Jennifer will now spend half her time in London and half in Kent. Amongst their many visitors, the London branch also warmly welcomed Shoba Raja (Visiting Fellow). Andrea Pratt, Molly Siegel, Pon-Hsui Yeh, Russell Bennetts and A-La Park worked at the LSE over the summer as Occasional Research Assistants. LSE also welcome students Julia Kite and Soraiya Shroff who are currently assisting on LSE projects, and Karin Cerri, Heba Elgazzar and Nika Fuchkan who have joined the Unit as PhD students. Anna García-Gonzalez, from the Universidad Autónoma de Barcelona also spent three months in the summer as a visitor at the LSE branch.

At Manchester we said goodbye to Judith Dennis, who has taken up a post as librarian for the National Coal Mining Museum in Bradford; Dan Venables, who moved to Wales and is now working at Cardiff University; and Judy Scott, who moved to Hexham, but still has links with the PSSRU.

The LSE branch said farewell to Andrew Healey, who moved permanently to the Ministry of Justice following his secondment and Demetra Nicolaou-Frini, who moved to the Department of International History at the LSE. Francesco Moscone moved to the National Collaborating Centre for Women’s and Children’s Health, but remains linked to the branch as a Visiting Fellow. We also said goodbye to Anna Melke, Joep Gerrichauzen and Dick Bemelmans who visited us during the previous year.

We offer many congratulations to all those staff who have been promoted in the last year: Jennifer Beecham (now Professor of Health and Social Care Economics at Kent); Karen Jones and Jacquetta Holder (now Research Fellows, Kent); Jacqueline Damant, Helen Mederios and Tom Snell (now Research Officers, LSE); Adelina Comas, Derek King and Roshni Mangalore (now Research Fellows, LSE); and José-Luis Fernández (now Senior Research Fellow and Deputy Director, LSE). Congratulations are also offered to Francesco Moscone (London); Roshni Mangalore (London); and Paul Clarkson (Manchester), who have been awarded PhDs.

We must also congratulate Francesco Moscone and Martin Knapp (LSE), who received an excellence in mental health and economics award for their paper entitled Exploring the Spatial Pattern of Mental Health Expenditure in the Journal of Mental Health Policy and Economics; Martin Knapp and David McDaid (LSE), co-editors of the book Mental Health Policy and Practice across Europe, the joint winner of the 2007 Baxter Award; and Julian Forder, José-Luis Fernández, Tom Snell and Francesco Moscone, who co-authored the report from the Wanless Social Care Review, which was awarded the 2006 Prospect magazine think tank publication of the year award.

On a more personal note, we also send all our very best wishes to Lisa Callaghan (née Nash, Kent) and Sue Davies (née Crompton, Manchester), who both got married this autumn, and to Vanessa Davey (LSE), Claire Grant (LSE) and Francesco Moscone (LSE) on the safe arrival of their daughters.
Assessment, Performance Measurement and User Satisfaction in Older People’s Services

David Challis, Michele Abendstern, Paul Clarkson, Sue Davies, Jane Hughes, Susan O’Shea, Caroline Sutcliffe and Sue Tucker

This programme includes work on evaluation of the Single Assessment Process (SAP), self assessment sites and a study of local approaches to performance measurement in social care of older people.

The SAP

As part of the programme, the PSSRU in Manchester was commissioned by the Department of Health to undertake an evaluation of the development and implementation of the SAP in England. The study, which has two stages, is now near completion. Stage one consisted of a literature review to explore major themes in the assessment of older people derived from previous research in both the UK and overseas and a focus group of SAP lead officers in the North West of England which highlighted issues of particular relevance to those responsible for implementing the new assessment arrangements for older people in localities. Stage two involved a series of studies (see box 1) which investigated the impact of the SAP from the perspective of multiple stakeholders including managers, clinicians and service users. One element of these is considered below.

The national survey of SAP lead officers This survey provides the first national picture of the development of the SAP in England approximately two years after its formal introduction. A cross-sectional survey method was used to capture service level data from lead officers in all 150 local authorities in England. One hundred and twenty two authorities completed the questionnaire, a response rate of 82%. A number of findings from this survey are summarised below. They focus in particular on the pace of implementation with reference to professional contributions and tools, and on issues identified by managers as being paramount to successful implementation.

The development of the SAP The original SAP guidance specified four different levels and types of assessment, ranging from the contact assessment at one end of the process to the comprehensive assessment at the other. The current data suggest an uneven development across these processes with the contact and overview assessment having achieved widespread use, whilst the comprehensive assessment and current summary record were only being used to a limited degree.

Professional contributions to the SAP were also found to vary. Social workers/care managers, district nurses and occupational therapists were reported as being the professional groups most involved. Medical professionals appeared to have only a limited role. Figure 1 shows the extent to which a range of professional groups involved in the assessment of older people contributed to the overview assessment.

Of the formal tools available to support SAP, FACE (Elzinga et al., 2001) was the tool reported to be in use by most participants (25% of respondents) with...
EASY-Care (Philp, 2000) following closely behind (24% of respondents). However, 66% of localities reported using locally developed assessment tools. It is possible that a high degree of agreement exists between different locally developed tools, suggesting more standardisation than would first appear to be the case. Further work is being undertaken to ascertain the extent to which this is the situation. These findings indicate that the implementation of the SAP to date has been uneven and suggest that the process of implementation will be a long one.

Implementation issues Respondents were asked to prioritise from a given list the issues that had been the most important during the implementation process to date, whether resolved or not. Figure 2 shows their responses.

Managers indicated a range of paramount issues which were key to the successful implementation of the SAP, not least the support of senior management and a commitment to a shared vision by professionals across agency boundaries. The extent to which this has been achieved is not yet clear.

Self assessment and local approaches to performance measurement in the social care of older people

Work on these studies is in progress. The first is an evaluation of the 11 sites which received funding from the Department of Health to pilot differing approaches to self assessment in preventative services, care management and occupational therapy services. The second has involved work with individual local authorities, as described in a recently produced book (Challis et al., 2006). A new project is described on page 23.

References

Commissioning and Performance

Martin Knapp, José-Luis Fernández, Julien Forder, Jacqueline Damant, Vanessa Davey, Catherine Henderson, Tihana Matosevic, Margaret Perkins, Tom Snell and Gerald Wistow

Among the questions dominating the policy landscape are:

- **Personalisation** – extending choice and control for people who use services and their carers.
- **Balance of care** – prevention of needs arising or worsening, and of admissions to care homes or hospital.
- **Variations in local provision** – differences in the extent and nature of social care services provided in local authorities in England.

PSSRU research, including much of the work of the Commissioning and Performance team at LSE, is addressing questions in these policy areas.

**Personalisation**

One of the most prominent issues in social care policy discussions is the quest for the *personalisation* of services, and the drive to shift responsibility from commissioners to users. Government has legislated for, and heavily promoted, the use of direct payments, which allow people to arrange their own social services, giving individuals control over the social care funding to which they are eligible. Yet implementation has remained disappointing with few people eligible for social care support receiving direct payments. In March 2006, for example, fewer than 42,000 of the approximately one million eligible people actually received a direct payment.

Two UK surveys on direct payments have recently been reported, one describing local authorities’ policies, practices and payment levels, and the other looking at support organisations. They identified enormous country-wide variation – in who gets offered a direct payment, the amount allocated per hour, the number of hours covered, access to one-off payments for equipment or respite care, and availability of support and advice (Davey et al., 2007a, 2007b).

There are big differences in take-up between user groups: direct payments are most commonly provided to physically disabled or sensorily impaired people, but rarely to mental health service users or older people. Moreover, the typical price of the care that needs to be purchased varies between user groups, while direct payment rates hardly vary at all. Local authority and support organisation respondents to our surveys identified factors that hindered progress, especially: concern among service users and carers about managing direct payments, social worker resistance, and difficulties finding people to work as personal assistants.

In addition to mapping direct payments practices, we are participating in the national evaluation of the Individual Budget pilots. Further details are provided on page 27.

**Balance of care for older people**

Given the acute resource constraints felt by many local authorities (most of which are no longer able to provide support to people with low or moderate needs) increasing attention is being focused on the potential for reducing need for intensive support by investing in low-intensity, preventative interventions. Our analyses suggest significant interdependence between the health and social care systems.
Members of the Commissioning and Performance team are contributing to the national evaluation of the Partnership for Older People Projects (POPPs), examining the impact of local initiatives to provide better information and develop better community-based support for people not yet eligible for local authority-brokered care and/or in contact with services but at risk of care home or hospital admission. We are evaluating one of the local projects (in Kent – see page 29), and also Kent County Council’s Brighter Futures initiative, which examines the impact of volunteers in social care, many of whom older people themselves. Following early results from the POPP evaluation, government announced the national roll-out of the programme in the 2007 Pre-Budget Report and Comprehensive Spending Review.

In 2008 we will finish a project funded by the Service Delivery and Organisation programme characterising and comparing local governance arrangements for joint health and social care efforts to reduce the use of inappropriate hospital stays by older people. This work is linked to our earlier evaluation of the Innovation Forum programme. In addition, we are contributing to Health England, established by the DH to look at health and social care promotion and prevention.

A new activity is participation in the DH-funded evaluation of the Whole Systems Demonstrator pilots, examining the impact of telecare and telehealth services on the welfare of a range of user groups in three sites in England.

**Variations in social care patterns**

Using local authority-level data, the Commissioning and Performance team is examining the factors behind the very significant differences in the local patterns of social care services provision in England. Among the range of factors examined are levels of need, local supply factors, local political control and historical local systemic policy preferences.

In earlier analyses, we explored demand, supply and local policy factors associated with patterns of take-up and intensity of direct payments. All English authorities were included, looking at data over three years for people with physical disabilities, older people, people with intellectual disabilities and mental health service users. Statistical analyses highlighted significant links between patterns of direct payment roll out and authorities’ overall levels of expenditure on care services, local supply conditions, and their commitment to community-based and out-sourced provision (Fernández et al., 2007).

Other analyses are examining variations in local levels of expenditure, balance of care, and their impact on the health care sector (Fernández and Forder, 2008).

**References**


Integrated services: what is their impact on care coordination?

There are developments designed to achieve greater integration between health and social care in many countries. The expectation underlying this is that greater structural integration will result in improved care for people by means of more ‘joined-up’ services. Part of this PSSRU programme of work examined the pattern of care management arrangements in relation to integrated services. It was undertaken in conjunction with Michael Donnelly of Queen’s University Belfast.

In England the pursuit of a more integrated approach to service provision has been a longstanding concern of successive governments. The Labour administration of the late 1990s stated its determination to bring down the ‘Berlin Wall’ between health and social care (Cm 4169, 1998, para. 6.5). However, at the turn of the 21st century in England, health care was provided through NHS Trusts which were responsible for providing hospital and community based health services in conjunction with general practitioners, and social care services were provided or commissioned mainly by local government. Conversely, in Northern Ireland, joint Health and Social Services Trusts provided community services and the full range of social care services, including the purchase of residential and nursing home beds. Hence, whereas health and social care in England were broadly separate, managed respectively by the NHS and local government, in Northern Ireland a single trust was and is responsible for both forms of care. This unique difference made possible an almost natural experiment by comparing the different service configurations in England and Northern Ireland so as to examine their influence on care management arrangements.

Here we summarise the findings of comparisons between England and Northern Ireland in mental health and older people’s services to explore whether a single service structure appears to be associated with more integrated practice. The findings can be examined in greater depth in Challis et al. (2006) and Reilly et al. (2007).

Method The work was based upon national surveys of social care services. Data were collected via two postal questionnaires completed by strategic managers in old age and mental health services within English local authority social services departments (101; 77%) and all trusts in Northern Ireland with responsibility for community health and social services, including care management (11; 100%). Summary scores of the presence of a number of key items indicative of integrated practice were also calculated: a maximum of eight in old age services and seven in mental health services.

Findings There were some consistent differences in care management practice between England and Northern Ireland. As would be expected, in Northern Ireland there was greater involvement of health care staff in the process. Care management was also more targeted in Northern Ireland, provided as a response to only some service users. This can be seen as an example of differentiation, the process within care management arrangements which helps to ensure users receive a level of response appropriate to their needs. There were also more specialist services linked to care management in Northern Ireland: rehabilitation and specialist dementia services. However, by
contrast, the size of caseloads appeared to be higher in Northern Ireland than in England. These findings are summarised in table 1.

Overall, using summary scores of indicators of integrated practice associated with care management arrangements, it appeared that in both old age and mental health services, the level of integration was higher in Northern Ireland than in England. This is shown in table 2.

Conclusions

Given the trends and influence of recent policy towards integration and partnership, it is possible that the differences between England and Northern Ireland have reduced since the study was conducted. The work lends support to the view that within care management arrangements more integrated structures are associated with greater integration in both mental health and old age services and therefore supports the direction of policy. However, there remains the more problematic issue as to whether integrated structures have contributed to changes in patterns of professional working and organisational culture consistent with greater integrated practice.

Current and future work

Since its inception a decade ago with three surveys of care management arrangements, this programme of research has evolved to take account of policy initiatives in respect of older people and adults with mental health problems, as is exemplified in the work described above. In the immediate future the research team will be focusing on long-term care coordination arrangements for older people at home. In 2006 a second national survey of care management arrangements in England was undertaken which achieved a response rate of 79% from local authorities. It will provide both an overview of current provision and, by comparison with data collected in the first survey, measures of how services have changed in terms of indicators of differentiation and integration between health and social care within care management arrangements for older people. Work is also being undertaken on care management arrangements in relation to long-term conditions.

Additionally the research team is revising a framework developed in the late 1990s for exploring care management arrangements which has been used to describe services in the four principal adult user groups. This work is in partnership with the Older People’s Assistant Directors Group within the North West region of the Association of Directors of Adult Social Services. It will be used to guide the analysis of local authority responses to the national survey of old age care management arrangements described above.

Table 1 Old age and mental health social care services: differences between England and Northern Ireland

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Old age: difference England versus Northern Ireland</th>
<th>Mental health: difference England versus Northern Ireland</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health involvement in assessment</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Shared assessment documents</td>
<td>+</td>
<td>Not significant</td>
</tr>
<tr>
<td>Targeted care management</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Care management in rehabilitation services</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Specialist dementia service</td>
<td>+</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Health care staff as care managers</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Caseload size</td>
<td>+</td>
<td>+</td>
</tr>
</tbody>
</table>

Note: + = greater in Northern Ireland than England

Table 2 Summary integration scores in England and Northern Ireland

<table>
<thead>
<tr>
<th>Service type</th>
<th>England</th>
<th>Northern Ireland</th>
</tr>
</thead>
<tbody>
<tr>
<td>Old age (maximum 8)</td>
<td>2.98</td>
<td>5.36</td>
</tr>
<tr>
<td>Mental health (maximum 7)</td>
<td>2.64</td>
<td>3.73</td>
</tr>
</tbody>
</table>

References


Costs, Quality and Outcomes
Ann Netten, Theresia Bäumker, Lesley Curtis, Karen Jones, Juliette Malley, Sima Sandhu and Nick Smith

The programme examines the measurement of costs, quality and outcomes of social care in a variety of contexts. The work in this programme is closely linked to the Quality Measurement Framework studies (see page 21) and has fed into the evaluations of the Individual Budget pilots (page 27) and the Somerset POPP (page 33). Activities include the compilation of the Unit Costs volumes (page 37) and studies taking forward a developing approach to measuring outputs and outcomes of social care (Netten et al., 2006). The latter includes working with councils in the South East on integrating outcome measurement into practice. Quality measurement has focused on the conduct and analysis of extensions to user experience surveys (UES), most recently an extension to the national 2006 older home care user survey (Malley et al., 2007) and the 2007 PSSRU survey of the experiences of younger adults with physical and sensory impairments. Here we focus on the results of the work that will be feeding into the 2008 UES that is focusing on users of equipment services.

Background

With an estimated 2 to 3 million adults using community equipment (CSED, 2007), community equipment services have developed as an important element in keeping older and younger disabled adults independent within their own homes. This has been mirrored by increasing policy interest in community equipment services with recognition (Royal Commission on Long Term Care, 1999) followed by increased funding (DH, 2000) and structural reforms which attempted to integrate health and social care equipment stores (DH, 2001; 2006) culminating with a new service delivery model which aims to be more responsive to the needs of equipment users and their carers (CSED, 2007). Despite this increasing interest in and recognition of the importance of community equipment service there is a dearth of quality and outcomes measures. The PSSRU has been working on developing quality and outcomes measures for the national 2007/08 UES.

Methods

The development of quality and outcome measures drew together a number of approaches. We carried out exploratory work on equipment services which involved reviewing the previous research and literature, running focus groups with equipment users, interviewing those who worked within equipment services and a short survey on quality measurement/assurance which was sent to all the equipment stores in England. This was combined with PSSRU’s previous work on social care outcomes to create domains of quality from which a draft set of questions was developed. These were then cognitively tested with equipment users and subsequently revised.

Findings

Service Quality Unlike much research on equipment, our quality measures focus more on service quality than the quality of the equipment itself. Our exploratory work found that equipment users have a clear and consistent view of what they considered to be a quality equipment service. Their views were the primary basis for our service quality domains (see box 1) and the resulting questions which were developed for the UES. The relevance of these domains
was confirmed during our cognitive testing with equipment users. The 2007/2008 UES contains questions drawn from each of these domains.

**Box 1 Service Quality Domains**

**Waiting/Delivery Time:** Having equipment delivered or an adaptation carried out within an acceptable time.

**Choice and Control:** Having choice or participating in decisions about the right sort of equipment.

**Communication and Understanding:** Having your situation, lifestyle and impairment understood by those who assess your needs. Being listened to and being provided with information.

**Respect and Dignity:** Having both the services and the staff treat you and your home with respect and dignity.

**Follow Up:** Having training, advice and support after the equipment has been delivered. Problems dealt with speedily.

**Outcomes** Our initial outcome domains and questions were drawn from previous work on social care outcomes (Netten et al., 2006). These were cognitively tested with equipment users to determine their relevance to equipment. The cognitive testing showed that there were some domains (accommodation, control over daily life, personal care, safety) that were more frequently relevant than others (activities and occupation, meals and nutrition, mobility outside the home, role support, social participation) and only the former domains went forward into the national 2007/2008 UES. However, this is not to say that these other domains were not relevant to people using equipment, indeed we added a new outcome domain, management of pain and discomfort. While these domains were less frequently identified, they were of great importance to those who did cite them. Thus to capture the diverse impact that equipment may have on users, all of the domains are included in the questionnaire for the PSSRU extension study. All local authorities in England have been invited to participate in this study, which will explore the quality and outcomes of equipment services in more depth.

**Seminar feedback**

In November 2007 the PSSRU held a seminar, sponsored by the Department of Health, on *User Experience Surveys: the process, their value and the future*. Research and experience in this area was discussed from a number of perspectives. Presentations from the day, and a summary of issues raised, are available at www.pssru.ac.uk/yaues/ues_event.htm.

**References**


Financing Long-Term Care for Older People
Raphael Wittenberg, Linda Pickard, Adelina Comas-Herrera, Derek King and Juliette Malley

The policy question
The question of how best to finance long-term care has prompted renewed debate since the publication of the report Securing Good Care for Older People (Wanless, 2006). The key issues are who is eligible for what publicly-funded care and with what user contributions, if any. Underlying the debate are concerns about both the future affordability of long-term care and the fairness of the current funding system.

The PSSRU long-term care financing model
The PSSRU long-term care financing programme, funded by the Department of Health, has developed a model to make projections of demand for long-term care by older people and associated expenditure, under clearly specified assumptions (Wittenberg et al., 2006).

The model has recently been updated to 2004 as base year and further development of the model is in progress. The model produces four types of projections: numbers of disabled older people likely to require long-term care, long-term care health and social services that will be required to meet demand, public and private expenditure on those services and on disability benefits, and social care workforce caring for older people.

Key projections
The PSSRU model does not forecast future policies or future patterns of care, but makes projections based on specific assumptions about future trends in key factors influencing demand for care. The base case projections take account of expected changes in factors external to long-term care policy, such as demographic trends, but hold constant policy-related factors, such as patterns of care and the funding system.

The latest base case projections project that the number of disabled older people will double between 2004 and 2041 to 4.6 million. The number of recipients of informal care is projected to increase from 1.7 million in 2004 to 3.3 million in 2041, assuming that receipt of informal care remains constant by age, gender, and marital status. Demand for formal services is also projected to increase between 2004 and 2041. This is reflected in a projected increase in total expenditure on services from £14.7 billion to £62.9 billion in constant 2004 prices.

Comparison with the projections from the previous version of the model are revealing. Expenditure as a percentage of GDP in 2041 was projected to reach 2.62% in the 2002 model compared to 3.07% in the 2004 model. This increase is driven by a real increase in expenditure on services between 2002 and 2004, reflecting especially an increase in home care services, and by changes in Treasury assumptions about future economic growth.

These projections are sensitive to the assumptions about key factors, such as trends in life expectancy, disability rates, supply of informal care, patterns of care and unit costs of care. An important finding from this study is that changes in these assumptions can have a significant effect on the projections (Wittenberg et al., 2006).
Marital status

The model incorporates the official 2003-based marital status/cohabitation projections (ONS, 2005) which show a rising proportion of older people who are married/cohabiting. It therefore takes into account a key aspect of expected changes in the supply of informal care, that is, changes in numbers of older people likely to have a spouse/partner. The projected percentage of the older population that would be de facto single in 2041 would be 45% using the ONS projections, rather than 48% if marital status rates remained unchanged. Long-term care expenditure is projected to reach 3.13% of GDP in 2041 under constant marital status rates, as against 3.07% under the base case (see figure 1). These extra costs, which arise because single people are more likely to receive formal services, are more likely to affect private than public expenditure, because single home-owners are generally required to use their housing assets to fund residential care.

Housing tenure

The model incorporates projections of housing tenure prepared by the University of Essex (Hancock et al., 2006). Housing tenure is included in the model because it is a simple socioeconomic variable for which projections are available and because it affects financing of care since home-owners generally are required to fund their own residential care. If the model had simply assumed that tenure rates, by household type, remained constant, projected total expenditure in 2041 would have been little different from the base case. Projected public expenditure, however, would have reached 1.99% of GDP compared to 1.94% under the base case (see figure 1). This difference reflects the high rates of home ownership amongst those currently aged 60 to 65 compared to those now aged 85 and over.

Future developments

The model produces base case projections on the basis of current patterns of care. These can be varied in scenarios to investigate the service, financial and workforce implications of different patterns of care. The research team are developing new scenarios involving changes in the supply of informal care by adult children and changes in the balance between residential and home-based care. They are also updating the social care workforce model using new data collected by Skills for Care – the National Minimum Data Set Social Care. This will enable the workforce projections to be more detailed, including variables such as job role. The model will then be able to investigate the impact that changes in demand for services or patterns of care will have on demand for different staff profiles.

Implications of the research findings

For projections to be robust, long-term care projection models need to take account of expected trends in a range of socio-demographic factors and not just trends in numbers of older people by age and gender. An important message for policy-makers is that they need to plan for uncertainty in future demand for long-term care for disabled older people.

References

One in four of us can expect to encounter mental health problems during our lifetime, so the impacts of poor mental health are – not surprisingly – enormous. What makes mental health unusual compared to physical ill-health problems are the many impacts outside the health system:

- stigma and discrimination are still pronounced;
- employment problems are widespread (in most European countries poor mental health is the leading or second most common cause of work cutback and premature retirement);
- many individuals find themselves homeless or in the criminal justice system.

The PSSRU’s Mental Health Economics and Policy programme is working to inform a better understanding of these social and economic impacts, and to generate knowledge of what solutions work, for whom, in what context or system structure and at what cost. Team members also aim to improve links between research and policy by providing expert advice to government and other bodies including the World Health Organization, European Commission, House of Lords and Scottish Parliament.

**Mental health in the United Kingdom**

**Estimating the costs of schizophrenia** One study recently estimated the total costs of schizophrenia in England in 2004/05 to be £6.7 billion (Mangalore and Knapp, 2007). Of this, direct costs of treatment and care were about £2 billion. Despite the shift of care away from hospital, health care costs of treating and supporting people with schizophrenia remain high. At the same time, the study again confirms that economic impacts extend well beyond the health system: nearly 80% of people with schizophrenia remain unemployed, incurring substantial productivity costs.

**Exploring equity and mental health** While there is a general recognition of the disadvantaged position of people with mental health problems, the extent of inequality, particularly its association with socio-economic characteristics, has not been widely studied. Using the Psychiatric Morbidity Survey 2000 for Great Britain, Roshni Mangalore and Martin Knapp, working with Rachel Jenkins (Institute of Psychiatry), examined income-related inequality in mental health. Results indicate a marked inequality unfavourable to lower income groups (Mangalore et al., 2007). The extent of this inequality increases with severity of problem; the greatest inequality is for psychosis. Much of the observed inequality is probably due to factors associated with income, many of which are potentially 'avoidable'.

**Impact of medication adherence** Derek King and Martin Knapp have been looking at how changes in service use and cost patterns are associated with the degree to which people with mental health problems (schizophrenia and depression) take the medications that they are prescribed. Links have been found between non-adherence to antipsychotic medication and higher costs; further research is ongoing to determine the impact of non-adherence over time. Another objective is to consider the impact of changes in schizophrenia treatment patterns on patient satisfaction. Derek and Martin, in partnership with Paul McCrone and Anita Patel (Institute of Psychiatry), presented a paper on the economic impact of non-adherence to medications using data from the multi-centre European QUATRO study at the recent International Health Economics Association conference in Copenhagen.
Understanding links between social exclusion and mental health
A systematic review, supported by the Gatsby Foundation, mapped the relationship between mental health and social exclusion, and factors that mediate impacts. Undertaking this review was complex, as described in a paper outlining the innovative process used, as well as challenges and opportunities for social scientists or multidisciplinary research teams carrying out similar reviews (Curran et al., 2007). Undertaken by Martin Knapp, David McDaid and Claire Curran, alongside Tania Burchardt and Bingqin Li from the LSE’s Centre for Analysis of Social Exclusion, work is ongoing to explore specific aspects of social exclusion and their relationship with mental health problems, funded by Mr and Mrs Brodersen, LSE alumni.

International mental health

Comparative analysis of mental health systems The PSSRU is involved in many cross-national mental health projects. The 32-country Mental Health Economics European Network (MHEEN), supported by the European Commission (EC), and coordinated by Martin Knapp, David McDaid and Helena Medeiros, has collated data on organisation and funding of services, the economic case for promotion of well-being and prevention of illness, impacts on employment and economic influences on service provision. The second phase of analysis will be completed by the end of 2007. Recently the Journal of Mental Health published six papers linked to phase 1 work covering 17 countries (Knapp and McDaid, 2007). Other recent MHEEN outputs include a review of economic evaluations in prevention and promotion (Zechmeister et al., 2008). A comparison of differences in economic incentive structures to promote workplace mental health in Europe and North America has also been recently published (Dewa et al., 2007).

Balancing institutional and community-based care The EC have also funded a study looking at the balance of institutional, as compared to community services for people with disabilities (broadly defined), and the evidence to support a shift away from such heavy reliance on institutional services in many European countries. Martin Knapp and Jeni Beecham (LSE) are working with Jim Mansell, Julie Beadle-Brown and Robert Hayward (University of Kent), as well as colleagues across Europe, in providing the first comprehensive statistical charting of institutional care (for people with physical or intellectual disabilities, sensory impairments, mental health needs). The report to the EC will be submitted towards the end of 2007.

Evaluating supported employment interventions Individual Placement and Support (IPS), where people with mental health problems are placed in open employment, has proved successful in the US in helping individuals sustain employment. The extent to which this approach might work in the very different European labour markets has been evaluated by a team from St George’s Medical School, London, with funding from the EC, through a six-country randomised controlled trial (EQOLISE). Martin Knapp, Adelina Comas-Herrera and Claire Curran (LSE), together with Anita Patel (Institute of Psychiatry) carried out a cost-effectiveness evaluation of IPS compared to standard vocational services and also looked into economic and policy contexts that might shape findings. Publications are due later this year.

References
The White Paper ‘Our health, our care, our say’ (Cm 6737) identified that a key aspect of social care policy is to provide a wide range of supported housing options. This research programme aims to improve the evidence base concerning housing and care arrangements for older people by investigating what works best, for whom, and at what cost. The programme is currently focusing on an evaluation of the extra care housing initiative and associated projects (see below). In addition, we have recently started a study partly funded by the Registered Nursing Home Association of the views and experiences of people newly admitted to care homes (see page 28).

Evaluation of the Extra Care Housing Initiative

The Extra Care Housing Fund provided £87 million for 2004–06, and a further £60 million for 2006–08, to develop innovative housing with care options for older people and stimulate effective local partnerships. PSSRU is undertaking an evaluation of 19 new build schemes funded in 2004–06, including three care villages and 16 smaller developments. The evaluation is examining the development of the schemes and following the residents’ service use, experiences and health over time.

In addition to the work funded by the Department of Health, the PSSRU has been awarded funding for three further studies that will complement the main evaluation. Two of the projects are supported by the Joseph Rowntree Foundation (JRF): a study of the development of social activity and community involvement in extra care (see below); and an in-depth study of one scheme to investigate and compare costs to all stakeholders before and after residents move into extra care. The third study is a joint project with colleagues from the University of Sheffield funded by the Engineering and Physical Sciences Research Council (EPSRC) to develop a tool for evaluating the design of schemes.

Seven of the 19 schemes opened in 2006 and a further three during the first half of 2007. Five more schemes are expected to open in 2007. Here we compare 239 residents who moved into the schemes that opened in 2006 with 820 residents admitted to care homes in early 2005 (Darton et al., 2006).

Characteristics of residents in extra care  Figure 1 shows that, compared with people moving into care homes, people who moved into extra care were younger, more likely to be male and less likely to be widowed or living alone prior to moving. The majority (85%) had been living in their own home or sheltered housing, whereas nearly two-thirds of the people admitted to care homes had been in hospital or a care home or had been receiving intermediate care. A slightly higher proportion had been renting their previous accommodation than among those who were admitted to a care home, as may be expected from the predominance of rented accommodation in the schemes.

Physical and cognitive functioning were measured by the Barthel Index and the Minimum Data Set Cognitive Performance Scale. Overall, the people who moved into extra care were substantially less physically and cognitively impaired than those who moved into care homes. The schemes have been developed to support residents with a range of levels of disability, and to provide an alternative to residential care for at least some individuals. Typically, the schemes are aiming for a balance of residents with high, medium and low care needs. Thirty per cent of residents had higher levels of
impairment (Barthel scores of 0–12 (max. 20)), suggesting that this is being achieved. Some of the schemes are aiming specifically to support residents with dementia, including one that opened in 2006, but most prefer to admit residents with fewer problems of cognitive functioning so that they can become familiar with their new accommodation before the development of more severe impairment. The low level of severe cognitive impairment among the new residents is consistent with this. However, it should be noted that the information presented here is based on the residents who have moved into the first few schemes, and the position may change once all the schemes have become established.

**Figure 1 Characteristics of new residents in extra care and care homes**

![Figure 1 Characteristics of new residents in extra care and care homes](image)

**Social well-being in extra care** The schemes being evaluated have put forward a variety of proposals for addressing social activity and community participation that are being evaluated by a JRF-funded study. Data are being collected from residents and staff six months after opening to identify how the social life develops initially, followed by resident views of the social life, levels of participation, well-being, and social climate of the scheme at 12 months.

Initial findings from the schemes that opened in 2006 indicate that resident involvement is key to schemes’ approaches to social activity: most scheme managers used the term ‘user-led’ in describing their approach. In practice, the user-led approach is played out differently across the schemes. Some schemes have a very active residents’ committee that organises social activities, while other residents’ committees take on a more consultative role regarding the social life at the scheme.

Certain facilities are emerging as important to the development of the social life of the schemes. Shops can provide an opportunity to get to know other residents, and in one scheme the shop was described as a catalyst to integration between residents. Restaurants can aid friendship development, particularly when residents eat a midday meal together.

Two schemes in particular see themselves as community resources, and most other schemes were aiming towards this: it was felt that both residents and the local community could benefit. In general, residents commented positively about people coming into the scheme, giving reasons such as the added opportunity for social interaction, and the financial benefit to the scheme.

**References**


Assessment of Older People in Care Homes
Angela Worden, David Challis and Irene Pedersen

Although assessment of older people living in the community has come progressively to the fore in government policy, less emphasis has been placed upon assessment in care homes. This is in contrast to the US where the Minimum Data Set/Resident Assessment Instrument (MDS/RAI), a systematic assessment, which can be used for both research and quality measurement, has been mandated for use in nursing homes (Challis et al., 2000). Thus, little is known about assessment in care homes in the UK.

In a recent research project, assessment forms collected from 126 care homes in Manchester and Cheshire were analysed using a form of content analysis developed from that employed previously (Stewart et al., 1999). This identified the presence or absence of four attributes – coverage, structure, detail and standardised scales – against 49 domains of assessment derived from the MDS/RAI, the National Service Framework for Older People (Department of Health, 2001a) and an additional domain reflecting the importance of end of life care in the National Minimum Standards for Care Homes (Department of Health, 2001b).

Box 1 gives some key findings from this project.

This study has identified a number of shortcomings in assessment tools, although it was carried out before the implementation of the National Minimum Standards in Care Homes (Department of Health, 2001b). However, findings from inspections for the year 2002 to 2003 suggest that only 57% of homes met or exceeded the National Minimum Standard on needs assessment (Dalley et al., 2004) confirming that there is still much scope for improvement if continuity of care is to be provided for vulnerable older people.

References

Quality Measurement Framework
James Caiels, Julien Forder, Ann Netten, Ann-Marie Towers and Jan Smith

The Quality Measurement Framework (QMF) programme is being funded for three years by the Treasury under Invest to Save and led by the Office of National Statistics (ONS). The aim of the programme is to create entirely new mechanisms for more effective and efficient measurement and monitoring of third sector provision of public services, reducing the burden on the third sector while releasing cash through more efficient use of public funds to provide public services. The purpose is to develop methodologies for measuring and assessing the value added of the relevant public services. They will constitute a framework/tool so that service commissioning authorities can assess and monitor the performance of public services delivered by third sector organisations in a way directly comparable with performance of public or private sector providers.

The work builds on previous research commissioned to feed into the Atkinson review of the measurement of government outputs and productivity for the purposes of National Accounts. This developed an approach which uses research findings and routinely collected information to identify the value of the outputs of services or interventions in terms of their potential to achieve (capacity for benefit) and the degree to which this is achieved (quality) (Netten, Forder and Shapiro, 2006).

The programme will last three years in total, starting in January 2007. The PSSRU will carry out four research projects:
- Measuring and monitoring the quality of outputs of care homes*
- Estimating and monitoring the quality of outputs of low level interventions
- The value of information and advice services
- A population preference study

There is a range of practical considerations in how to measure the outcomes of social care services, having identified what to measure. The conceptual work highlights the complexity and range of options in developing outcome measurement tools in social care. Key design questions include: relevance; measurability; attribution and association; aggregation; comprehensiveness; and universality. Initial conclusions are to adopt an inferred wellbeing approach based on a set of measurable outcomes or functionings. The theoretical basis is with Sen’s functionings and capabilities approach (Alkire, 2002; Gasper, 1997; Robeyns, 2003; Sen, 1982, 1993). This strategy is also consistent with the work on the older people’s utility scale (OPUS) (Netten et al., 2002). Questions that remain at this stage include finding the balance between more ‘final’ outcome dimensions and the use of more service-specific proxy measures. Also to resolve is the question of how to incorporate subjective happiness into the measure (if at all), how to balance capability against actual outcome achievement, and how to frame and anchor levels of achievement of outcomes. This work will culminate in the development of the Adult Social Care Outcomes Toolkit (ASCOT).

References

* With Dr Julie Beadle-Brown and Professor Jim Mansell of the Tizard Centre, University of Kent
Partnerships for Older People Projects
Julien Forder

In 2006 the Department of Health established the Partnerships for Older People Projects (POPP), with 19 pilot local authority sites and 48 (at the time) PCT partners. The aim of the projects was to shift resources and ‘culture’ away from the focus on institutionalised and hospital-based crisis care towards earlier and better targeted interventions within community settings. PSSRU has undertaken an analysis of impact of the projects on the use of hospital bed-days. The expectation was that POPP would generate a reduction in use of emergency bed-days per month for people over 65 from the 5000 or so PCT average (up to December 2006).

An extract of 9999 PCT-months of data for the period between April 2004 and December 2006 was interrogated using a difference-in-difference model. The model was used to predict the hypothetical bed-day use in POPP PCTs at the time the projects were in operation (from April 2006) if the projects had been absent. This was done by benchmarking against non-POPP PCTs and non-POPP time trends. The result was compared with the actual bed-day use in the POPP PCTs to see if there was any difference.

The main result was that the operation of a POPP project compared to having no POPP project in same POPP PCT was associated with a reduction in emergency bed-days of 137 per month (or approximately £16,000 per month). Put in cost terms, a £1 increase in spend on the average POPP project would result in around a £1 reduction in the cost of emergency bed-day use in hospital. Figure 1 gives the month-by-month results.

The main conclusions are that POPP does have a statistically significant effect on hospital use (coming mainly through reductions in admission). However, it was not possible to identify the ‘cause’ of the savings as such with this study design. Also to be addressed: will the savings persist after nine months; are the Hospital Episode Statistics data of good enough quality; are we missing some other confounding effects? Furthermore, this is cost analysis and says nothing about people’s outcomes. But overall the results are more than encouraging and certainly justify continuation of the pilots. They make a strong case for specific randomised/control group study at an individual level.
The Design and Use of Local Metrics to Evaluate Performance: A Comparative Analysis of Social Care Organisations

Sue Davies, Paul Clarkson, David Challis with Michael Donnelly* and Roger Beech†

This PSSRU project has been funded by the Economic and Social Research Council (ESRC) as part of the Public Services Quality, Performance and Delivery Programme. With little existing knowledge regarding local performance monitoring practices there is a need to better understand how local authorities measure and manage their own performance and how this relates to centrally-set performance ratings. The study investigates the measurement of local performance in the provision of social care services for older people in England and Northern Ireland and how this relates to national performance.

The study will have a number of stages (box 1), each of which reflects the research aims.

Box 1 Summary of Research Stages

- A questionnaire survey of local authorities in England and Northern Ireland to assess the variation in local systems of performance measurement
- Multivariate analysis of items from the questionnaire survey with national performance data to examine the relationship between local data use, processes and environment with the rating of organisations nationally
- A series of interviews with managers in selected authorities to supplement statistical findings
- Cross country comparisons to assess how top-down approaches to measuring performance in England compare with more locally based approaches in Northern Ireland and Japan.

A comprehensive literature review has explored the issues in social care performance measurement. The key findings of the review include:

- A lack of prior empirical research has been undertaken concerning local performance measurement and monitoring regimes, particularly in social care.
- Recent government proposals emphasising the importance of the identification and monitoring of local issues bring the issue of local performance management to centre stage.
- A number of principles of effective performance management have been outlined in the review and have been used in the construction of the questionnaire to help determine if national measures are used primarily as a guide to local management in preference to locally-derived ones.
- The nature of performance measurement in England has generated unintentional consequences. Processes related to these consequences may influence how performance data are used by an authority and may along with social desirability bias lead to cautious responses from managers.
- Performance may be influenced by particular aspects of both internally managed operations, such as strategy and culture and also by the characteristics of a local authority’s external environment, not all within management control.

The design of the study has been informed by this work with these issues being addressed by the national survey taking place in 2007/08.
After Transition: Health and Social Care Needs of Young Adults with Long-Term Neurological Conditions

Jennifer Beecham, Tom Snell, Margaret Perkins and Martin Knapp

The Neurological Alliance (2003) has estimated that 10 million people in the UK are living with a neurological condition, over 8 million of whom manage their daily lives with short-term support. More than 1 million need some help with daily tasks and will be out of full-time employment, including most people with congenital conditions, acquired brain injury or illness, and those who have had a stroke or who live with motor neurone disease, multiple sclerosis, Parkinson’s disease or dementia. There are also about 350,000 people who require help for most of their daily activities.

The National Service Framework for Long-Term Conditions (Department of Health, 2005) lays down care standards that people with long-term neurological conditions should be able to expect from services. These include early recognition, specialist and community rehabilitation, vocational rehabilitation, equipment and accommodation, and personal care and support.

Transition – service needs and costs

Young people with long-term neurological conditions who are facing the transition from child to adult services often encounter particular challenges. Accessing the right support has been seen by many people as key in achieving independence and maximising opportunities to contribute to society and is an important policy concern.

There has been little work on the costs of services required to enable young adults with these conditions to live independently. PSSRU was asked by the DH to look at young adults with neurological conditions who have started to be supported by adult services. Links were made with the Department’s Research Initiative for Long Term Neurological Conditions (www.ltnc.org.uk) which started in 2007.

From the large number of neurological conditions relevant to this study, three were selected because of their relatively high prevalence, and because they encompass a range of impairments found among those with long-term conditions:

- Epilepsy is an intermittent condition, often stabilised with medication but where specialist services are needed during acute episodes or to respond to changing development or age-related needs.
- Cerebral palsy is an early onset condition that can have serious consequences for a child’s life that continue into adulthood.
- Acquired brain injury is a sudden onset disorder, often affecting people in this age group, where there is higher-than-average incidence of trauma from car accidents and sporting activities.

For each we addressed the same questions:

- What health and social care supports and services are currently used by young adults with these conditions?
- What are the costs of these health and social care supports?
- What unmet needs for health and social care services do they have?

Here we concentrate on cerebral palsy. Our full report will be available in 2008.
Cerebral palsy (CP) covers a group of disorders that are permanent but not unchanging. Most people with CP (91%) have spastic cerebral palsy in which some muscles become stiff and weak, affecting their movement.

Our estimates show that at any one time CP will affect 9,400 young adults in the UK aged between 18 and 25 years. Around half of this group will have moderate to severe ambulatory disability and a similar proportion will have a moderate to severe manual disability. At least one in ten young adults with CP will have epilepsy, and about half will have moderate to severe intellectual disability.

Only five UK studies of young adults with CP were found that quantified health and social care needs or reported the costs of support. A common finding was that, compared to children, fewer young adults were using support services, and – where services were still used – it was at a lower intensity than before.

Only about 7% of young adults with CP are living in a staffed care setting; the great majority live with their parents. Around half of these young adults will be attending further education establishments, but one in six is not involved in constructive activity during the day and may have poorer quality of life as a result.

GPs and out-patient clinics are the most commonly used health care services. Although about a quarter of the young adults will be using physiotherapy, there appears to be considerable under-provision of this service. These young adults also want better access to counselling, orthopaedic and neurology services, and occupational therapy.

Just one in five young adults with CP is in contact with a social worker, yet research shows that this contact is a key resource for getting access to respite care. Contact with social services is similarly a pre-requisite for grants to adapt homes, referrals to housing departments, supported living grants and direct payments. We found no information on the levels of personal support required by young adults with CP yet such support is crucial in helping them achieve independent lives.

Costs of health and social care for a typical person with CP are £7,900 per annum (2005 prices), although this excludes the costs of transport help, aids and equipment, or formal (paid) personal assistance at home or in education. Our estimate for personal assistance would almost double the costs to health and social care services, adding £6,600 per person per year. There is likely to be a steep gradient linking costs to disability level.

Addressing unmet needs for community-based therapy would add another £800 per year to the costs of the ‘typical’ person with CP. For those currently unoccupied during the day, attendance at day activities (£1,730) or further education (£1,440) would increase costs again.

The total health and social care costs for supporting young adults with CP in the UK are estimated at £74.3 million or £136.6 million if the costs for formal (paid) personal assistance are included.

References


Dementia: Contributing to the National Debate
Martin Knapp, Adelina Comas-Herrera, José-Luis Fernández, Catherine Henderson, Juliette Malley and Tom Snell

The ageing of the population is focusing attention on the needs of older people, the services required to meet them, and how to finance those services in affordable, efficient, politically acceptable ways. These are enduring themes of PSSRU research, exemplified by the work of the Long-Term Care Finance programme at LSE (pp. 14–15) and the Unit’s analyses for the 2006 Wanless report. Recent dementia studies at LSE have continued in this vein.

Dementia costs the UK £17 billion a year. This was one of the many findings from Dementia UK, commissioned by the Alzheimer’s Society from a team at King’s College London and the LSE (Knapp et al., 2007a). Two-thirds of people with dementia live in the community, with the imputed costs of unpaid care by families amounting to over £6 billion a year. Delaying the onset of dementia by five years would halve the 60,000 deaths a year directly attributable to it. These and other findings were built on new prevalence estimates, which also generated the projection that there will be over 1 million people in the UK with dementia by 2050.

In a separate study funded by the Alzheimer’s Research Trust, projections were made of numbers of older people with cognitive impairment and the associated costs of their support (Comas-Herrera et al., 2007). Expenditure in England on long-term care for this group is projected to rise from £5.4 to £16.7 billion between 2002 and 2031. The challenge for financing mechanisms is considerable.

In July, the National Audit Office (NAO) published Improving Services and Support for People with Dementia. PSSRU research contributed in numerous ways, including two commissioned studies. A review of dementia care made comparisons between countries (Knapp et al., 2007b). Prevalence rates vary little, but care systems identify and diagnose dementia in different ways, and identify and assess needs in sometimes distinct ways. Markedly variable amounts of resources are allocated to meet those needs, channelled through various financing mechanisms, and treatment and support arrangements also diverge.

The NAO also commissioned an assessment of in-patient stay for people with fractured neck of femur who also have dementia and how services might be improved. Costs associated with delayed discharges from acute care were estimated, and potential savings investigated (Henderson et al., 2007). A simple model was developed to show the expenditure required to treat hip fracture patients compared to psychiatrically well patients. Potential cost savings arose from some models of good practice, such as early supported discharge schemes and geriatric hip fracture programmes. Generally, however, the evidence base on interventions remains quite limited.

Dementia research will continue to feature significantly in the Unit’s future work programme.

References

Individual Budgets: Some Early Findings

Individual budgets collate different streams of funding into a single user-controlled budget for the purchase of social care services, offering transparency, choice and control. Pilot projects are underway in 13 English local authorities and a major evaluation of this programme is being undertaken by the PSSRU, the Social Policy Research Unit and the Social Care Workforce Research Unit. Although both pilots and evaluation are ongoing, a number of early messages have emerged and are summarised in the box below.

Implementation Issues

- Resource allocation systems (RASs) to turn assessments into individual budgets are taking time to formulate and test. Most sites have implemented different RASs for different client groups, but the Department of Health have since requested that a single RAS be developed.
- Re-allocating money systematically according to needs and priorities has produced both winners and losers. Where support packages have significantly decreased, local authorities have commonly offered transitional payments as a temporary buffer.
- Integrating certain funding streams has proved quite difficult, especially where there are strict criteria or legislative barriers to flexible use.
- Individual budgets pose a number of challenges to financial planning, including keeping packages cost-neutral, costing in-house service provision and aligning assessment processes with charging policies.

Training and development

- Barriers to effective training include a perceived professional threat to care managers, resistance to change, the timing of training in relation to the project’s development, and organisational restructuring.
- Opportunities have been perceived in some care managers’ enthusiasm for redefining professional roles, links to other policy initiatives and funding streams, and senior management support.

Costs

- Subject to a number of assumptions, the mean cost of setting up individual budgets in the first year was estimated at £270,000. Second year set-up costs ranged between £140,000 and £170,000.
- Lower costs can be expected where individual budget systems are located within existing infrastructure e.g. IT systems. Higher costs are expected where individual budgets are offered to multiple client groups and/or more service users.

Users’ experiences

Early cases may be unrepresentative of individual budget recipients in the longer term. However,

- Service users generally felt that individual budgets offered more choice and flexibility and saw self-assessment as simpler and more empowering than conventional approaches.
- There were mixed views about the possible impact of individual budgets on informal carers. While some people believed they offered more opportunity to plan long-term support, relieving pressure on carers, others felt that the management of support arrangements required greater input from carers.
- Some individuals were confused over what they could and could not use their individual budget for and said they lacked information.
- Users stressed the importance of support from outside their own caring networks. Access to free brokerage, professional advocates and/or mentoring by someone who had been through the individual budgets process was seen as crucial.
New Projects

These two pages highlight some of our current and planned work. For a more comprehensive outline of the PSSRU programme of research with details of publications, see the section starting on page 30.

Outcomes and Quality of Services for Carers

Kent County Council (KCC) has commissioned the PSSRU at the University of Kent to explore the outcomes and quality of social care services for carers.

The study aims to establish the key aspects of quality and domains of outcome and other contextual and process related factors associated with quality variation in services for carers. This information will be used to design a survey of carers’ experiences for use by KCC. The work builds on the approach to measuring quality and outcomes developed by the PSSRU in relation to home care services for older people, services delivered to younger adults with physical and sensory impairments, and equipment services.

The staff involved in the project include Jacquetta Holder, Ann Netten, Nick Smith and Juliette Malley.

National Trends and Local Delivery in Old Age Mental Health Services: towards an evidence base

The PSSRU at Manchester is to lead a major programme of work to explore the cost-effectiveness of different ways of structuring and delivering services for older people with mental health problems. This four-year project is funded by the National Institute for Health Research and has two main strands: an examination of the mix of in-patient, residential and community services needed in localities and the balance of provision between primary and secondary care; and an exploration of those factors which make for effective working in community mental health teams for older people. These will be complemented by three national surveys of NHS Trusts.

PSSRU staff working on this project include David Challis, Sue Tucker, Dave Jolley and Martin Knapp.

Care Home Residents’ and Relatives’ Expectations and Experiences

This study based at the Kent branch will examine the differences between older people’s expectations and experiences of living in a care home. There is anecdotal evidence that although people dread moving into a care home, their experiences once there are very different. The Registered Nursing Home Association approached the PSSRU to examine the neglected area of residents’ own views of living in care homes. The Department of Health also agreed to support the study, in particular to examine concerns about the possibility of abuse of residents in care homes.

The study involves a survey of new residents admitted to care homes for older people in England for long-term care over a three-month period. The methodology has been developed in collaboration with the British Market Research Bureau (BMRB). Residents will be interviewed two to three weeks after admission to collect background demographic information, information on their care needs, their reasons for moving into a care home and their expectations about care homes. A second interview three months later will focus on residents’ experiences of living in a care home and examine whether their expectations had been borne out by their experience so far. Parallel surveys of relatives will be conducted where residents are unable to participate themselves.

For further information contact Robin Darton.

EVOLVE: Evaluation of Older People’s Living Environments

The Engineering and Physical Sciences Research Council is funding a three year research project to evaluate emerging models of extra care housing for older people. This is a cross-disciplinary project which will develop a design evaluation tool for new and upgraded housing schemes and survey the quality of life of people living in extra care housing.

Ann Netten and Robin Darton of PSSRU at the University of Kent are working with Judith Torrington, Kevin McKee and Sarah Barnes at the University of Sheffield and the project partners are Elderly Accommodation Counsel and the Department of Health Housing Learning and Improvement Network.

Recruitment and Retention of the Social Care Workforce for Older People

This Department of Health project, which is being undertaken jointly with Jill Rubery and colleagues at the Manchester Business School, explores the influence of key environmental, organisational and work factors on the recruitment and retention of the social care workforce for vulnerable older people. The project has three stages:

- A national postal survey to explore local variations in the policy and practice of commissioning in English local authorities.
- Telephone interviews with independent and in-house providers of domiciliary and residential care, and with key actors responsible for commissioning arrangements, in a number of systematically selected sites.
- In-depth case studies of selected providers, both in-house and external.

This research will identify good practice in policy/ commissioning and provider practices relating to the recruitment and retention of social care staff.

The PSSRU staff involved with this project are: David Challis, Jane Hughes and Helen Chester.

Evaluating the Implementation of Active Case Management in Greater Manchester

This study, funded by the Department of Health and supported by the Association of Primary Care Trusts (PCTs) in Greater Manchester, will investigate whether service utilisation outcomes are associated with different approaches
NEW PROJECTS

to active case management (ACM) for people with long-term conditions. The project will collect data from ten Greater Manchester PCTs and conduct a questionnaire and follow up interview with the lead for ACM. Taking advantage of the Tactical Information System, which is an online access and analysis tool, resource utilisation outcome data for patients who have received the ACM service will also be explored.

The PSSRU staff working on this project are David Challis, Jane Hughes, Siobhan Reilly, Kathryn Berzins and Jessica Abell.

Strategic Commissioning

Two of the principal drivers for public service reform in the health and social care sectors are the promotion of public and user involvement and the strengthening of commissioning processes. This project addresses both issues through its focus on the more effective involvement of older people in commissioning.

The research is being funded by the Joseph Rowntree Foundation as part of its Independent Living Programme. It has been designed to obtain a more complete picture of how older people are being engaged in different components and levels of commissioning. The project has three main aims:

- To extend understanding of participation by older people in the commissioning process at individual, locality, and strategic levels.
- To understand the tensions and connections between those levels.
- To develop a framework that will specify how to ensure meaningful contributions from older people in the development and design of services at different stages of the commissioning process.

This work has significant potential to influence policy and practice in a context where commissioning capacities and capabilities are seen to be in need of reinforcement. It is being conducted by Vanessa Davey, Eileen Waddington and Gerald Wistow.

Economics of Early Intervention Services: scoping study

This exploratory project by Martin Knapp and Roshni Mangalore, in collaboration with Paul McCrone from the Centre for the Economics of Mental Health at the Institute of Psychiatry, is looking at what data might be available to allow the building of economic models of early intervention for psychosis. Building on earlier work that produced a general model to estimate the economic impact of early intervention services, this new scoping study focuses on the possibilities for further work in relation to young people, offenders, people from black and minority ethnic groups, rural areas and suicide, as well as considering the cost of lost opportunities. The study is funded by the Department of Health.

Local Evaluation of the Kent POPP Project

Independence through the Voluntary Action of Kent’s Elders (INVOKE) is one of nine projects in the second round of the Partnerships for Older People Projects (POPPs). INVOKE has the following aims:

- To support independence and interdependence through the creation of new forms of support: providing the extra assistance older people need when facing life-changing circumstances that could affect their long-term health.
- To put older people in personal control, providing integrated care and support through joint working across public and voluntary sectors.
- To focus on the prevention of ill health and the promotion of wellbeing, allowing older people to be both healthy and independent.

A key purpose of the local evaluation, which is being conducted by Margaret Perkins, Catherine Henderson and Martin Knapp, is to examine the extent to which INVOKE meets its objectives over the period from September 2007 to July 2009. The local evaluation will also assist the national POPP evaluation.

Self Care and Case Management in Long-Term Conditions

The NHS Service Delivery Organisation (SDO) R&D programme is funding this research at PSSRU Manchester, to investigate the role of self-care for people with highly complex multiple long-term conditions.

The study will map current provision of NHS case management services in primary care for people with long-term conditions; identify self-care initiatives within this service; classify programmes on features of case management implementation with a focus upon integration between primary and secondary care and health and social care and investigate self-care initiatives in service entry and exit.

It employs a mixed method approach incorporating a national postal questionnaire survey; comparison with existing data on care management arrangements for vulnerable adults and older people; a detailed investigation of different forms of case management arrangements; interviews with case managers and PCT lead officers; and focus groups with service users.

PSSRU staff working on this project are David Challis, Jane Hughes, Siobhan Reilly, Kathryn Berzins and Jessica Abell. For further information contact Kathryn.Berzins@manchester.ac.uk.

Externally Led Projects

LSE staff are contributing to a number of other studies, including:

- Developing the evidence base for mental health promotion and prevention in Europe: A database of programmes and the production of guidelines for policy and practice (DataPREV) – a multi-country 6th Framework European project led by Radboud University, the Netherlands.
- The economic impact of crisis resolution teams – a short-term study funded by the National Audit Office and led by the Centre for the Economics of Mental Health at the Institute of Psychiatry.
- The Schizophrenia Trial of Aripiprazole (STAR) – a 26-week naturalistic study funded by Bristol Myers Squibb.
- Development of a Social Inclusion Index to capture subjective and objective life domains – a multi-centre project funded by the UK National Institute for Health Research Health Technology Assessment Methodology Programme and led by the Department of Applied Social Science at the University of Swansea.
Current Research Projects and Recent Publications

These pages give a brief listing of most work current at September 2007, categorised by programme (groups of related studies) and individual projects or clusters of projects, which are shown in bold.

Also listed under each programme of work are relevant publications by PSSRU authors (often in collaboration with colleagues at other institutions) since the previous Bulletin in November 2006. Articles are arranged in alphabetical order of title.

Assessment and Performance Measurement

Programme leader: Professor David Challis
See pages 6–7 for more information on work in this programme.

The Unit has a tradition of work in relation to assessment of older people’s needs both in research and development. Current and planned work will examine changes in assessment processes, its impact and consequent effects upon roles of staff as new assessment processes develop. Changes occurring in performance management processes will be examined. With regard to both the assessment of older people and developments in care coordination, the planned work is designed to identify and explore the impacts of the new arrangements through examination of new patterns of working, the contribution of different professional groups and organisations, and the experiences of service users and their carers. Work is underway in two areas:

Assessment processes: staff involvement, care pathways and service outcomes

There are two significant pieces of work underway. The first involves the evaluation of the implementation of the Single Assessment Process from the perspective of multiple stakeholders. It has included a national survey of lead officers, examination of the involvement of geriatricians and old age psychiatrists, a detailed before/after examination of assessment processes in three local authorities, delimitation of the effects of SAP processes on assessment quality by practitioners also using a before/after design, and an examination of the impact upon user satisfaction with assessment processes.

The second study involves the evaluation of the piloting of a range of approaches to self assessment in 11 local authorities selected by the DH. The self assessment processes are mainly directed to facilitating access to equipment services, but some also involve pre-assessment guidance and advice, and access to other services.

Performance measurement

This part of the programme aims to explore the use of these indicators and associated techniques at both national and local levels. A new study, funded by the ESRC’s Public Services Programme, is examining the links between national and local performance through a survey in England and Northern Ireland.

Recent publications from this programme

A cluster randomised trial to reduce the unmet needs of people with dementia living in residential care
International Journal of Geriatric Psychiatry, 22, 11, 1127–1134

Depressed mood, cognitive impairment and survival in older people admitted to care homes in England
American Journal of Geriatric Psychiatry, 15, 8, 708–715

Factors associated with higher quality assessment tools in care homes
Journal of Care Services Management, 2, 1, 79–91

Implementing the Single Assessment Process for older people in England: Lessons from the literature
Abendstern, M., Clarkson, P., Challis, D., Hughes, J. and Sutcliffe, C.
Research, Policy and Planning, forthcoming

Specialist clinical assessment of vulnerable older people: Outcomes for carers from a randomised controlled trial
Ageing and Society, 26, 6, 867–882

Services for Children and Young People

Programme leader: Professor Jennifer Beecham
See pages 24–25 for more information on work in this programme.

Focusing on children and young people who have additional needs and who use specialist services alongside universal supports, this programme brings an economic perspective to studies of cross-agency service provision and use of services. It has its roots in the earlier Economics of Social Care programme but reflects the broader vision found in the Change for Children policy agenda. Current research includes exploring support for disabled children, mental health services, adoption services, specialist foster care, and the interfaces between health, education and social care. Strong links are maintained with the Mental Health Economics and Policy programme and the Centre for the Economics of Mental Health at the Institute of Psychiatry, London.

Access to child and adolescent mental health services

In this project we will build on work already undertaken with adult mental health services to explore two issues; the potential for access through availability of services, and the actual access made as indicated by utilisation rates of child and adolescent mental health services (CAMHS).

Models of multi-agency services for transition to adult services for disabled young people and those with complex health needs: impact and costs

This study is undertaken in collaboration with researchers at the Social Policy Research Unit, University of York. There is considerable evidence from research that, for most young people with disabilities or complex health needs, the process of transition from child to adult services is problematic. Current policy developments and the growth of multi-agency working may lead to improvements in this situation. However, there is little research which can identify the components of models of good practice in transition services or the costs of such services. This research will address both these issues in order to inform good practice in services for disabled young people and their families at transition.

Health, social care and education interface

Provision of integrated services is a central component of the policy to improve access to a range of supports for children and families. This project will identify these ‘interface’ services and explore the ways in which they are provided, to whom and at what cost. The focus is on the way that health services are supporting particular groups of children in a range of non-health settings.
An investigation of linking and matching in adoption
Little is known about what makes a good match in adoption or how much it might cost. A national survey will provide a broad picture of linking and matching practices. Innovative as well as more routine approaches will be examined in more detail through a catch-up prospective study of 150 children from 5–10 adoption agencies in the public and voluntary sectors. In collaboration with researchers at the School for Policy Studies, University of Bristol.

An exploration of different models of key worker services for disabled children and their families: effectiveness and costs
Research has shown that families of disabled children who have a key worker benefit from this service and recent policy initiatives emphasise the importance of such provision. Alongside the recent expansion of these services (30 were found in a recent national survey) has come a proliferation of models of service delivery. Findings from this study, undertaken with researchers at the Social Policy Research Unit, University of York, are reported in the journal articles listed at the end of this section.

Education services for young people living away from home
This study, in collaboration with researchers at the Department of Applied Social Studies, University of Bedfordshire, was funded under the Department of Health Quality Protects research initiative. The research focused on quality of care for different groups of ‘difficult to manage’ adolescents living away from home, educational and wider outcomes and the costs of care and education services they used. Publications will be available shortly.

Recent publications from this programme
Foster carer training, Resources, payment and support
Adoption and Fostering, 30, 3, Autumn, 6–16

Gaining satisfaction? An exploration of foster carers’ attitudes to payment
Kirton, D., Ogilvie, K. and Beecham, J. (2007)
British Journal of Social Work, 37, 1205–1224

Key worker services for disabled children: the views of parents
Children & Society, 21, 162–174

Social services support and expenditure for children with autism
Autism, 11, 43, 43–61

Still the poor relations? Perspectives on valuing and listening to foster carers
Kirton, D., Ogilvie, K. and Beecham, J. (2007)
Adoption & Fostering, 31, 3, 6–17

The costs of key worker support for disabled children and their families
Child: Care, Health & Development, 33, 5, 611–618

Why costs vary in children’s care services
Beecham, J. (2006)
Journal of Children’s Services, 1, 3, November, 50–62

Commissioning and Performance
Programme leader: Professor Martin Knapp
See pages 8–9 for information on previous work in this programme.
The Commissioning and Performance programme describes and evaluates key aspects of social care, particularly focussing on commissioning, service provision, market development and choice. This work builds on earlier work that looked at social care markets. Currently, the programme is concentrating on:

- Balance of care: examining the range and balance of services needed to provide cost-effective and equitable outcomes, and the interaction between social care and other services, particularly health care.
- Care services evaluations: including for instance the national evaluation of the Whole Systems Demonstrators pilots.
- Consumer-directed care: exploring commissioning of services by users, through direct payments and individual budgets.
- Local variations: exploring the extent of, and factors associated with, the marked variability in social care provision patterns, including funding, eligibility, service mix, costs and outcomes.
- European social care: examining recent trends in social care policies in Europe.

In addition to projects mentioned elsewhere (pages 8–9) the following are underway.

Choice and direct payments for adult mental health service users
Direct payments have been seen as a central policy instrument in recent years to promote choice and independence for service users, yet various reports highlight difficulties in advancing uptake among mental health service users. This work is investigating how choice and direct payments are being promoted, through the views of care coordinators in integrated community mental health teams.

Institutional and community care balance and costs
This project examined the economic challenges of developing community-based services as alternatives to institutions for disabled people across Europe. It assessed (i) the number of people with disabilities in institutional care in 28 European countries, and (ii) the costs and policy dilemmas involved in replacing care in institutions with a system of community-based services.

Social economy and liberalisation of services
The study explored the impact on performance of social care systems for older people of recent changes in the role of the state as service provider/ regulator. Comparisons in policy developments were made between Belgium, France, Italy and the UK. The analysis examines arguments for and against public intervention in social care and the relationship between the state and different types of providers, and its implications for regulatory frameworks.

Mainstreaming ambient technology
The EC-funded MonAMI project is testing assistive technology for older and disabled people across a number of European sites. PSSRU at LSE is contributing to the multidisciplinary evaluation of feasibility, usefulness and cost-effectiveness.

Care vouchers
Care vouchers for working carers could offer employees a cost-effective means of providing support to a dependent person while minimising the impact on their own employment opportunities. Our economic evaluation of a care voucher scheme built a model to explore assumptions about take-up rates and consequences. Using findings from similar schemes, the analysis showed take-up to depend crucially on the effective promotion of care vouchers among employers. With successful implementation and appropriate administration, however, a care voucher scheme could offer significant benefits to dependent adults, their carers, and employers.

Motivations of care providers
This project looked at motivations expressed by care home providers (and some behavioural correlates) and compared them with local authority commissioners’ views of what motivates providers. Commissioners see providers as highly altruistic, but also relatively financially motivated. There were significant
differences between perceived and expressed views about profit maximising – providers gave this little emphasis while commissioners saw it as very important. Commissioners’ perceptions were closely linked to the nature of their relationships with providers.

**Recent publications from this programme**

**Care home providers as professionals: understanding the motivations of care home providers in England**
_Aging and Society_, 27, 103–126

**Direct payment rates in England**
Davey, V. (2006)
in L. Curtis and A. Netten (eds) _Units Costs of Health and Social Care_ 2006, PSSRU, University of Kent

**Free personal care in Scotland: A narrative review**
_British Journal of Social Work_, 37, 3, 459–474

**Motivation and commissioning: perceived and expressed motivations of care home providers**
_Social Policy and Administration_, forthcoming

**Organisation and features of hospital, intermediate care and social services in English sites with low rates of delayed discharge**
_Health & Social Care in the Community_, 15, 4, 295–305

**Securing good care for older people: Taking a long-term view**
Davies, B. (2007)
_Aging Horizons_, 6, 12–27

**Social care: choice and control**

**Social care for older people in England**
Davey, V. (2006)
_Newsletter of the Observatory for the Development of Social Services in Europe_, 2/2006

**Tax Exemptions on Care Vouchers for Working Carers**
Westminster Advisers, London

**The formal impact of informal care on social care services and hospital care**
_Health Economics_, forthcoming

**Time and Other Inputs for High Quality Social Care**
Background paper for Wanless Social Care Review, www.kingsfund.org.uk

**Variability in older people social care expenditure in England: local autonomy or widespread inefficiency?**
Fernández, J.L., Forder, J. and Moscone, F. (2006), HESG conference paper

**Why do we spend so much on health care when social care is the real challenge of an ageing population?**
_Journal of Health Services Research and Policy_, 12, 3, 192 (question & answer)

**Coordinated Care and Care Management Arrangements for Older People**

**Programme leader:** Professor David Challis

See pages 10–11 for information on previous work in this programme.

A distinct theme of the work at PSSRU Manchester has been field-level experimentation and evaluation to address policy questions such as the impact of assessment prior to care home placement. Current work is designed to identify and explore the impact of the new care management arrangements through examination of new patterns of working, the contribution of different professional groups and organisations, and the impact upon service outcomes. Work is underway in two areas:

**Towards the new care coordination for older people: exploration of emergent arrangements for the provision of care at home**

The project aims to explore the different emerging arrangements for coordinated care provision and to discern changes in them since the late 1990s. A number of specific questions are being addressed to determine the extent to which services are differentiated and integrated, to address the needs and wishes of older people against the criteria of flexibility, choice and responsiveness. A national survey of care management and care coordination arrangements for older people in England is currently underway and the development of this work is linked with the North West ADASS group.

**Links between care management provided through the social care system and NHS case management**

This work is exploring the different linkages and interfaces between care management as provided through the social care system and NHS case management, as developed for people with complex, long-term conditions. One study is underway in North West England, working with PCTs in the Greater Manchester area to examine the nature of care management arrangements, linkages with social care and variations in outcomes associated with different approaches to case management. A second national study of Long Term Conditions Case Management and its relationship with self care support is also underway.

**Recent publications from this programme**

**Are different forms of care management for older people in England associated with variations in case-mix, service use and care managers’ use of time?**
_Aging and Society_, 27, 1, 25–48

**Assessing the impact of care management in the community: Associations between key organisational components and service outcomes**
_Age and Ageing_, 36, 3, 336–339

**Care management arrangements for people with physical and sensory disabilities: Results of a national study**
Xie, C., Hughes, J., Challis, D. and Stewart, K.
_Research, Policy and Planning_, forthcoming

**Care management for older people: Does integration make a difference?**
_Journal of Inteprofessional Care_, 20, 4, 335–348

**Care management in mental health services in England and Northern Ireland: Do integrated organizations promote integrated practice?**
_Journal of Health Services Research and Policy_, 12, 4, 236–241

**Care managers’ time use: Differences between community mental health and older people’s services in the United Kingdom**
_Care Management Journals_, 7, 4, 169–178

**Care staff working with people with dementia: Training, knowledge and confidence**
_Dementia: The International Journal of Social Research and Practice_, forthcoming
Commissioning services for older people with mental health problems: Is there a shared vision?  
*Journal of Integrated Care*, 15, 2, 3–12

From care management to case management: What can the NHS learn from the social care experience?  
*Journal of Integrated Care*, 14, 3, 22–31

Implementing evidence-based training in dementia care for frontline workers in the social care workforce: Reaching the horizon?  
*Journal of Care Services Management*, 1, 3, 294–302

Old Age Mental Health Services in England: Implementing the National Service Framework for Older People  

The balance of care – Reconfiguring services for older people with mental health problems  
Tucker, S., Hughes, J., Burns, A. and Challis, D.  
*Aging and Mental Health*, forthcoming

**Projects and Publications**

**Programme leader:** Professor Ann Netten  
See pages 12–13 for information on previous work in this programme.

The programme has three aims:

- to develop and improve the measurement of costs, quality and outcomes
- to investigate factors associated with variations in costs, quality and outcomes of services and contribute to our understanding of how it is possible to improve efficiency while maintaining or improving key aspects of quality and outcome
- to enhance the value of both research and routine statistical information for monitoring, evaluative and ongoing policy purposes.

**Unit costs of health and social care**

This continues a long running stream of work which aims to identify, improve and disseminate information about unit costs of health and social care.

The project enables findings from research studies to be updated and remain easily accessible in the public domain. The project’s annual volumes (see page 37) are widely used.

**An extension to the younger adults user experience survey (UES)**

The principal aims of this research are:

- to explore the problem of non-response in the UES
- to consider how performance indicators might be developed using such data given the problem of non-response
- to add value to a sample of participating local authorities by collecting data on the quality of services delivered to younger adults with physical and sensory impairments (PSI)
- to facilitate the further development of a measure of the quality of services for adults with PSI
- to investigate variations in younger adult service users’ experience.

**Costs, quality and outcomes of equipment services**

Our objectives are:

- to identify methods of measuring equipment service outputs, quality and outcomes for younger and older disabled adults
- to identify the use of equipment and adaptations over time
- to provide an understanding of the relationship between costs, quality and outcomes
- to investigate factors underlying variations in efficiency.

**Quality measurement framework**

The Quality Measurement Framework (QMF) programme is being funded for three years (from January 2007) by the Treasury under Invest to Save and led by the Office of National Statistics (ONS). The aim of the QMF programme is to create entirely new mechanisms for more effective and efficient measurement and monitoring of third sector provision of public services, reducing the burden on the third sector while releasing cash through more efficient use of public funds to provide public services. See page 21.

**Evaluation of the Partnerships for Older People Projects**

In 2006 the Department of Health established the Partnerships for Older People Projects (POPP), with 19 pilot local authority sites and 48 (at the time) PCT partners. The PSSRU has undertaken an analysis of impact of the projects on the use of hospital bed-days. See also page 22.

**Somerset POPP**

The DH Partnership of Older People Projects (POPP) challenge conventional ways of working in health and social care on a number of fronts, particularly the wide age range of those being targeted, which starts at age 50.

POPP was implemented in two rounds. Somerset was one of the first round sites. Local evaluators worked closely with the national evaluation (see above and page 22). A brief summary of initial findings is available at pssru.ac.uk/pdf/rs046.pdf.

**Outcomes and quality of social care services for carers**

Kent County Council (KCC) and the Department of Health have commissioned the PSSRU to explore the outcomes and quality of social care services and support for informal carers. Exploratory work will be conducted to identify the types of outcomes and benefits experienced by carers, and the context and process factors associated with quality. Findings from this exploratory work will be used to develop survey questions about carers’ experiences of support and services, for use by KCC. The research will include group interviews with carers and interviews with key stakeholders, and a series of one-to-one interviews with carers to test the phrasing and objectives of the survey question(naire)s (see page 28).

**Development of PSS output index**

This project will continue to develop the approach to the measurement of personal social services outputs developed for the Atkinson Review of National Statistics and to explore the wider potential for the measurement of productivity and efficiency. A number of projects are involved, particularly the Quality Management Framework studies mentioned above. This will comprise four projects at PSSRU over a three year period starting October 2006:

- Measuring and monitoring quality of outputs of care homes
- Estimating value and monitoring the quality of outputs of low-level interventions
- The value of information and advice services
- A population preference study of social care outcomes.

The care homes project is being conducted in conjunction with the Commission for Social Care Inspection and will aim to both feed into the review of care standards and build on these for monitoring quality.

**Recent publications from this programme**

**Incorporating older service user experiences in performance monitoring of home care**

Jones, K., Netten, A., Francis, J. and Bebbington, A. (2007)  
*Health and Social Care*, 15, 4, 322–332

**Estimating value and monitoring the quality of outputs of low-level interventions**

**The value of information and advice services**

**A population preference study of social care outcomes.**
Organisation and features of hospital, intermediate care and social services in English sites with low rates of delayed discharge

Provider and care workforce influences on quality of home care services in England

The influence of individual characteristics in the reporting of home care service quality by service users

Using discrete choice experiments to estimate a preference-based measure of outcome – An application to social care for older people

Younger Adults’ Understanding of Questions for a Service User Experience Survey

**PROJECTS AND PUBLICATIONS**

**Long-Term Care Finance**

Programme leader: Raphael Wittenberg
See pages 14–15 for information on previous work in this programme.

Within this programme projections have been made of the demand for, and expenditure on, long-term care for older people in England, focusing on trends in disability, informal care, patterns of formal care, workforce and financing arrangements. A specific objective of the programme is to assess the likely impact of different policies and approaches to funding long-term care for older people on the balance of expenditure between sectors. Close links between PSSRU and the DH allow widespread use of this work for policy purposes.

**Long-term care projections project**

This Department of Health-funded project is concerned with projections of demand for long-term care for older people in England to 2041 and associated public and private expenditure under different assumptions about key factors affecting demand. The project has involved the construction of a cell-based computer model to make projections, the development of scenarios on trends in the key drivers of demand for long-term care and the production of projections under variant assumptions and scenarios. A wide range of formal health and social services and disability benefits are covered.

Within this project is a component focusing on the future supply of informal care to 2041, particularly care provided to older people by their adult children, examining a number of potential scenarios around the future supply of informal care by children, and b) the extent to which a decline in informal care by working age carers might contribute towards meeting the demands of the long-term care workforce, using long-term care projections for informal care and for the workforce.

**Modelling Ageing Populations to 2030**

In collaboration with researchers at the University of Essex, University of Leicester, London School of Hygiene and Tropical Medicine and Pensions Policy Institute, this three-year study, led by Professor Mike Murphy (LSE), is using simulation models to project up to 2030 the numbers, family circumstances, income, pensions, savings, disability and care needs (formal and informal) of older people, the key determinants of their resources and needs. Special attention will be given to the inter-relationships between care needs (and their determinants) and economic resources in later life, and to the affordability, and distribution of costs and benefits. For the first time, long-term care and pensions policy reform options may be analysed together – including co-payments systems for long-term care and proposals in the Government White Paper on pension reform.

Part of this research is work on informal (unpaid) care which will primarily undertake analyses of receipt of informal care by older people with functional disabilities, mainly using the English Longitudinal Study of Ageing (ELSA), with the aim of producing projections of trends in informal care and projections of long-term care expenditure under a range of scenarios on trends in informal care.

**Recent publications from this programme**

Care by spouses, care by children: Projections of informal care for older people in England to 2031

Cognitive impairment in older people: future demand for long-term care services and the associated costs

Compression or Expansion of Disability? Forecasting Future Disability Levels under Changing Patterns of Diseases

Financing long-term care for older people in England

Modelling an entitlement to long-term care in Europe: Projections for long-term care expenditure to 2050

Projections of future expenditure on long-term care for older people in England

PSSRU Long-Term Care Finance Model and CARESIM: Two linked UK models of long term care for older people

Unpaid care and the family

Winners and losers: Assessing the distributional effects of long-term care funding regimes

**Housing and Care**

Programme leader: Professor Ann Netten
See pages 18–19 for more information on this programme.

This work investigates the implications and potential of current developments in housing and care for the welfare of older people and the efficient use of resources. In particular, the planned projects will look at the feasibility, affordability, desirability and implications of moves away from care homes towards alternative housing and care options. To what extent do developments such as extra care housing deliver improved outcomes and at what cost? What are the implications for care homes?

The PSSRU also coordinates the Housing and Care for Older People Research Network (www.hcoprnet.org.uk).
The work outlined below is current in this programme.

**An evaluation of extra care housing for older people**

The longer-term aims of this project are to monitor how the schemes funded under the Department of Health’s Extra Care Housing Funding Initiative develop over time, to track long-term outcomes for schemes and residents and to compare the costs and outcomes with people moving into care homes.

In addition to the main evaluation of the schemes supported by the initiative, funding has been obtained for three further studies focusing on the design of extra care schemes, the social well-being of the residents and the relative costs of extra care, as described below. Funding has also been obtained to extend the data collection to a second scheme in one of the local authorities participating in the main evaluation.

See pages 18–19 for some early results from the evaluation of the initiative and the study of social well-being of residents in extra care.

**EOLVE**

The Evaluation of Older People’s Living Environments project aims to develop and validate an evidence-based tool for the evaluation and assessment of extra care housing design. The three-year project (from October 2007) is funded by the Engineering and Physical Science Research Council. Researchers at the PSSRU are working in partnership with researchers from the School of Architecture, the Sheffield Institute for Studies in Ageing and the School of Health and Related Research, at the University of Sheffield. The study will build on the Sheffield Care Environment Assessment Matrix (SCEAM), which was developed to assess the extent to which residential care buildings meet the needs of building users.

**Social well-being in extra care housing**

This project, funded by the Joseph Rowntree Foundation, is investigating the social well-being of residents living in the extra care schemes involved in the main evaluation. The project is focusing on the first year after opening, when new communities are being formed, and aims to identify:

- How the variety of approaches to developing social activities and community involvement identified in the bids are implemented in practice
- Residents’ expectations and experiences of these approaches
- The relative effectiveness of different approaches in terms of friendship formation and activity participation by individual residents
- The variation in social climate and incentives to participate 12 months after opening.

**Study of an extra care scheme in Bradford**

This in-depth study (funded by the Joseph Rowntree Foundation) of one of the schemes in the overall extra care housing evaluation will investigate and compare costs to all stakeholders before and after residents move into extra care.

**Analysis of evidence about the contribution of care homes and extra care to the support of older people**

This work will draw on previous and recent data collections to examine the implications of changing patterns of use of care homes and extra care housing for older people.

**Care home residents’ and relatives’ expectations and experiences**

This study will examine the differences between older people’s expectations and experiences of living in a care home setting. An outline of the project is available at www.pssru.ac.uk/pdf/p068.pdf.

**Recent publications from this programme**

- **Extra Care Housing: Is it really an option for older people?**
  Housing, Care and Support, 9, 23–29

- **Managing the care home closure process: Care managers’ experiences and views**
  Williams, J., Netten, A., and Ware, P. (2007)

**Mental Health Economics and Policy**

**Programme leader:** Professor Martin Knapp

See pages 16–17 for information on work in this programme.

Programme research focuses on mental health policy and practice, drawing somewhat on economic approaches and associated empirical methods, and includes research on intellectual disabilities.

Recent research has focused on life-course consequences of child mental disorder, feeding into UK and European Commission policy discussions, social exclusion, inequalities in needs and service use, dementia prevalence and cost, and analyses of suicide prevention strategies. Internationally, work commissioned by the EC on economic aspects of mental health has informed policy debates across Europe, while other research includes charting the institutional-community balance, and economic incentives to change.

Recently started projects include:

**The economic impact of health visiting in post-natal depression**

We are examining costs and consequences of health visiting in supporting women with post-natal depression using a model built from available evidence, current statistics and (as needed) expert opinion to represent care and related pathways and to chart future economic impacts (Martin Knapp, Pan-Hsui Yeh, Derek King and Jennifer Beecham in collaboration with the Community Practitioners’ and Health Visitors’ Association).

**European network for promoting the health of residents in psychiatric and social care institutions (HELPs)**

This multi-country project is funded by the EC and involves a systematic literature review, an iterative Delphi process, and focus groups involving experts, staff and residents to develop a guidance tool to promote the health of residents with mental health problems. David McDaid (LSE) is leading work to identify effective and cost-effective health promoting interventions for people with severe mental health problems, and then considering whether they can routinely be implemented in institutions.

**Evaluation of the Mental Health Improvement Partnerships Programme**

Four mental health trusts and local partner agencies piloted the Mental Health Improvement Partnerships (MHIP) Programme, set up by the National Institute for Mental Health in England. Each site has implemented MHIP in a different way, set out to achieve different aims, and focused on different service delivery areas. A Realistic Evaluation framework is used to assess the extent to which MHIP had an impact on the Trust and care and treatment. The research also aims to identify the resources absorbed while implementing MHIP and the outcomes achieved. The evaluation is in collaboration with the Clinical Trials Research Unit, Royal College of Psychiatrists and is due to report in 2008.

**ProCEED: Proactive Care and its Evaluation for Enduring Depression**

This research explores ways of improving primary care support for people with chronic depression. A structured pro-active approach is being trialled in 45 general practices with the aim of...
improving medical and social outcomes for patients. The intervention will include training nurses to improve their assessment and follow-up care. The control group will receive routine care. The research is undertaken in collaboration with Dr Marta Buszewicz at UCL and the cost-effectiveness analysis will be undertaken by researchers at PSSRU, LSE.

A list of all current projects can be found on the PSSRU website.

Recent publications from this programme
(a complete list can be found on the PSSRU website)

A randomized controlled trial of family therapy and cognitive-behavioral guided self-care for adolescents with bulimia nervosa or related disorders

Clinical practice with anti-dementia drugs: a consensus statement from the British Association of Psychopharmacology

Cognitive behavioural therapy in addition to antipsychomod therapy for irritable bowel syndrome in primary care: randomised controlled trial

Cognitive remediation therapy in schizophrenia: Randomised controlled trial

Comparison of alternative methods of collection of service use data in the POMCMT trial

Cost-benefit analysis of psychological therapy

Cost of schizophrenia in England

Development of a new measure of health-related quality of life for people with dementia: DEMQOL

Economic outcomes and levers: impacts for individuals and society

Economics methods in Cochrane systematic reviews of health promotion and public health related interventions

Equity in mental health

Financing mental health care in Europe

Implementing mental health economic evaluation evidence: building a bridge between theory and practice

Is it worth investing in mental health promotion and prevention of mental illness? A systematic review of the evidence from economic evaluations

Longitudinal analysis of the impact and cost of person-centered planning for people with intellectual disabilities in England

Maintaining Good Health for Older People with Dementia who Experience Fractured Neck of Femur

Measuring the tail of the dog that doesn’t bark in the night: the case of the national evaluation of Choose Life (the national strategy and action plan to prevent suicide in Scotland)

Mental health and employment: An overview of patterns and policies across western Europe

Mental health expenditure in England: a spatial panel approach

Mental Health Policy and Practice across Europe

Mental health problems: What are their socio-economic costs and what can be done to tackle them and promote mental well-being?

Mental health reform in Russia – an integrated approach to achieve social inclusion and recovery

Money matters: funding care

Moving beyond the mental health care system: an exploration of the interfaces between health and non-health sectors

Patterns of, and factors associated with, atypical and typical antipsychotic prescribing by general practitioners in the UK during the 1990s

Pharmaceutical policy reform in Spain

Quality of life in dementia – more than just cognition: An analysis of associations with quality of life in dementia

The effectiveness of supported employment for people with severe mental illness: a randomised controlled trial
Tax Exemptions on Care Vouchers for Working Carers: An Economic Analysis

Tom Snell, José-Luis Fernández and Russell Bennetts

This recently published report describes the results of an economic evaluation of a care voucher scheme for working carers, based on a model exploring the policy implications of alternative assumptions about take-up rates of the scheme. The research examines the likely effectiveness of the proposed scheme in providing extra funding for support for disabled people while increasing employment opportunities for those providing care.

Dementia: International Comparisons


Report for the National Audit Office
Summary report available at www.pssru.ac.uk/pdf/dp2418.pdf

Given the seriousness of the impact of dementia, the ageing of the world’s population, and the increase in the prevalence of dementia with age, much attention is focused on the treatment, care services and support arrangements needed by people with dementia and their families – both today and over coming decades.

Taking England as a reference, this report compares the situation in a number of different countries, and explores variations in:
- demography and prevalence
- approaches to diagnosis of dementia
- financing arrangements
- service range and balance (including services in place especially for older people with dementia)
- informal care
- attitudes

Direct Payments: A National Survey of Direct Payments Policy and Practice


This report, which describes the results of the survey of direct payment practices in local authorities across the UK, is now available to download at www.pssru.ac.uk/pdf/dplra.pdf. A limited number of hard copies are available. Please download and complete an order form if you wish to purchase a hard copy at £12 (including post and packing in the UK).

A second report, A National Survey of Schemes Providing Support to People using Direct Payments, will be available shortly.

Costs of Schizophrenia in England

Roshni Mangalore and Martin Knapp


This report, commissioned by Eli Lilly & Co Ltd, estimates the costs of schizophrenia in England in 2004/5 and throws light on the relative share of these costs borne by public services and society at large. Separate estimates are made for people with schizophrenia living in private households, institutions and prisons, as well as for the homeless.

An estimated 122,347 people in England suffer from schizophrenia and the total annual direct and indirect cost of schizophrenia is put at £6.7 billion. Health and social care services account for about 30% of this sum, with an estimated cost of £2 billion. However, the indirect cost of lost productivity, including the cost of unemployment and/or absence from work of both patients and carers, as well as the premature mortality of patients, is the major cost to society, accounting for nearly 52% of the total. Other major costs borne by the community include the costs of providing informal care, costs to the social security system, and costs to the criminal justice system.

Unit Costs of Health and Social Care 2007

Compiled by Lesley Curtis

This is the latest updated volume in a well-established series bringing together information from a variety of sources to estimate national unit costs for a wide range of health and social care services. This report provides detailed and comprehensive information on more than 130 types of service and quotes sources and assumptions so that users can adapt the information for their own purposes. The editorial this year describes how the publication has evolved over the years, outlining its boundaries and providing examples of the kind of cost information we include. It also discusses new developments and introduces three brief articles.

The first article discusses the costs which will need to be identified and addressed by those implementing telecare schemes; the second article draws on information collected in the European Commission’s HealthBASKET Project and describes and discusses the methodology used to identify and cost health treatments in several European countries. The third describes a systematic and prospective method of collecting detailed information on professional input into the care of people with severe mental health problems.

The 2007 edition is available in full at the PSSRU website. Printed copies are available from the librarian at the PSSRU in Canterbury, price £36. Volumes for previous years to 1995 (with articles on different aspects of costing research and methodology) are available, and are priced at £15 for the 2006 volume and £3 each for previous years (when ordered with the current volume). All prices include post and packaging.
Dementia UK
Martin Knapp (PSSRU) and Martin Prince (Institute of Psychiatry, King’s College London), with Emiliano Albanese, Sube Banerjee, Sujith Dhanasiri, José-Luis Fernández, Cleusa Ferri, Paul McCrone, Tom Snell and Robert Stewart (2007)


This research provides the most detailed and robust picture to date of the prevalence and economic impact of dementia in the UK. The report shows that there are currently 700,000 people (and 15,000 younger people) with dementia. As the UK’s population ages, the number of people with dementia will grow substantially, raising many challenges for public policy.

The report found that:
- by 2025 there will be over a million people with dementia
- two-thirds of people with dementia are women
- the proportion of people with dementia doubles for every five year age group. One-third of people over 95 have dementia
- 60,000 deaths a year are directly attributable to dementia. Delaying the onset of dementia by five years would reduce these deaths by 30,000 a year
- the financial cost of dementia to the UK is over £17 billion a year

Maintaining Good Health for Older People With Dementia who Experience Fractured Neck of Femur
Catherine Henderson, Juliette Malley and Martin Knapp (2007)

Report for the National Audit Office, London

This report explores the cost implications of the current system in England for treating those older people with dementia who have fractured a hip compared to people without dementia. Utilising a base case model that applies the proportions of psychiatrically well and those with dementia progressing through a ‘usual care’ pathway from admission to discharge, variations in costs and outcomes are investigated in a number of ‘best practice’ scenarios. The costs associated with acute care lengths of stay and the potential financial savings for the tax payer if the hospital stay could be reduced are identified.
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