

Choice and Independence over the Lifecourse

Final Report to the Department of Health

December 2011

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Choice and Independence over the Lifecourse

Final Report to Department of Health

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Section 1 Plain English Summary

Between 2006 and 2011 the Social Policy Research Unit (SPRU) at the University of York carried out a programme of research on choice for disabled and older people who need social care support, and their family carers, called Choice and Independence over the Lifecourse. At the heart of the programme was a major long-term study of disabled young people, working age adults and older people as their health and other circumstances changed. We talked to these people over a three-year period about the choices they made as a result of the changes in their lives. We have also investigated the choices that family carers make, particularly when they are involved in making choices with or for a disabled relative; and about carers' own choices about paid work and retirement. To prepare for these studies, we first carried out reviews of existing research so we could build on what was already known about making choices in relation to social care and support.

Choices are only possible if information about potential alternatives and the options that people want are both available. We therefore looked at how far government and other organisations are making information about social care more easily available. We examined the challenges that organisations providing home care services face in responding to service users' choices and the help that local authorities can give these organisations to meet such challenges. We also reviewed the available research evidence on how service users, carers and professionals balance the benefits of choice against the potential risks involved.

SPRU co-ordinated the evaluation of a major national initiative to increase choice and control for users of social care services. Between 2006 and 2008, individual budgets (IBs) were tried out in 13 English local authorities and SPRU led the national evaluation of these projects, working with four other DH-funded research units. The evaluation found that people using an IB were more likely to feel in control of their lives, compared with people using conventional services; mental health service users had the highest levels of satisfaction and older people were least satisfied with IBs. SPRU led a linked study of the impact of IBs on carers of service users. Carers of people using IBs also reported benefits for their own quality of life.

Other DH-funded research in SPRU's programme has examined the longer-term impact of home care re-ablement services. Many English local authorities are developing short-term, intensive re-ablement services for people who need personal and practical help at home.

Re-ablement gives people the confidence and skills to look after themselves. Our research found that re-ablement had long-term benefits; people who used re-ablement were less likely to need further home care services for up to a year afterwards than those using conventional home care services.

SPRU has contributed evidence on how other countries fund and organise their care services to government consultations on the reform of adult social care; and has reviewed evidence for the European Commission on the numbers and needs of family carers across Europe.

SPRU's research has provided valuable evidence on how disabled adults and older people make choices over time. It has also evaluated the benefits and costs of recent policies. Because SPRU carries out high quality research in social care, it has become a founder member of the new School for Social Care Research.

SPRU involves people who use services, and their families, in all aspects of its research. Many studies described in this report have been discussed, on one or more occasions, with one of our standing Consultation Groups. These Groups are: working age and older adults with disabilities or serious health problems, and their carers; parents of with severely disabled children; and disabled young people themselves.

Section 2 Overview of the Unit's Work Programme

SPRU has had a series of DH-funded research programmes since the 1980s. These focused latterly on identifying the outcomes that disabled children, working age adults and older people, and their carers, desired from social care services. SPRU's DH-funded programmes also worked closely with social care service providers, to find ways in which outcomes-focused approaches could be successfully embedded within mainstream social care practice.

A scientific review in September 2004 signalled a shift of emphasis in the focus of SPRU's DH-funded research. It was decided to move away from the service development activities that had constituted a growing element of the programme, and towards a greater emphasis on conducting high quality research that would both inform policy and contribute to wider academic debates. The new programme would build on the extensive knowledge derived from earlier research on the outcomes of social care and other services, but would focus on the two key issues of choice and independence.

This shift in focus coincided with the transfer of responsibility for children's social care to the Department for Education. It was agreed with DH that the new programme would cover older people, people of working age, and young people in or following transition to adult services, whose lives were affected by disability and/or serious chronic illness; and parents and carers supporting disabled and/or chronically ill people of all ages.

SPRU's new programme was planned during 2005 in the context of a renewed policy emphasis on extending choice to the users of public sector services, including users of social care services. In 2005 policy proposals were published (Cabinet Office, 2005, DH, 2005; DWP, 2005) that aimed to increase the opportunities for the users of health and social care services to exercise choice and control over their own support arrangements and, correspondingly, to reduce the roles of professionals (care managers, doctors and other professionals) in purchasing and managing services for individuals. At the same time, building on research and development activities conducted in the course of previous DH-commissioned research programmes in SPRU, both DH policy and local social care practice gave renewed emphasis to the achievement of desired outcomes for service users, rather than the delivery of service inputs.

These developments raised important questions for research. Over which aspects of services did users consider it was particularly

important to be able to exercise choice? What were the information and other preconditions for making choices? Were preferred service options actually available, so that individuals' choices could be met? What changes would be required in the roles of social care organisations and their staff, to support choice by service users and manage its consequences?

There are strong arguments for paying close attention to choice and its role in promoting and sustaining independence on the part of disabled and older people. Many of these arguments have been articulated by organisations of disabled people and were also supported by earlier SPRU research, which showed how the capacity to exercise choice and control is a commonly desired outcome of social care. However, choice may be problematic for those groups who have traditionally been the focus of SPRU's research, particularly those disadvantaged by ageing, long-term illness or impairment. Furthermore, within the context of the quasi-markets in social and health care that had developed since the early 1990s, policy ambitions to increase individual choice raised some challenging questions for research. In addressing these questions, the programme aimed both to inform policy and to contribute to wider academic debate and knowledge.

The programme aimed to investigate:

- ◆ The kinds of choices that are important to disabled young people, adults, older people, parents and carers.
- ◆ The domains or aspects of services within which exercising choice is particularly important.
- ◆ The options that exist for the exercise of choice, and users' preferences and priorities.
- ◆ The barriers and constraints, both individual and organisational, that impede the exercise of choice.
- ◆ Initiatives and interventions that enable service users to exercise (more) choice.
- ◆ The tensions and trade-offs between different choices and between the choices of disabled people and the choices of carers.
- ◆ How choice can contribute to improved independence and wellbeing among disabled young people, adults, older people, parents and carers.

The programme therefore aimed to contribute to:

- ◆ Debates about the role of individual consumer choice and other types of choice in public services; the barriers to increased consumer choice that exist; and the benefits, risks and other

consequences of individual consumer choice within public sector services.

- ◆ Academic debates about the meaning of 'independence' and citizenship within the context of public sector services.
- ◆ Knowledge about the implementation of policy initiatives, such as direct payments and individual budgets, that aim to increase opportunities for choice; and the conditions and circumstances that are required for this aim to be achieved.

As well as supporting SPRU's main research programme, for the first time DH required an element of SPRU's funding to be ring-fenced for 'responsive mode' projects – pieces of work that could be commissioned and carried out quickly to meet urgent policy needs. Initially about ten percent of the research programme budget was set aside for this purpose. Subsequently further funding for responsive mode studies was channelled through this route. An Advisory Group that included DH policy customers, social care managers, academic and service user representatives was established, in the expectation that it would play a role in advising on priorities for responsive mode studies. Unfortunately it was difficult to sustain continuity among the members of the Advisory Group because of retirements, illnesses and deaths among its members; moreover, the expected pressures on SPRU's responsive mode capacity did not materialise. The Advisory Group therefore ceased meeting part way through the programme.

SPRU has a long-established reputation for ensuring that the views of services users and carers are reflected fully in its research programmes. The projects that formed part of the Choice and Independence over the Lifecourse programme were discussed with one or more of SPRU's three standing Consultation Groups. These groups include, respectively: working age and older adults who are disabled or have serious health problems, and family carers; parents of severely disabled children; and disabled young people themselves. Consultations with these groups usually focused on specific aspects of a project, such as participant recruitment and retention; designing questionnaires; or interpretations of early study findings.

Section 3 Research Programme

The following account of SPRU's Choice and Independence over the Lifecourse research programme is divided into three sections:

- ◆ Projects funded from the main DH programme grant.
- ◆ Projects funded through SPRU's 'responsive mode' capacity.
- ◆ Other projects linked to the DH programme.

3.1 Projects funded from the main DH programme grant

Welfare consumerism, disability and social care: a narrative review

This narrative review examined primary research evidence from advanced welfare states on 'cash-for-care' schemes. It identified the preconditions for choice – the arrangements and facilities that need to be in place so that users of 'cash-for-care' schemes are able to exercise effective choice over their support arrangements. It also identified a number of important methodological weaknesses in the evidence base on the outcomes of 'cash-for-care' schemes, particularly the lack of comparative studies and the risk that evidence is derived only from self-selected samples of cash-for-care users; the predominance of small scale qualitative studies; and the lack of longitudinal evidence.

¹ The full list of papers and other publications (numbered 1 to 80) and presentations (numbered P1 to P79) from the programme can be found at the end of this report. In this example, paper number 46 can be found on p.35.

Timetable:	January to September 2006
Researchers:	Hilary Arksey, Peter Kemp, Sue Clarke
Outputs:	46 ¹

Understanding the dynamics of decision-making and choice about social care and related services: a scoping review

This scoping review examined relevant psychological literature on decision-making and choice, and assessed its relevance to the choices likely to be made by disabled adults and older people, and their carers, about social care and related services. It included evidence on decision-making with and for another person, including the roles of parents and carers. It reviewed the evidence on the processes by which people make choices and the constraints shaping these processes; and the personal and environmental preconditions for exercising choice and the personal costs involved.

Timetable:	January to June 2006
Researchers:	Bryony Beresford, Tricia Sloper, Sue Clarke
Outputs:	48

Both of these scoping reviews, plus a third on carers and choice (see 3.3.2 below) informed the design of the Choice and Change Panel Study.

Choice and Change: Panel Study

This qualitative longitudinal study formed the core of SPRU's DH-funded research programme. It aimed to maximise the opportunities offered by five-year programme funding to examine the realities of making choices about services and support, as health and other circumstances change over time. The study provided the opportunity to examine the consequences of support-related choices – how far current choices were shaped by the outcomes of earlier choices; whether choices actually had the desired outcomes and benefits; whether choices were subsequently found to have had unanticipated benefits or costs; and the durability of choices in the context of changing circumstances. The study also examined the impacts of choices on subjective outcomes such as independence; and the roles of others in making and implementing choices.

The Choice and Change study involved four groups of people, all of whom were expected to experience high levels of change and/or experience the exercise of choice as problematic, in various ways:

- ◆ Disabled young people with degenerative conditions.
- ◆ Working age adults and older people with fluctuating support needs arising from their health or disability.
- ◆ Working age adults and older people who had recently experienced the sudden onset of a serious health or disabling condition.
- ◆ The parents of the young people.

Each participant was interviewed at least three times over a four-year period. Some of the young people, and one of the adults, had limited verbal communication, so simplified topic guides and Talking Mats[®] techniques were used.

The study found that individuals brought differing types and levels of psychological and material resources to choice-making. There were some marked contrasts between those with fluctuating conditions, who had long-term experience of managing their condition and previous extensive contacts with services and sources of information, and those recently disabled, who tended to be more reliant on professionals for information and advice. People living alone or with limited social networks had less access to information and support in making choices. People who were either ineligible for publicly-funded support or who chose to purchase their own services were similarly disadvantaged in accessing information and other support. Where participants were prompted by changes in their social or personal circumstances, rather than by an exacerbation of symptoms, to review or revise a past choice, it was harder to secure professional support. Indeed, in such circumstances, participants were unsure even whether it was legitimate to seek professional help to change earlier choices. Such differences in circumstances risked being reflected, and further amplified, in the outcomes of choices.

Making a choice was rarely a simple, discrete activity. Making choices took time, especially in order to realise desired options. Indeed, time itself was an important factor, in prompting the need to make new choices (for example, when major life transitions were involved); in developing experience in making choices (which was often transferred to other situations or shared with other people); and in the emergence of satisfaction with the outcomes of choices.

Choices were often linked, either simultaneously or sequentially, so that one choice could give rise to others. Although having choice was central to feelings of independence, negative emotions were also

often involved in making choices. Partly because of this latter experience, there was reluctance to revise earlier choices, even where circumstances had changed and previously chosen arrangements were no longer optimal. Access to information was confirmed as critically important in initially alerting people to the possibilities of choice, as well as in appraising choice options.

Choice was rarely a private, individual experience. Family members played important roles in supporting choice-making and the needs of others were taken into account in appraising options.

Among people with chronic health problems, the study highlighted the importance of long-term relationships with professional workers in making choices, particularly in view of the negative emotions that were often involved. Parents cited the transition from children's to adult services as a damaging break in such continuity, especially when the young people's health conditions meant they were not expected to live long into adulthood. Study participants who had no long-term relationship with a health or social care professional were particularly disadvantaged in accessing information that could alert them to the fact that new options were possible, and in justifying making changes to existing arrangements.

The study also generated the first longitudinal data on experiences of using direct payments; this showed that users need on-going support and help in managing direct payments as their circumstances and capabilities change over time.

More generally, health and social care professionals need to consider their roles in supporting choice and thereby helping to reduce the inequities that can arise from policies that emphasise choice.

The study has generated some 16 papers that have been accepted by, or are currently under consideration by, a range of academic journals (only those papers that have already been published or accepted for publication are included in the list in section 6). In addition, two summary overview papers, one a technical report on the study's design and methods and the other a summary of the main findings, have been submitted to DH. Two short, lay summaries of the project findings are in preparation. One will be targeted at disabled adults and older people and the professionals, voluntary organisations and user organisations working with them. The other will be targeted at disabled young adults, their families and relevant statutory and voluntary organisations. Copies of each summary will be widely distributed. A further expected output from the study will be to make the data available for secondary analysis through the Timescapes longitudinal qualitative data archive, which is part of the UK Data Archive; arrangements for depositing the study data are currently being discussed.

Timetable:	May 2006 to February 2011
Researchers:	Caroline Glendinning, Hilary Arksey, Kate Baxter, Bryony Beresford, Janet Heaton, Jane Maddison, Wendy Mitchell, Parvaneh Rabiee, Tricia Sloper
Outputs:	1, 2, 7, 8, 10, 11, 12, 19, 22, 30, 57, 59 P1, P2, P7, P8, P10, P12, P14, P15, P16, P17, P21, P22, P24, P27, P28, P29, P30, P31, P32, P38, P46, P47, P48, P49, P57, P58, P60, P72, P73, P78

Domiciliary care agencies' responses to increased user choice: perceived threats, barriers and opportunities from a changing market

Choice is only possible if desired options are available. This study examined, from the perspectives of home care service providers, the barriers to and opportunities for responding to increases in user choice through mechanisms such as direct payments and personal budgets.

The study found that changes in local authority contracting arrangements, to create smaller geographical zones for providers, risked restricting opportunities for users to choose between different home care providers. The closer relationships that smaller agencies had with clients offered better opportunities for negotiating personalised home care services; however, larger agencies were thought to be better protected against new financial risks arising from the personalised purchase of services. Because the personal budgets can be used in a wide variety of ways, they were expected to create opportunities for providers to offer new services, such as shopping, pet care and help with social activities.

Home care provider agencies had to operate within very tight labour markets and were also aware of the risk of losing home care workers to private employment by personal budget holders. They were trying to counter this risk by emphasising the advantages to staff of working for an agency rather than a private employer.

Timetable:	January 2007 to March 2008
Researchers:	Kate Baxter, Sue Clarke, Caroline Glendinning (SPRU) Ian Greener (University of Durham)

Outputs:	3, 4, 47, 67, 76 P3, P37, P44, P50, P51, P52, P61, P62
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Transition to adult services of disabled young people leaving 'out of authority' residential schools

This small study examined the choices available in planning transitions to adult services by disabled young adults leaving residential schools outside their home local authority area. It found that the generic difficulties associated with transition for this group were magnified by the young people's lack of familiarity with services and opportunities in their home local authority, and by the fact that they were less well known by their home local authority staff. Consequently, post-transition placements and support arrangements for this group were considered more susceptible to breakdown. It was also harder to adopt person-centred planning approaches in these young people's transition arrangements.

Earlier initiation of transition planning processes, and the designation of staff with specific responsibility for out-of-authority placements could help overcome geographical barriers. Specific attention is needed to identifying clear transition pathways to adult health services in the home authority.

Timetable:	February to June 2008
Researchers:	Bryony Beresford, Judy Cavet
Outputs:	40, 62 P23

National Evaluation of the Individual Budget (IB) Pilot Projects (IBSEN)

Most of this large national evaluation was funded through additional Policy Research Programme grants. It involved SPRU along with the other four DH-funded social care research units. The contract for the project was based in SPRU, which also employed the lead researcher and evaluation project manager. In addition, SPRU's DH programme funding contributed to the initial development of the evaluation, by funding staff time to help design the evaluation and establish data collection arrangements in some of the pilot sites. SPRU's DH programme funding also supported some of the evaluation's dissemination activities (both writing and presentations to academic and practitioner audiences) by SPRU-based IBSEN team members, that were not covered by the additional DH grant for dissemination.

At the core of the IBSEN evaluation was a randomised controlled trial – one of the very few conducted in English adult social care. This large scale study of the costs, outcomes and cost-effectiveness of IBs was complemented by process evaluations of the implementation of IBs, conducted through interviews with key local authority managers and front-line staff; and by in-depth interviews with a subsample of people recently offered IBs.

The study found that IBs were generally welcomed by users because they offered more opportunity for choice and control over support arrangements than conventional social care arrangements. However, there were variations in outcomes between different groups of IB users; satisfaction was highest among mental health service users and physically disabled working age people and lowest among older people. There was little difference in the average cost of an IB compared with conventional social care

support, although again there were marked variations between user groups; the costs of an IB were lowest for mental health service users and highest for people with learning disabilities. IBs appeared to be cost-effective in relation to social care outcomes, but not for psychological well-being. Indeed, for older people, there were no differences in social care outcomes between IBs and conventional services; the latter were slightly more cost effective and older people receiving these felt happier.

The implementation of IBs involved numerous practical, organisational and cultural challenges for staff at all levels in local authorities. Challenges included devising new assessment mechanisms and processes for determining the levels of IBs; agreeing support plans with IB users; and managing personal and financial risks. Front-line staff were particularly concerned about establishing what were legitimate and appropriate uses of an IB.

Although IBs were intended to integrate resources from a number of funding streams (and reduce duplicate assessments in the process), numerous legal and accountability barriers were encountered, despite enthusiasm on the part of pilot site staff. On the other hand, NHS resources were excluded from IBs, despite the integration of health and social care services in some of the pilot sites.

The impact of this study is described in section 4.3 below.

Timetable:	April 2006 to March 2008
Researchers:	Caroline Glendinning, Nicola Moran, Mark Wilberforce (SPRU) David Challis, Sally Jacobs (PSSRU, University of Manchester) Martin Knapp, José-Luis Fernández (PSSRU, LSE) Ann Netten, Karen Jones (PSSRU, University of Kent) Jill Manthorpe, Martin Stevens (Social Care Workforce Research Unit, Kings College London)
Outputs:	5, 6, 9, 14, 16, 17, 18, 20, 21, 23, 24, 35, 37, 49, 68, 69, 70, 71, 77, 78, 79, 80 P11, P25, P26, P39, P40, P43, P45, P53, P54, P56, P75, P76

Lessons from early users' experiences

Early in the evaluation of the IB Pilot Projects, DH asked the IBSEN team based at SPRU to conduct some additional work to examine the impacts of IBs on the first few service users to receive an IB. This was in addition to the main funded evaluation and additional funding was provided by DH.

Timetable:	August to November 2006
Researchers:	Caroline Glendinning, Nicola Moran, Parvaneh Rabiee
Outputs:	25

3.2 Responsive mode projects

Access to information about social care: response to recommendation from Better Regulation Task Force

Following a recommendation from the Better Regulation Task Force, SPRU was commissioned to undertake a scoping review of evidence about the accessibility and availability of information for service users and carers across the spectrum of adult social care. The review examined current government research and development activities that aimed to investigate or improve the accessibility of information about social care services. It found no government-related initiatives or recent research evidence on the specific information access needs relating to some user groups and services, for example, people from ethnic minority groups. For other groups, such as people with chaotic lifestyles, there was evidence about their information needs but no development work planned to address these needs.

Timetable:	January to June 2006
Researchers:	Kate Baxter, Sue Clarke, Caroline Glendinning
Outputs:	29, 54

Review of research evidence surrounding risk perceptions, risk management strategies and their consequences in adult social care

DH commissioned SPRU to review recent research evidence on perceptions of risk and risk-related practice in adult social care. The review focused on identifying differences in perceptions of risk within and between groups of adult social care service users and service providers; and how any such

differences were negotiated and managed in practice. The review also identified gaps in evidence on the perceptions and management of risk.

Timetable:	April to September 2006
Researchers:	Wendy Mitchell, Caroline Glendinning
Outputs:	33, 51 P59, P69, P70, P79

Individual budgets/IBSEN: impacts and outcomes for carers

This study was conducted jointly with PSSRU, University of Kent and built on the main national evaluation of the Individual Budget (IB) Pilot Projects (see 3.1.6 above) to examine the impacts of IBs on carers. It found that service users' receipt of IBs was significantly associated with positive impacts on carers' reported quality of life and also, when other factors were taken into account, with carers' social care outcomes. Carers' involvement in and satisfaction with service users' support planning was an important predictor of positive outcomes for them; indeed, IBs offered more opportunities than conventional social care support arrangements for carers to be involved in planning how the IB was to be used. Carers of older IB users were more likely than carers of IB users with learning disabilities to report positive experiences of IBs, particularly if they had been able to build some choices over how they used their time into the service users' support plan.

However, pilot sites varied in how the help given by carers was treated in IB assessments and how far carers' own support needs were also considered.

The positive outcomes for carers that were achieved with no additional public expenditure costs suggest that IBs for service users are cost-effective for carers. The impact of this study is discussed in section 4.1.3 below.

Timetable:	January 2007 to October 2008
Researchers:	Caroline Glendinning, Hilary Arksey, Nicola Moran, Parvaneh Rabiee (SPRU) Ann Netten, Karen Jones (PSSRU, University of Kent).
Outputs:	13, 41, 63 P41, P71

Investigating the longer-term impacts of home care re-ablement services. Retrospective longitudinal study

Many English local authorities are developing home care re-ablement services. These provide intensive home care support, free of charge, for up to six weeks; they aim to enhance the confidence and self-care skills of service users in order to reduce needs for longer-term home care support.

This small study was commissioned by DH's Care Services Efficiency Delivery (CSED) Programme and led by Acton Shapiro (www.actonshapiro.co.uk). The study analysed routine service use data from four local authorities, two of which operated inclusive 'intake' re-ablement services and two of which had selective 'hospital discharge support' services. The analysis suggested that re-ablement could bring immediate, but relatively short-term, benefits for some users; but could delay needs for home care support for others for a year or more.

Timetable:	June to September 2007
Researchers:	Liz Newbronner, Jane Maddison (Acton Shapiro) Hilary Arksey, Caroline Glendinning (SPRU)
Outputs:	32, 52

Home care re-ablement services: investigating the longer-term impacts. Prospective longitudinal study

This large study was also commissioned by CSED and led by SPRU in partnership with PSSRU, University of Kent. It aimed to follow up the earlier study by providing robust evidence on the longer-term impacts of home care re-ablement. It collected data on the costs of the health and social care services used and on user-level outcomes after 10-12 months for people who had used re-ablement services in five local authorities. These were compared with the service-related costs and outcomes for a similar sample of people using conventional home care services over the same time period in another five authorities that did not have re-ablement services.

The study found that re-ablement was associated with a significant decrease in subsequent use of social care services, although any cost savings were almost wholly offset by the initial costs of the re-ablement intervention. Re-ablement had positive impacts on users' health-related quality of life and social care outcomes; the probability that re-ablement is a cost-effective service was therefore very high.

The study also investigated the organisation and delivery of home care re-ablement services; and interviewed a subsample of re-ablement service users and carers about their expectations and experiences of the service. From these data, the study was able to

identify the organisational and wider environmental factors that contributed to effective and efficient re-ablement services. The impact of this study is described in section 4.5 below.

Timetable:	April 2008 to December 2010
Researchers:	Caroline Glendinning, Hilary Arksey, Kate Baxter, Parvaneh Rabiee, Alison Wilde (SPRU) Karen Jones, Lesley Curtis, Julien Forder (PSSRU, University of Kent).
Outputs:	15, 38, 44, 45, 58, 60, 61 P4, P5, P13, P18, P19, P34, P35, P36, P42

Reforming long-term care: recent lessons from other countries

As the previous Government considered the options for reforming the funding and organisation of long-term care services in England, this scoping study provided background evidence on recent reforms in Germany, Denmark, Netherlands, Australia and Japan. All of these countries were actively renegotiating the balance between growing demands for care arising from population ageing and economic constraints on welfare expenditure. Information on reforms in each country was obtained from recent publications, including grey literature, in English; and from key informants in each country.

All countries, apart from Australia, have retained clear principles of equity and universality, regardless of age or income, for everyone with support needs above a given threshold. Modest increases in income-related contributions to social insurance

schemes appeared to be politically feasible, given the widespread popular support for such schemes. Other mechanisms for managing cost pressures included reducing public funding for domestic (household) services; requiring relatives to provide care for the first few months of a new disabling condition; and altering reimbursement structures for service providers. It was striking how, even in federal countries with strong traditions of regional autonomy, successful management of long-term care funding was helped by central government taking a clear lead role; and by single funding streams that are separate from acute health care.

Timetable:	April 2008 to January 2009
Researchers:	Caroline Glendinning, Nicola Moran
Outputs:	42, 66 P9

Scoping review of research on interventions to support carers

This scoping review was commissioned by the Standing Commission on Carers and the Department of Health. It was conducted in partnership with the Centre for Reviews and Dissemination, University of York. It aimed to provide an overview of the evidence base on the outcomes and cost-effectiveness of support for unpaid carers of older or disabled people. It covered national and international literature reviews; summarised their main findings; and identified gaps and weaknesses in the evidence base. The strongest evidence of effectiveness was in relation to targeted education, training and information interventions for carers. However, overall the evidence base is poor.

Timetable:	August 2009 to January 2010
Researchers:	Gillian Parker, Hilary Arksey
Outputs:	39 P20, P33

3.3 Other research projects linked to DH programme

Knowledge review on outcomes-focused services for older people

The Social Care Institute for Excellence commissioned and funded this review of research on the outcomes of social care valued by older people and progress in developing outcomes-focused services for older people in England and Wales. SPRU led the study, in partnership with Acton Shapiro (www.actonshapiro.co.uk). The study included a literature review; and a postal survey and audits to identify a wide range of local initiatives. The outcomes valued by older people fell into three clusters relating to: change and improvement; maintenance and prevention; and the processes of receiving services. The survey found that outcomes-oriented approaches in social care appeared to be fragmented, but with strong approaches in some specific services and localities.

Timetable:	April 2005 to February 2006
Researchers:	Caroline Glendinning, Sue Clarke, Jan Heaton, Inna Kotchetkova (SPRU) Liz Newbronner, Philippa Hare, Jane Maddison (Acton Shapiro)
Outputs:	31, 55, 73 P55, P63, P64, P65, P74

Choice in the context of informal care-giving

This research review, funded through a University of York 'Anniversary Lectureship', complemented the other two scoping reviews conducted at the start of the programme (see 3.1.1. and 3.1.2). It showed how the choices made by carers are shaped by the nature of the care-giving relationship, and by wider organisational factors. Existing research suggested that exercising choice could be problematic for carers, if it generated tensions with the obligations and reciprocities on which care-giving relationships were based.

Timetable:	January to July 2006
Researcher:	Hilary Arksey
Outputs:	34

Carers' aspirations and decisions around work and retirement

This study was commissioned by Department for Work and Pensions. It aimed to explore the aspirations and decisions around work and retirement of people looking after disabled or sick relatives or friends. It included a research review; in-depth interviews with 80 purposively-sampled carers; and focus groups with a range of professionals from social care and Jobcentre Plus offices. It concluded that decisions about work, retirement and care-giving were shaped by a complex interplay of financial, health, work-related and service-related considerations. The implications for future pension entitlements were rarely taken into account; instead carers prioritised the management of current financial pressures and care-related commitments. Adult social care services did not readily accommodate the needs of employed carers, but workplace

flexibility was important in helping employed carers to remain in work.

Timetable:	May 2004 to September 2005
Researchers:	Hilary Arksey, Peter Kemp, Caroline Glendinning, Inna Kotchetkova, Rosemary Tozer
Outputs:	27, 28, 56, 74

Carers and asset management for older people

This small scoping study was funded through a grant from the Actuarial Profession. It built on a pioneering stream of research at the University of Queensland that has examined the roles played by family carers in managing the money and assets of older people as they begin to lose the capacity to do so themselves. The scoping study identified existing research evidence, good practice guidance and relevant policy and legal frameworks relating to the management of older people's money and assets by carers; stakeholder perspectives on key problem areas; and gaps in the existing evidence base.

The study formed the basis for a full application to the Nuffield Foundation for funding to conduct a major study on this topic.

Timetable:	January to June 2006
Researchers:	Hilary Arksey, Caroline Glendinning, Anne Corden, Michael Hirst
Outputs:	26, 53, 72 P66, P67, P68, P77

Respite care for frail older people: an appraisal of effectiveness and cost-effectiveness.

SPRU contributed to this systematic review, which was led by the Centre for Health Economics and also involved the Department of Health Sciences and the Centre for Reviews and Dissemination, all at the University of York. It was funded by the National Co-ordinating Centre for Health Technology Assessment. Overall, the effects of respite on carers were found to be small, with better controlled studies showing only modest benefits for carers, although carers' satisfaction was high.

Timetable:	March 2005 to February 2006
Researchers:	Hilary Arksey, Caroline Glendinning (SPRU) Joy Adamson, Karen Spilsbury (Department of Health Sciences) Mike Drummond, Anne Mason and Heather Weatherley (Centre for Health Economics) Su Golder (Centre for Reviews and Dissemination).
Outputs:	36, 50

for a disabled or elderly relative. However, there were no comparable national or EU-wide definitions of carers; evidence on carers of older people predominated; and the levels and quality of evidence on carers varied significantly between different EU member states.

Timetable:	March to December 2008
Researchers:	Caroline Glendinning, Hilary Arksey, Nicola Moran (SPRU) Frits Tjadens, Marjolein Morée, Henk Nies (Vilans)
Outputs:	43, 64, 65, 75 P6

Care provision within families and its socio-economic impact on care providers

The European Commission (DG5) funded this study from SPRU with support from Vilans, the Dutch Centre of Expertise on Long-Term Care. The study reviewed available evidence on the numbers and characteristics of family carers across Europe and the consequences of care-giving. It found that, in 2005, an estimated 19 million people across the EU were providing at least 20 hours care a week

Section 4 Choice and Independence over the Lifecourse: Relevance of the programme to DH policy 2006 to 2010 and examples of work that have influenced policy and practice

This section of the report provides an account of the relevance of the research programme to DH policy, and its implementation at local levels. It is of course far from straightforward to identify the impacts of research on policy and practice; influences are often serendipitous and not closely related in time to the publication of research findings, so causality can be difficult to establish. Nevertheless, examples of SPRU's DH-funded research that have influenced policy and practice can be identified and are integrated into this account.

4.1 The policy context

Throughout the period covered by SPRU's DH programme, and despite a change of government, there has remained a consistent policy emphasis on choice and personalisation in adult social care and other services. Although increasing choice for service users was an important aim of the 1993 community care reforms that first introduced quasi-markets into health and social care, these reforms located the resources for exercising choice in the hands of statutory health and social care organisations and associated professionals such as general practitioners and care managers. These arrangements were challenged by disabled people, who lobbied for the right to control their own support arrangements through the allocation of cash 'direct payments' instead of services in kind. Direct payments were introduced in 2007 for working age disabled people and subsequently extended to older people and

carers. However, take-up of the direct payment option remained low and highly variable, between different groups of adult social care service users; between the countries of the UK; and between the local authorities within those countries. It was therefore clear that significant barriers to exercising choice through this mechanism remained.

The immediate context for SPRU's DH-commissioned programme was set by a raft of proposals published during 2005 (Cabinet Office, 2005; DH, 2005; DWP, 2005) that were underpinned by principles of active citizenship and social inclusion for users of social care. More importantly for the purposes of SPRU's research programme, these proposals advocated a significant extension of the opportunities for people needing social care support to exercise choice over the services and help they received. Acknowledging the low take-up of direct payments, the introduction of individual budgets (IBs) was proposed. These would bring together the resources from a number of different funding streams to create an individualised funding allocation for each individual. S/he would use these to secure the range and mix of support that best met his/her needs and preferences. Correspondingly, service providers would need to focus on the outcomes desired by individual users rather than on delivering a standard range of task-based services. This ambition, of delivering desired outcomes for each social care service user through individualised funding and service plans, has proved remarkably robust. It continues to sit at the heart of Coalition Government policy.

The recent *Vision for Adult Social Care* (DH, 2010a) restates the importance of outcomes-focused services and the availability of information about care options for all. Above all, it emphasises the need to extend personal budgets, ‘preferably as direct payments’ (DH, 2010a: 15) to all eligible people.

SPRU’s research programme has been centrally concerned with this policy priority and has contributed evidence in several different ways.

4.2 Service users’ experiences of choice: evidence for policy and practice

Through the Choice and Change Panel Study in particular, SPRU’s research programme has examined the lived experiences of making choices over time by people experiencing long-term illness or disability, including people with life-limiting conditions. Through its responsive mode studies, SPRU has also examined other important issues associated with increasing choice for service users, particularly equitable access to information, and perceptions and management of risk. SPRU’s research has shown how changes in health or other circumstances can prompt choices across a wide range of domains, including housing, training, employment and health, as well as personal and social care. Choices are rarely discrete events, but often involve multiple, linked decisions and protracted difficulties in realising a desired option.

For many of the participants in SPRU’s Choice and Change Panel Study, choices were often made in the context of a very limited range of options. Many choices were themselves not optional but were prompted by deteriorating health or changes in other circumstances.

Making choices could involve a range of negative emotions, leading study participants to be hesitant about revising a choice even when the original option was no longer appropriate.

SPRU’s research has shown how information is essential, not just about the range of available options from which a choice can be made, but also at an earlier stage, as a precondition for identifying that a choice might be possible. However, a range of barriers were shown to impede choice-making. People with long-term conditions who had no recent contact with professionals appeared particularly disadvantaged in identifying the availability of new options and the possibility of new (or revised) choices. Similarly, people with deteriorating health had difficulty in recognising and regarding as legitimate any new support needs that arose. Young people planning a transition from an out-of-area residential school faced additional organisational and geographical barriers in finding out about and accessing appropriate adult services in their home authority. There is an important role for professionals in all these situations, in helping people with long-term and/or deteriorating conditions to anticipate and respond to changes in their health, capacity and other circumstances, by setting out a range of options and by providing support in making new choices.

SPRU’s research has also demonstrated the social contexts of choice. While the internet and leaflets are useful, information that was personalised and conveyed through discussion with professionals was more highly valued. Peer advice and experience were similarly valued sources of information. Other people, especially families and carers, were involved in choices; and choices about support arrangements were also made with the interests and needs of others in mind. Conversely, choices by carers were often constrained, not least by the dynamics of the

care-giving relationship. This was especially the case where choices about paid work were concerned, where services also commonly failed to offer realistic substitute care options.

Through examining the realities of choice, over time and from a number of different perspectives – those of disabled and older people, their carers and wider families, information and service providers – the programme has identified both individual and social factors that have the potential to disadvantage people in making choices. People living alone, coping with fatigue or pain, who experience difficulty in weighing up complex information, and those who had recently become disabled were all relatively disadvantaged. People who were ineligible for publicly-funded services, or who were reviewing and revising earlier choices, found it especially difficult to obtain information and appropriate professional support in making choices.

SPRU's research shows that choice is undoubtedly important for disabled and older people, in safeguarding their quality of life and sustaining independence. However, the experiences of making choices are not always positive and can involve anxiety, stress and other negative emotions. These negative experiences can lead to sub-optimal outcomes and a reluctance to make further, potentially ameliorating, choices.

A consistent approach to the provision of information would help to reduce the risks of inequity arising from choice-based policies. Further, information delivered in the course of relationships with knowledgeable professionals is particularly valued, both because the information can be personalised and because the relationship itself is a source of support and legitimacy. Without appropriate recognition of, and support for, the challenges and difficulties involved in making choices, choice-based policies risk not

just inequity but also less than optimal outcomes.

A further major finding from this research is about the social contexts within which choices are made by disabled, chronically ill or older people. These present challenges to individualised models of funding and delivering support that focus primarily on service users or on carers. While disabled and older people and family carers have struggled to ensure that their respective rights to recognition, choice and control are appropriately reflected in policy and practice, SPRU's research has drawn attention to the close and complex interdependencies and reciprocities that underpin many supportive relationships. These are not always easily accommodated within policy and practice paradigms of personalisation.

Because of the scale of SPRU's Panel Study, its findings have been analysed and written up in some 16 separate academic journal papers (many of which are still awaiting publication) and summarised in two short lay summaries which will be widely distributed to practitioners, third sector and user organisations. These outputs will make major contributions to academic and policy debates on choice and how choice-based policies can best be implemented. They will also provide useful information for a range of professional and third sector organisations who work with disabled young people, working age and older adults, and their families, about the support that these groups need in order to maximise the potential benefits of choice.

4.3 Evidence on the implementation and impact of individual budgets

SPRU, along with the other four DH-supported social care research units, conducted the national evaluation of the Individual Budget (IB) Pilot Projects (IBSEN) (see 3.1.6 above). The IBSEN contract and project manager were based in SPRU and SPRU therefore provided overall co-ordination of the evaluation. Although much of the funding for the evaluation was in addition to SPRU's main DH programme, some resources from the DH programme were used to support early development work of setting up the evaluation and data collection from sites, and to disseminate the results of the evaluation to a wide range of academic, policy and practice audiences. In addition, SPRU was able to respond to the needs of policy-makers for early evidence on the impact of IBs, by carrying out an additional series of interviews with early IB holders (with additional DH funding). SPRU's DH programme also supported an additional analysis of the evaluation data on the impacts of social care IBs on relationships with local NHS partners.

SPRU's responsive mode funding was used to design and conduct a linked study into the impact of IBs on carers (3.2.3 above) – an important piece of research which had been omitted from the main commissioned evaluation of the pilot projects.

Presentations summarising the evaluation findings were made to the (then) Minister for Adult Social Care, Ivan Lewis, and to the Improving the Life Chances of Disabled People Inter-Ministerial Group. SPRU published a full and summary report and three widely circulated *Research Works* (4-page summaries written for non-academic audiences; one of these was distributed directly to front-line

staff in adult social care). In addition, two national conferences (in Manchester and London) were organised by the IBSEN team to showcase the findings, while SPRU staff undertook a wide range of speaking engagements to social care audiences in the UK and internationally. SPRU also organised a well-attended symposium on the IBSEN evaluation for the 2009 Social Policy Association annual conference. Subsequently:

- ◆ DH published a detailed commentary on the evaluation findings. This stated 'the report [of the evaluation] confirms to us that the introduction of personal budgets in social care is the right approach' (DH, 2008: 4). An extensive range of good practice guidance was commissioned in response to evidence from the evaluation on the challenges of implementing this new approach.
- ◆ The evaluation found that the implementation of IBs was particularly problematic for people with mental health problems and older people. Further research to identify good practice with these two groups, and their respective carers, was therefore subsequently commissioned by the Social Care Institute for Excellence on behalf of DH. SPRU contributed to this further study, which was led by Acton Shapiro and also involved the National Centre for Independent Living (SCIE, 2011).
- ◆ The experiences of the evaluation shaped the DH approach to the piloting and evaluation of NHS personal health budgets (PHBs). In particular, the PHB evaluation was commissioned in such a way as to allow extended follow-up of the outcomes of PHBs; and with attention from the start to establishing relationships between the evaluation team and pilot sites – issues that had been highlighted by the IBSEN team in discussions with DH customers.

- ◆ Evidence from the evaluation on the integration of funding streams shaped the Department for Work and Pension's 'Right to Control' trailblazer pilot projects that were introduced by the Welfare Reform Act 2009. The experience of IBSEN also informed the design of the evaluation of the 'trailblazers'.
- ◆ The IBSEN evaluation was cited by the House of Commons Health Committee in its report on Social Care (HC, 2010).
- ◆ The Audit Commission drew on the IBSEN evaluation to shape its investigation into the financial management of personal budgets (Audit Commission, 2010).
- ◆ A personalisation 'toolkit' for local authorities <http://www.dhcarenetworks.org.uk/Personalisation/Topics/> was informed by the learning from the evaluation.
- ◆ Both the main IBSEN evaluation and the linked study of the impact of IBs on carers were cited in the recent *Vision for Adult Social Care* (DH, 2010a)

These have procured relatively large volumes of services, involving block contracts and significant economies of scale. Service providers have also experienced increasing labour recruitment and retention difficulties, partly because of the constraints on costs and increases in staff wages.

Given these difficult contexts, SPRU has conducted research into the challenges experienced by providers of home care and other services in responding to increased opportunities for user choice. Significantly, SPRU has been able to bring together evidence from one of the strands of the IBSEN evaluation (see 3.1.6 above), which investigated the experiences of commissioning managers and service providers in four of the IB pilot sites, with a purposively designed study of home care service providers in four other local authorities where providers had so far only had experience of direct payments (see 3.1.4 above). The 'added value' created by combining these two studies considerably strengthened the evidence base in an area where many providers had yet to experience major changes in their local authority contracts.

The two studies found that providers faced new financial and organisational risks as more people eligible for social care were offered personal budgets. Providers also risked losing trained and qualified staff who could move to work as privately employed personal assistants. There appeared to be few mechanisms for informing service providers about the choices made by direct payment or personal budget holders, so that they could respond appropriately to new user demand.

The research findings were widely publicised by the UK Home Care Association in its members' newsletter. Two academic papers have been published in *Public Money and Management*, which is read by a wide range

4.4 How social care markets respond to increased opportunities for user choice

Choice-based policies can only deliver beneficial outcomes if the service options that users desire are actually available. There is as yet little evidence on how service providers are responding to users' choices, particularly if direct payments and personal budgets offer the opportunity to choose different and innovative support options and modes of delivery.

Since 1993, social care quasi-markets have developed largely in response to the requirements of local authority purchasers.

of public sector managers. In its response to the IBSEN research, the Department of Health asserted that 'It is clear that councils should be now focusing their commissioning activities on creating options for choice in services ... It is clear that to enable personalisation, commissioning needs to include a stronger emphasis on understanding people's choices ... The ability of local authorities to develop the market, including new and different services that promote people's independence and well-being, will clearly be crucial to implementation.' (DH, 2008: 26-27).

4.5 Research on the long-term impacts of home care re-ablement services

SPRU has conducted two studies (see 3.2.4 and 3.2.5 above) that examined the longer-term impacts of home care re-ablement services on subsequent use of social care and health services, in order to determine how far this relatively intensive intervention reduces longer-term demands for services. Both studies were commissioned at the request of the Care Services Efficiency Delivery (CSED) Programme through SPRU's responsive mode capacity.

The first study (3.2.4) of routine service data showed promising outcomes, with evidence that re-ablement could delay needs for standard home care support and other social care services. However, this small study lacked any comparison group of people receiving standard home care, so it was not possible to conclude that such delays would not have occurred anyway. A further, large scale comparative study (3.2.5) was therefore commissioned at the request of CSED. This second study showed that re-ablement was associated with significantly reduced

subsequent use (and costs) of social care services, although over the period of a year these savings were largely offset by the higher costs of the initial re-ablement intervention. The study was also able to demonstrate that, using National Institute for Health and Clinical Excellence guidelines, re-ablement was cost-effective in relation to health-related quality of life and social care outcomes.

- ◆ The results of both studies were placed on the CSED website, along with a commentary from CSED research customers.
- ◆ Both CSED and the study team have given many presentations to local authority and NHS audiences, including national events such as *Community Care Live*. These activities by the SPRU study team are ongoing and will continue throughout summer 2011.
- ◆ A submission alerting key policy customers to the study findings was prepared within DH during autumn 2010. Consequently, evidence drawn from the second, large scale comparative study on the positive impacts of re-ablement was cited in the autumn 2010 *Vision for Adult Social Care*, to support the announcement of new funding for Primary Care Trusts to spend on developing re-ablement services (DH, 2010a: 29).
- ◆ The positive impacts of re-ablement were also repeatedly cited in the revised Operating Framework for the NHS in England 2011/12 (DH, 2010b *passim*).
- ◆ Subsequently SPRU (together with PSSRU, University of Kent) was asked by DH to draw up an agenda for further research into re-ablement services that took into account the new NHS funding for re-ablement services. This was submitted to DH in January 2011.

4.6 Contributions to consultation and debate about the future funding and organisation of long-term care

Throughout the period of the SPRU programme, successive governments have conducted extensive consultation exercises and formal inquiries into the design of financially sustainable and politically acceptable alternatives to the funding of social care. SPRU has contributed to these debates, both directly and indirectly. Our small scoping study (3.2.6 above) fed directly into the proposals published by the Department of Health in July 2009 (DH, 2009: 91), which cited evidence from the study on the ages at which people in Japan contribute to and are entitled to benefits from that country's long-term care insurance programme. Less directly, evidence from this study was subsequently included in a discussion paper commissioned by Dartington/Research in Practice for Adults as part of its review on the future of adult social care (Glendinning, 2010).

instances we have been able to ensure that the reports of these responsive mode studies are widely disseminated, through short, lay summaries targeted at practitioners and /or through academic journal articles and presentations at academic conferences.

4.7 Other examples of research relevance to policy

Smaller responsive mode studies commissioned by DH to meet immediate policy needs have included a review of initiatives to improve access to information, following a recommendation from the Better Regulation Task Force; a review of evidence on the perceptions and management of risk in adult social care; and a review of evidence on the effectiveness of initiatives to support carers. Throughout the period of the programme, SPRU has been able to respond positively to requests from DH to conduct responsive-mode studies. Moreover, in all

Section 5 Conclusions

The research conducted by SPRU within its DH-funded programme has, for the most part, been concerned with issues of choice, from the perspectives of users, carers, service providers and managers. This theme has been, and continues to be, central to DH policy; to the statutory, private and third sector organisations that implement policy and deliver social care services; and to the disabled and older people who need social care support, and their families. We are delighted that we have been able to maintain this core theme throughout most of our responsive mode research and other linked studies, as well as in our core DH-funded programme.

As well as providing immediate and longer-term policy-relevant research, SPRU's DH-funded programme has had a further important function. It has also provided an organisational foundation and a volume of expertise on which other research has been able to build. Thus we have described (section 3.3 above) how we have been able to conduct a range of other studies that draw on the substantive knowledge of adult social care and the methodological expertise that has been developed through conducting the DH-funded programme. We consider these additional studies provide important 'added value' to the DH programme funding.

At the core of the main DH programme has been a major qualitative longitudinal study that has enabled us to examine the lived experiences of making choices over time by a diverse sample of people with social care support needs. It is rare for research to be able to take this longitudinal perspective and we have been delighted that the DH programme has provided this unique opportunity. The study has generated a

wealth of insights into the challenges that people making choices about services and support can experience; and the conditions under which both the processes and the outcomes of choice can be optimised. Because the study has only just been completed and many of the potential outputs are still under consideration by journal editors (and, indeed by DH itself), it is not yet possible to assess its overall impact and contribution. Nevertheless, some important outcomes of the study can already be identified. First, the study has made a significant contribution to the development of expertise and capacity in applied qualitative longitudinal research. Qualitative longitudinal studies are increasingly recognised as a valuable resource for policy research, because they uncover and explain processes of change over time, particularly the factors that shape individual behaviours. They can thus provide rigorous evaluations of existing policies; and offer insights on which new policies can be founded (see for example *Social Policy and Society*, 2007). Through their experience of the study, members of the study team have themselves developed expertise in designing, conducting and analysing qualitative longitudinal research. Moreover, if SPRU is successful in lodging the data with the Timescapes archive (part of UK Data Archive), this rich data set will become a resource for secondary analysis, alongside other qualitative longitudinal studies of social change over time.

SPRU's research has always had a strong focus on researching the voices and experiences of people who are marginalised or disadvantaged, whether by poverty, ill health, disability or old age. The DH programme has taken this focus one step further, by including in the Choice and Change Panel Study people

whose cognitive or communication abilities meant they were unable to participate in standard verbal interviews. Instead, simplified topic guides and Talking Mat[®] techniques were used to ascertain their preferences and choices. This is a considerable ethical and methodological advance on conducting interviews with carers as 'proxy' respondents and several of the Panel Study papers have described these methods in some detail. We are now building on this experience and focusing two of our new studies on people who have severe and complex needs, including cognitive or communication impairments that require modified and personalised approaches to communication.

All the research in SPRU's DH programme has been conducted to the highest academic standards. Those studies whose final reports have been externally reviewed on completion have been endorsed as scientifically sound. The high quality of our research has also meant that all our submitted journal articles have passed scientific scrutiny by academic journals.

At the same time, we have maintained throughout the DH programme SPRU's long-standing commitment to disseminating our research widely to local authorities, Primary Care Trusts, other NHS organisations, third sector and user organisations; and to the managers and front-line staff within them. Research from all SPRU's DH programme studies has been disseminated through our website, by email, RSS and Twitter; by distributing short hard copy lay summaries free of charge to a wide range of organisations and individuals; and through presentations at conferences and seminars to managers and front-line practitioners. For example, we have close relationships with regional Making Research Count networks and have used these to engage practitioners in discussions about how their practice might

adapt to take account of the latest research findings.

In 2009, the quality and capacity of SPRU's research into adult social care was recognised through an invitation to become a founder core member of the National Institute for Health Research's new School for Social Care Research. The School for Social Care Research brings together the six departments and units conducting the highest quality (as reflected in the last Research Assessment Exercise rating) research in adult social care and has a budget of £15 million over five years. Its mission is to develop the evidence base for adult social care practice by commissioning and conducting world-class research. Through its membership of the School, SPRU has been able to develop new projects that build, both substantively and methodologically, on its DH-funded programme.

Section 6 SPRU DH-commissioned Research Programme 2006-11: Published outputs

NB this list excludes:

- ◆ papers that are still under consideration by refereed journals;
- ◆ overview and summary papers from the Panel Study that are still under review by DH customers.

Peer reviewed journal articles

2011 and forthcoming

1. Arksey, H. and Baxter, K. (forthcoming) Exploring the temporal aspects of direct payments, *British Journal of Social Work*.
2. Baxter, K. and Glendinning, C. (2011) Making choices about support services: disabled adults' and older people's use of information, *Health and Social Care in the Community*, 19, 3, 272-279.
3. Baxter, K., Glendinning, C. and Greener, I. (2011) The implications of personal budgets for the home care market, *Public Money & Management*, 31, 2, 91-98.
4. Baxter, K., Wilberforce, M. and Glendinning, C. (2011) Personal budgets and the workforce implications for social care providers: expectations and early experiences, *Social Policy and Society*, 10, 1, 55-65.
5. Glendinning, C., Moran, N., Challis, D., Fernandez, J-L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Netten, A., Stevens, M. and Wilberforce, M. (2011) Personalisation and partnership: competing objectives in English adult social care? The individual budget pilot projects and the NHS, *Social Policy and Society*, 10, 2, 151-162.
6. Jacobs, S., Abell, J., Stevens, M., Wilberforce, M., Challis, D., Manthorpe, J., Fernandez, J-L., Glendinning, C., Jones, K., Knapp, M., Moran, N. and Netten, A. (forthcoming) The personalisation of care services and the early impact on staff activity patterns, *Journal of Social Work*. (Available online from 6 July 2011).
7. Maddison, J. and Beresford, B. (forthcoming) Decision-making around moving on from full-time education: the roles and experiences of parents of disabled young people with degenerative conditions, *Health and Social Care in the Community*.
8. Maddison, J. and Beresford, B. (forthcoming) The development of satisfaction with service-related choices for disabled young people with degenerative conditions: evidence from parents' accounts, *Health and Social Care in the Community*.
9. Manthorpe, J., Stevens, M., Rapaport, J., Challis, D., Jacobs, S., Netten, A., Jones, K., Knapp, M., Wilberforce, M. and Glendinning, C. (2011) Individual budgets and adult safeguarding: parallel or converging tracks? Further findings from the evaluation of the Individual Budget pilots, *Journal of Social Work*, 11, 4, 422-438.
10. Mitchell, W. (forthcoming) Making choices about medical interventions: the experiences of disabled young people with degenerative conditions, *Health Expectations*.
11. Mitchell, W. (forthcoming) Perspectives of disabled young people with degenerative conditions on making choices with parents and peers, *Qualitative Social Work*.

12. Mitchell, W. and Sloper, P. (2011) Making choices in my life: listening to the ideas and experiences of young people in the UK who communicate non-verbally, *Children and Youth Services Review*, 33, 4, 521-527.
 13. Moran, N., Arksey, H., Glendinning, C., Jones, K., Netten, A. and Rabiee, P. (forthcoming) Personalisation and carers: whose rights? Whose benefits? *British Journal of Social Work* (Available online from 7 June 2011).
 14. Netten, A., Jones, K., Knapp, M., Fernandez, J-L., Challis, D., Glendinning, C., Jacobs, S., Manthorpe, J., Moran, N., Stevens, M. and Wilberforce, M. (forthcoming) Personalisation through individual budgets: does it work and for whom?, *British Journal of Social Work*.
 15. Rabiee, P. and Glendinning, C. (2011) Organisation and delivery of home care re-ablement: what makes a difference? *Health and Social Care in the Community*, 19, 5, 495-503.
 16. Stevens, M., Glendinning, C., Jacobs, S., Moran, N., Challis, D., Manthorpe, J., Fernandez, J-L., Jones, K., Knapp, M., Netten, A. and Wilberforce, M. (2011) Assessing the role of increasing choice in English social care services, *Journal of Social Policy*, 40, 2, 257-274.
 17. Wilberforce, M., Glendinning, C., Challis, D., Fernandez, J-L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A. and Stevens, M. (2011) Implementing consumer choice in long-term care: the impact of individual budgets on social care providers in England, *Social Policy & Administration*, 45, 5, 593-612.
 18. Manthorpe, J., Stevens, M., Rapaport, J., Jacobs, S., Challis, D., Wilberforce, M., Netten, A., Knapp, M. and Glendinning, C. (2010) Gearing up for personalisation: training activities commissioned in the English pilot individual budgets sites 2006-2008, *Social Work Education*, 29, 3, 1470-1227.
 19. Mitchell, W. (2010) 'I know how I feel': listening to young people with life-limiting conditions who have learning and communication impairments, *Qualitative Social Work*, 9, 2, 185-203.
 20. Moran, N., Glendinning, C., Stevens, M., Manthorpe, J., Jacobs, S., Wilberforce, M., Knapp, M., Challis, D., Fernandez, J-L., Jones, K. and Netten, A. (2010) Joining up government by integrating funding streams? The experiences of the Individual Budget pilot projects for older and disabled people in England, *International Journal of Public Administration*, 34, 4, 232-243.
 21. Jones, K. and Netten, A. (2010) The costs of change: a case study of the process of implementing individual budgets across pilot local authorities in England, *Health and Social Care in the Community*, 18, 1, 51-58.
 22. Rabiee, P. and Glendinning, C. (2010) Choice: what, when and why? Exploring the importance of choice to disabled people, *Disability & Society*, 25, 7, 827-839.
- 2010**
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