THE QUEEN'S
ANNIVERSARY PRIZES
FOR HIGHER AND FURTHER EDUCATION
2009

spru | Social Policy Research Unit

Annual Report 2011

Excellence in social policy research

THE UNIVERSITY *of York*

Contents

Special Features

Introduction by the Director

Last year I finished my introduction to the annual report by signalling the challenges that the research world was experiencing, as funding remained static or reduced. Little has altered in the national picture in the past 12 months, but SPRU has always responded to changing times by adjusting to the new environment while keeping to our core values of producing high quality research to inform policy and practice. The current situation is no exception.

As we describe here, we continue to extend our success with a wide range of public funders – particularly the National Institute for Health Research – and are developing fruitful relationships with the private sector. Similarly, while we build on existing expertise and policy knowledge, we are also expanding into new areas; two that are particularly significant this year are dementia and issues of work-related stress in the children's health care workforce. This latter is also taking us into new methodological areas as we develop skills in psychometric measure development.

We also continue to expand our partnerships with UK researchers, service providers and users. This year has seen links made with Innovations in Dementia, Dementia UK and the Life Stories Network, and new research collaborations with the Universities of Leeds, Leicester, Manchester, Sheffield, and King's College London. We look forward to seeing these bear fruit in the coming years.

We have also expanded our international reach in the past year, with invited presentations and refereed papers at international conferences and seminars, longer-term academic visits from Norwegian and Spanish researchers and to the University of Queensland, and new collaborative relationships with academics and policy makers in Australia, Canada, and Norway.

'Impact' is an increasingly important measure of the value that our work contributes to society from research funding. Another of our core values, over what is now almost 40 years, is to build effective, long-term partnerships with service users, policy makers, and practitioners. This means not only that our work is relevant to their concerns, but also that the knowledge it generates is transferred effectively to where it can do most good. As an innovation to the annual report this year, we have highlighted work that has had particular influence in relation to looked-after children, welfare reform, integrated services for people with long-term neurological conditions and care closer to home for children and young people (page 5).

Another of the distinctive features of SPRU over the years has been its commitment to developing its newer researchers to become independent investigators and to lead programmes of their own. I am delighted to report that Bryony Beresford, who joined the Unit straight from her PhD work in 1991, was this year awarded a personal chair in recognition of the quality and influence of her research on disabled children and young people and their families. Bryony has been acting leader of the children and families team since Professor Tricia Sloper retired in 2009, and has now taken on the role of Research Director of the team. Other researchers gain skills and knowledge in the Unit and move on to other settings. This year two of our newer researchers, Ala Syrriyeh and Alison Wilde, were appointed to lectureships at, respectively, the University of Bradford and Bangor University.

We have worked on 31 different projects through the year, maintained an international network and been involved in an ESRC seminar series. Two new research students have joined us, both working on White Rose Partnership projects in collaboration with the Universities of Leeds and Sheffield and as part of the new ESRC Doctoral Training Centre. Project funders include, among others: Department of Health, Department of Work and Pensions, Department for Education, National Institute of Health Research (NIHR) Service Delivery and Organisation, NIHR School for Social Care Research, NIHR Health Services Research, Centre for Excellence and Outcomes in Children and Young People's Services (C4EO), ESRC, Big Lottery, Joseph Rowntree Foundation, NSPCC, Cancer Research UK, City of York Council and the French Ministry of Health, Welfare and Sport. Our thanks go to them all.

Managing and delivering so many projects - the hard work behind our achievements - and to such a wide range of funders, requires skilled, experienced and highly committed researchers and support staff alike. We are lucky in having both in SPRU, and I thank them all, too.

SPRU continues to experience the effects of international and national uncertainty but as ever - resilient and fleet of foot - we adapt to challenge and change by consulting our maps and adjusting our route. I hope that you enjoy reading about this year's journey.

Gillian Parker
Director

The impact our work and expertise had on policy and practice in 2011

'Impact' is an increasingly important measure of the value that our work contributes to society from research funding. One of our core values, over what is now almost 40 years, is to build effective, long-term partnerships with service users, policy makers, and practitioners. This means not only that our work is relevant to their concerns, but also that the knowledge it generates is transferred effectively to where it can do most good. Here we have highlighted work that has had particular influence this year.

Welfare reform

This year we saw the Welfare and Employment Team's stream of work on radical benefit simplification being reflected in the Welfare Reform Bill currently going through its parliamentary passage. This work began back in 2006 when Roy Sainsbury responded to ongoing debates about the complexity of social security by proposing a radical reform of benefits. The idea for a 'single working age benefit' to replace the multiple benefits for people out of work was taken up by the last Labour Government. In its 2008 Green Paper *Raising Expectations and Increasing Support: Reforming welfare for the future*, the then Secretary of State, James Purnell, wrote: "We remain attracted to the idea of a single working-age benefit and will continue to explore whether, over the longer term, this is the right approach for our aims for the social security system". In 2009 SPRU was commissioned to carry out research into the public understanding of a single working age benefit. The Coalition government was also persuaded by the merits of such a benefit and published its own version of the idea, Universal Credit, in a 2010 Green Paper *21st Century Welfare*, referencing our 2010 report. Powers to implement Universal Credit are contained in the current Welfare Reform Bill.

Looked-after children and child protection

This year the Children and Young People's Social Work Team's work has contributed to developments in child protection, family reunification and care for looked-after children. In October Nina Biehal was invited as an expert witness to give evidence to the House of Commons Education Select Committee Inquiry into the Child Protection System in England. The team's study of the reunification of maltreated children in care was cited in the government-commissioned Munro Review of Child Protection and the Family Justice Review. It was also included in the Department for Education's overview of research on child protection. Our work on neglected adolescents was also reference in the Munro Review.

Mike Stein contributed to the development of *The Children Act 1989 Guidance and Regulations, Vol. 3: Planning Transition to Adulthood for Care Leavers*, which was implemented by the Department for Education in April. His work on leaving care was cited in the NICE Guidance on looked-after young people (NICE Public Health Guidance 28). Research on resilience and leaving care was widely cited in the Demos report *'In Loco Parentis'*. Our work has had an international impact too with invitations in 2011 to speak to policy makers and practitioners at conferences in Austria, Denmark, Poland, Italy, Sweden and Ireland and an interview on Polish radio.

Integrated services for people with long-term neurological conditions: evaluation of the impact of the National Service Framework

The findings from this four-year study were a timely contribution to the debate around the management of long-term conditions and the integration of health and social care. Evidence from this project fed directly into the 2011 consultation for the Social Care White Paper (scheduled for spring 2012) as part of the Department of Health Research Initiative for Long-term Neurological Conditions (LTNCs). In addition, it was used by Parkinson's UK in their submission of evidence to policy makers for the Health and Social Care Bill. The findings were well received by commissioners and managers in the NHS and social care. We were invited to speak at three NHS Confederation events, nationally and regionally, and the major National Institute of Health Research (NIHR) event *Delivering Better Health Services*. Further workshops and presentation events included invitations from the North of Tyne Neurological Forum and the North Yorkshire and York Regional Neurological Alliance, where we spoke to staff from the statutory and non-statutory sectors, service users and carers, and generated further training and dissemination events for practitioners. Key messages from the study particularly resonated with those in the voluntary sector who have campaigned for the better co-ordination of services and a higher profile for LTNCs. Knowledge exchange events were hosted by Headway, UK Acquired Brain Injury Forum and a Motor Neurone Disease Association Care Centre. In December 2011 the National Audit Office published a report *Services for People with Neurological Conditions* and cited this study as providing high quality evidence.

'Integration' continues to be a much debated topic that has re-surfaced politically in the current NHS reforms. Messages from the research, specifically relating to LTNCs, but also to integration generally, remain highly relevant. It has generated further interest in developing ways of assessing outcomes of integrated care, work that is currently being undertaken by SPRU (see page 15).

Delivering care closer to home for children and young people who are ill

This year saw the dissemination of a three-year project in the Children and Families Team that enhanced the evidence base on models of care delivered closer to home for children and young people who are ill. Whilst national policy has repeatedly advocated such care, the evidence base on which to develop services was limited. Our study addressed this gap, with an overwhelmingly positive response from policy makers, NHS commissioners and managers alike. Further details of the impact of our work are available in a special feature on page 8.

Choice and independence over the lifecourse
SPRU's Department of Health Research Programme 2006 – 11

We are proud of this programme and all it has achieved and hope that the insights it has provided continue to influence the shape of future services for the better.

It is rare for research funding to allow longitudinal studies to be conducted, and we are delighted to have had this opportunity through our DH-commissioned research programme from 2006-11. At the heart of the programme was a qualitative longitudinal study of disabled young people (and their families), working age adults and older people, which examined the choices about services that they made over a three-year period, as their health and other circumstances changed. The study generated a wealth of insights into the challenges experienced by people making choices about services and support, and the conditions under which both the processes and the outcomes of choices could be optimised. The study also helped to develop the expertise and capacity of SPRU researchers in applied qualitative longitudinal studies, which are increasingly recognised as valuable resources for policy research. We are lodging the study data with the Timescapes archive (part of UK Data Archive) so that this rich data set will also become a resource for secondary analysis.

There are strong arguments for paying close attention to choice and its links to disabled and older people's experience of independence. Earlier SPRU research showed that exercising choice and control is a commonly desired outcome of social care. However, choice may be problematic, particularly for people disadvantaged by ageing, long-term illness or impairment. Furthermore, policy ambitions to increase individual choice bring new challenges for the social care quasi-markets that have developed since the early 1990s. In addressing these questions, the programme aimed both to inform policy and to contribute to wider academic debates.

Other choice-related studies

Choice is only possible if information about potential alternatives and the options that people want are both available. Other research studies in the DH programme included investigations of the availability of information about social care services and the challenges faced by home care services in responding to increased opportunities for choice on the part of service users. We also reviewed research evidence on how service users, carers and professionals balance the benefits of choice against the potential risks involved. Other, linked, studies investigated the choices that family carers make, particularly when supporting a disabled relative; and carers' own choices about paid work and retirement.

Responsive studies

DH required some of its programme funding to be ring-fenced for responsive projects – pieces of work that could be commissioned and completed quickly to meet urgent policy needs. This added flexibility and currency to our portfolio of research within the programme. One such study was a major, high-profile evaluation of the individual budget (IB) pilot projects in 13 English local authorities. Working with four other DH-funded research units, SPRU led the national evaluation of these pilots. The evaluation found that people using IBs were more likely to feel in control of their lives, compared with people using conventional services. This study influenced the subsequent extension of personal budgets across the whole of English adult social care. SPRU also 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.

A second major responsive study examined the longer-term impacts of home care re-ablement services. Many English local authorities are developing short-term, intensive, re-ablement services; these aim to give people the confidence and skills to look after themselves and hence reduce their need for support. Our research found that people who used re-ablement were less likely to need further home care support for up to a year afterwards than those using conventional home care services. It also helped to highlight good practice for new services being commissioned around the country.

Other studies linked to the DH programme included reviews of how other countries fund and organise long-term care; these have been referenced in the 2009 Green Paper on the reform of English adult social care, *Shaping the Future of Care Together.*

Users' perspectives

SPRU has a long-established reputation for building the views of services users and carers into its research programmes. The studies in SPRU's DH programme were discussed by members of our permanent Consultation Groups. These Groups include: working age and older adults who are disabled or have serious health problems; 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, as well as generating new research ideas.

Achievements

Choice continues to be central to government policies; to older and disabled people needing social care and their families; and to the statutory, private and third sector organisations that implement policy and deliver social care services. We maintained this focus throughout the DH-funded core and responsive research programmes. Moreover, this focus offered an organisational foundation and body of expertise for related research commissioned by other funders; these additional studies 'added value' to the DH programme funding.

The research was rated 'excellent' by independent academic referees who were asked by DH to review the programme. Reviewers commented on the 'commendable array' of publications arising from the programme; its 'significant' and 'impressive' impact on health and social care policy; and particularly commended the use of DH programme funding to develop skills and expertise in qualitative longitudinal research.

As well as academic outputs, the DH programme built on SPRU's long-standing commitment to disseminate its research widely to user, carer and third sector organisations, managers and practitioners within local authorities and NHS services, using social and digital as well as conventional media. We also gave numerous conference presentations to academics, policy makers and practitioners. These provided opportunities to debate the research findings and their implications in open forum.

In 2009, the quality and capacity of SPRU's research into adult social care was recognised through an invitation to become a founder member of the National Institute for Health Research's new School for Social Care Research (SSCR). SSCR's 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 developed a number of new studies that build, both substantively and methodologically, on its DH programme.

Leading this programme of research has been a long and illuminating journey into the heart of changes taking place in our health and social care systems today, and how they are experienced by service users. It has touched on the fundamental issues of choice and change that affect the lives of millions of service users in our country. We are proud of this programme and all it has achieved, and hope that the insights it has provided continue to influence the shape of future services for the better.

Caroline Glendinning
Programme Director

Glendinning, C. ... [et al.] (2012) *Choice and Independence over the Lifecourse: Final report to the Department of Health*, Social Policy Research Unit, University of York, York.

How to deliver children's care closer to home

Our research provides new, important, insights into developing community services for children and young people who are ill.

In 2004, the government introduced new policy arguing that children and young people who are ill should receive their care as close to home as possible (*National Service Framework for Children, Young People and Maternity Services*, Department of Health, 2004). This care is typically provided in the family home by community children's nursing teams and outreach nurses, but can include other settings, such as the child's school. Hospital-based paediatric assessment units that aim to prevent inpatient admission and reduce length of hospital stay also enable care closer to home (CCTH).

Between 2007 and 2010, SPRU carried out a large multi-method study to evaluate this type of service provision. The methods used were: a systematic review, a national survey, qualitative case studies with commissioners, managers, service practitioners and service users, and cost analysis. Prior to our study, little was known about the extent and full range of CCTH services in England, and what factors need to be considered when developing them. Our study addressed this gap, showing that service coverage is still patchy, and providing an evidence base to inform the development of future CCTH services.

Key factors that we found need to be in place to enable development of high quality CCTH services include:

- good working relationships between commissioners and providers
- better or more readily available data from services on their costs, caseload and contacts
- making sure that good quality, holistic support for families is a key part of services, especially when families are taking on responsibility for nursing tasks as part of their child's care at home
- sufficient capacity in services to provide this type of support
- adequate support structures for CCTH staff who operate as lone workers in family homes.

Both during the project and since its completion, there has been significant interest in, and use of, the study's findings. For example:

- Findings from the study's national survey fed directly into the 2011 Department of Health publication *NHS at Home: Community Children's Nursing Services*, a report aimed at helping commissioners and providers improve services.
- Members of the research team have been invited to meet with commissioners and service planners from NHS organisations who are keen to develop children's community nursing teams.
- Invited presentations have been given by members of the research team at SDO and HSR Network seminars focused on reaching senior NHS managers with messages about improving services for children and young people who are ill. Other invitations to speak included the Royal College of Nursing's Children's Community Nursing Conference and a NHS Institute for Innovation and Improvement event which focused on improving emergency care pathways for children and young people.
- Members of the research team have given presentations about the research at international conferences, for example the Annual Congress of the European Academy of Paediatric Societies.

These activities demonstrate how the findings are being disseminated directly to the people who can influence both policy and development of CCTH services.

Findings from the study have also given way to new sets of research questions. For example, the qualitative study with families using CCTH services demonstrated how parents often become responsible for technical nursing care as part of caring for their ill child at home. However, little is known about how this can affect the parent and child when such nursing care is invasive and distressing for the child. We are developing new research to address this issue. The qualitative study also demonstrated how GPs are a common source of referral to CCTH services, and thus their decisions will mediate the use of these services. Findings from service staff suggest that some GPs may be hesitant to refer families to their service. Further research should explore what factors affect GPs' referral decisions, producing helpful findings about how to optimise service use.

Publications

Gridley, K., Spiers, G., Aspinal, F., Bernard, S., Atkin, K. and Parker, G. (forthcoming) Can general practitioner commissioning deliver equity and excellence? Evidence from two studies of service improvement in the English NHS, *Journal of Health Services Research & Policy.*

Parker, G., Spiers, G., Gridley, K., Atkin, K., Cusworth, L., Mukherjee, S., Birks, Y., Lowson, K., Wright, D., and Light, K. (2011) *Evaluating Models of Care Closer to Home for Children and Young People who are Ill: Main report*, NIHR Service Delivery and Organisation programme, Southampton.

Parker, G., Spiers, G., Gridley, K., Atkin, K., Birks, Y., Lowson, K., and Light, K. (2011) *Evaluating Models of Care Closer to Home for Children and Young People who are Ill: A systematic review*, NIHR Service Delivery and Organisation programme, Southampton

Parker, G., Spiers, G., Cusworth, L., Birks, Y., Gridley, K. and Mukherjee, S. (forthcoming) Care closer to home for children and young people who are ill: developing and testing a model of service delivery and organization, *Journal of Advanced Nursing*, (Available online from 6 December 2011).

Parker, G., Spiers, G., Gridley, K., Atkin, K., Birks, Y., Lowson, K. and Light, K. (forthcoming) Systematic review of international evidence on the effectiveness and costs of paediatric home care, *Child: care, health & development*.

Spiers, G., Parker, G., Gridley, K. and Atkin, K. (2011) The psychosocial experience of parents receiving care closer to home for their ill child, *Health and Social Care in the Community*, 19, 6, 653-660.

Spiers, G., Parker, G., Gridley, K., Cusworth, L., Mukherjee, S., Heaton, J., Atkin, K., Birks, Y., Light, K., Lowson, K. and Wright, D. (forthcoming) Understanding models of 'care closer to home' for children and young people who are ill: a mixed methods study, *Nursing Children & Young People*.

More information on the project, and its subsequent outputs, is available here:
http://php.york.ac.uk/inst/spru/research/summs/closer.php

Interested in carrying out research, but don't know how to start?

"The 2 days have been excellent in the fact that it has introduced me to the concept of research and encouraged me to move forward to actually doing some research. It has given me the confidence to have a go!!"

The Big Lottery Fund (BLF) Research Programme has identified the need to increase research capacity within the third, or voluntary, sector. One of our studies (the STEPP project) is funded by BLF and and we have joined with three third sector partners in the hospice and palliative care sector on this project. This presented us with an ideal opportunity to provide training in 'getting started in research' to practitioners working in these partner organisations.

"It has given me confidence in embarking on a research project."

We delivered two one-day workshops, held two months apart, designed specifically for practitioners with little or no experience of doing research, but who were keen to start engaging in research and recognised the need for more evidence-based practice in the settings in which they worked. We mixed direct teaching and interactive sessions. Participants also worked on their own research idea over the workshop period, with one-to-one tutorial support available when requested. Since completing the workshop a number of participants have made significant steps forward in embarking on, or securing funding for, a piece of research.

"This introduction to research has been excellent, allowing interaction and confidence building within a very important area. An extremely large area to cover in a concise understandable way. It has been a very worthwhile 2 days. All topics covered in a manageable way. Thank you."

The workshops sessions included: the differences and similarities between research, audit and consultation; research design, methods and sampling; research ethics; identifying and using existing research evidence; using existing datasets; dissemination; user involvement; doing research with 'hard to reach' groups; research funding and judging the quality of published research.

Participants were primarily practitioners working in children's hospices. They identified a wide range of topics where further evidence was required, something that had stimulated them to attend the workshop. Feedback from participants suggests the workshop was extremely successful in achieving its objectives, with all participants reporting improved understanding (and confidence) in how to go about doing a piece of research.

SPRU's Research Directors go to the heart of government as expert witnesses

On being a witness before Parliament - a researcher's tale

Roy Sainsbury

When I acted as a Specialist Adviser to a Parliamentary Select Committee I had the opportunity to fashion some of the questions that are put to the witnesses who appear at the Committee hearings. It was a chance to ensure some difficult or controversial issues were not ducked or fudged. It was with a certain sense of trepidation therefore that I received invitations in 2011 to appear myself as a witness, first before the House of Commons Standing Committee exploring the Welfare Reform Bill and secondly before the Work and Pensions Select Committee as part of its inquiry into replacing Disability Living Allowance (DLA).

But at least I knew what to expect. And having done work with SPRU colleagues on both subjects I felt well placed to contribute hard empirical evidence into both debates. There was also the chance to challenge some of the rhetoric and misinformation that always surrounds policy debates. It was particularly gratifying to make the point that the proposed reform of DLA would not benefit a single disabled person. Most benefit reforms create both 'winners' and 'losers' but this reform was an exception – it was losers all the way. Not a happy point to have to make but an important one.

On a completely different note I remember when MP and acting great, Glenda Jackson, said one word to me after a minor disagreement between us about the effect of benefit cuts: she said "Sorry". A moment to cherish.

Research knowledge transferred to the live policy arena

Nina Biehal

In October 2011, I was asked to be an expert witness to the inquiry of the House of Commons Select Committee into the child protection system in England. The Select Committee was particularly interested in the long-term consequences of a delay in intervention where there is evidence of neglect, thresholds for taking children into care, and the protection of adolescents who experience abuse or neglect. Since SPRU's Children and Young People's Social Work Research Group has addressed all of these questions in recent studies, I was pleased to have the opportunity to discuss the research evidence with the Committee. I particularly wanted to challenge the widespread assumption that being 'looked after' is necessarily damaging for children - our research on maltreated children suggests the opposite. I also wanted to draw their attention to evidence on the impact of abuse and neglect on adolescents, an issue we have explored in a number of studies. Prior to this appearance before the Education Committee, I also contributed to the discussion of these issues at a round table on thresholds for care which was held by the National Society for the Prevention of Cruelty to Children (NSPCC) to inform their own written evidence to the Select Committee. On both occasions it was rewarding to be able to discuss the real application of policy to children and young people, and to try to influence the thinking about making improvements to our current systems.

SPRU Seminar Series 2011

In 2011 we explored the potential impact of a wide variety of comparative research on the construction of scientific knowledge and on policy making. Some important questions that we tackled were:

- Why consider comparative perspectives? How can comparative research contribute to the development of academic knowledge and local/global policy changes?
- Can comparative research challenge what seem to be well-established concepts, assumptions, theories and responses to social policy?
- What are the different meanings of comparative research in social policy?
- What are the methodological possibilities, challenges and innovations in comparative research?

Social Policy in Context: Comparisons across countries and cultures

De-industrialization and dynamics of 'race' and 'class' in the US and the UK
Dr James Rhodes, School of Social Sciences at the University of Manchester

Europeanisation of disability policy
Professor Mark Priestley, School of Sociology and Social Policy, University of Leeds

Good practice in international comparative social policy research
Professor Linda Hantrais, Department of Politics, History and International Relations, Loughborough University

Long-term care options in Europe
Ricardo Rodrigues, European Centre for Social Welfare Policy & Research, Vienna

Markets and migrants in the transnational care economy: A three levelled analysis
Professor Fiona Williams, OBE, School of Sociology and Social Policy, University of Leeds

Work with young people and families at the 'edges' of care in England, Denmark, France and Germany
Dr Janet Boddy, Thomas Coram Research Institute, University of London

Globalization and child welfare: Cross-national study of children in out-of-home care
Professor June Thoburn, Department of Social Work & Psychology, University of East Anglia

Children of imprisoned parents: a pan-European study of mental health, resilience and well-being
Professor Adele Jones, Director of the Centre for Applied Childhood Studies, University of Huddersfield

Queen's Anniversary Prize Lecture 2011

For the 2011 Queen's Anniversary Prize lecture we were delighted to welcome one of our past researchers back to SPRU to give an excellent and thought provoking lecture on *Social policy in context - reflections on ethnicity, religion and social policy*. Professor Waqar Ahmad worked at SPRU in the 1990s and is now the Deputy Vice-Chancellor Research and Enterprise at Middlesex University. A large, enthusiastic audience gathered to hear Professor Ahmad, among them former and current colleagues. Professor Ahmad treated the audience to an erudite discussion of the place of British Muslims in Britain today and the causes of the rising Islamaphobia that we are experiencing. He discussed the problem of the state's relationship to Muslim communities as it becomes predominantly articulated through the discourse of security. He then showed how this discourse underplays the diversity within the Muslim community and disregards how Britain's Muslims are making social and political spaces for themselves, thus transforming themselves and British society.

Professor Waqar Ahmad and SPRU Director, Professor Gillian Parker

Professor Ahmad is a major contributor to literature in the sociology of health and social policy and was the Chief Social Scientist in the Office of the Deputy Prime Minister (ODPM) for three years. While there he launched the ODPM/ESRC Fellowship and Studentship Scheme and the ODPM Research Networks - a model of research partnership between Whitehall and the ESRC that had been emulated by several government departments.

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The Social Policy Research Unit (SPRU) is a research centre based at the University of York. Since it was established in 1973, it has become recognised as one of the leading centres for research in social policy in the UK. SPRU has an international reputation for excellence in research in key areas of social policy, especially children, disability and long-term conditions, social work, health and social care, poverty, welfare, family and employment.

Research within the Unit is organised around four research teams, each of which is led by a Research Director:

Children and Young People's Social Work Team
- led by Professor Nina Biehal

Children and Families Team
- led by Professor Bryony Beresford

Welfare and Employment Team
- led by Professor Roy Sainsbury

Adults, Older People and Carers Team
- led by Professor Gillian Parker

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Social Policy Research Unit

Director: Professor Gillian Parker

Adults, Older People & Carers

Research Director:
Professor Gillian Parker

Children & Families

Research Director:
Professor Bryony Beresford

Welfare and Employment

Research Director:
Professor Roy Sainsbury

Children & Young People's Social Work

Research Director:
Professor Nina Biehal

SPRU Support Staff

The administration of the Unit is organised by the Support Staff Team

Adults, Older People and Carers

The Adults, Older People and Carers Team is led by Professor Gillian Parker. Research carried out within the Team focuses on social care and other services for adults and older people with disabilities or long-term conditions and their families.

Research undertaken during 2011

Assessing outcomes of integrated care for long-term neurological conditions

Ongoing project
The National Institute for Health Research, Service Delivery and Organisation Programme
April 2010 to September 2012
Gillian Parker, Fiona Aspinal, Sylvia Bernard, Gemma Spiers

Recent policy promotes integrated care provision in order 'to enable partners to join together to design and deliver services around the needs of users rather than worrying about the boundaries of their organisations'. It is assumed that these 'arrangements should help eliminate unnecessary gaps and duplications between services'.

This research will explore the different ways in which integrated care is provided. Qualitative case studies will be conducted in four areas in England with innovative models of integrated practice. The research team will also look at how the structures of the organisations around these models may affect them. Crucially we will ask people with long-term neurological conditions (LTNCs) what outcomes they want from their services and whether an integrated approach is helping to deliver these. We have developed a way of assessing whether these outcomes are being delivered by the different models of integrated care and will be tracking this in the coming years. Finally we will explore if and how this assessment will influence practice within the different models. Research methods include in-depth interviews, documentary analysis and non-participant observation.

Services for people with long-term neurological conditions (LTNCs) are a good exemplar because LTNCs may pose complex challenges for effective health and social care integration. Adults with LTNCs are generally younger than most long-term users of health and social care services. As a result, their roles as partners, parents, and economically active adults should be considered as part of their overall needs. The 'boundaries' that are important thus go beyond the conventional ones of health and even of social care, making the task of co-ordination potentially more complex. For these and other reasons, we might expect mechanisms for integration that 'get it right' for people with LTNCs would also be effective for other adults with complex, long-term conditions.

This project will produce messages about what works in integrated health and social care that can be used elsewhere. This will include how structures and ways of working can support how integrated services are delivered, in order to make a difference at the individual level. It will indicate which models of integration offer potential for being implemented more widely. It will also outline the outcomes that people with LTNCs, rather than professionals, want from integrated services. It will also demonstrate ways in which these outcomes can be used to influence the ways services are delivered.

Given the forthcoming structural changes in public services, this research also provides a real-time observation of the impact of policy on integrated approaches to health and social care provision and commissioning in general, as well as its effect on the models of integrated practice involved in the research.

Care and support for people with complex and severe needs: innovations and practice: a scoping study

Ongoing project
National Institute for Health Research, School for Social Care Research
June 2010 to February 2012
Kate Gridley, Jenni Brooks, Caroline Glendinning

People with complex and severe needs constitute a relatively small proportion of all adult social care users. However, they are growing in number, and meeting their needs can be problematic for service commissioners and providers. In particular, they often need personalised, co-ordinated and specialised services from a wide range of providers, which can be difficult to commission and deliver.

The study aims to generate evidence to inform social care practice in commissioning and providing personalised support to people with complex and severe needs. More specifically, we set out to identify:

- key features of the service and support arrangements desired by different groups of disabled adults and older people with severe and complex needs
- examples of initiatives to deliver support to disabled people with complex and severe needs. These should have features desired by users and carers and the potential to constitute examples of 'good practice'. Examples may focus on some or all of the different levels of commissioning, operational organisation and front-line delivery.

To do this we have:

- consulted with 67 key stakeholders, including people with severe and complex needs, their carers and organizations of and for these groups
- spoken to ten case examples of good service provision or commissioning (identified through the consultation) about the ways that they deliver these key features of good practice
- reviewed recent research and literature on relevant service developments and initiatives (on-going).

We recently held a feedback workshop, where organisations of and for people with complex needs were invited to hear the findings of the consultation and make comments. These comments were useful in checking the findings and helping to think about their implications.

Study findings will be disseminated to all English adult social care departments, key NHS bodies and relevant voluntary sector organisations, as well as through the NIHR School for Social Care Research's knowledge transfer activities. We will also publish summaries of the ten case examples of good practice on the SPRU website.

Publications

Brooks, J. (forthcoming) It's like having a friend around, in M. Davies (ed.) *Social Work with Adults: From policy to practice*, Palgrave Macmillan, London.

Gridley, K. (forthcoming) A good arrangement - now under threat, in M. Davies (ed.) *Social Work with Adults: From policy to practice*, Palgrave Macmillan, London.

National evaluation of the Personal Health Budget Pilot projects

Ongoing project
Department of Health
November 2009 to October 2012
Caroline Glendinning, Jacqueline Davidson, Annie Irvine, Kate Baxter (SPRU); Julien Forder, Karen Jones, James Caiels, Lizzie Welch, Karen Windle (Personal Social Services Research Unit, University of Kent); Paul Dolan (London School of Economics); Dominic King (Imperial College, London)

Personal Health Budgets (PHBs) are being piloted in 70 English Primary Care Trusts (PCTs) from 2009 to 2012, for patients with a range of long-term conditions. PHBs allow patients to know how much money is available to them, and to exercise greater choice and control over how their health-related support needs are met. PHBs can be held by healthcare professionals or by patients themselves in the form of a cash direct payment.

Twenty PCTs are participating in an in-depth evaluation. The evaluation aims to establish whether PHBs lead to better health and social care outcomes, compared with conventional services. The evaluation is examining:

- the processes of implementing PHBs
- the impacts of PHBs on different groups of patients and carers
- the cost-effectiveness of PHBs, compared to conventional services
- the impacts of PHBs on healthcare professionals, NHS organisations and the wider health and social care systems.

The evaluation has a quasi-experimental design: clinical and experiential outcomes for specific groups of patients receiving PHBs will be compared with those for patients using standard healthcare. The evaluation will also inform decisions on the wider implementation of PHBs beyond the pilots.

SPRU's role in the evaluation is conducting semi-structured interviews with subsamples of PHB holders: three months after the offer of a PHB, to assess patients' experiences of planning how to use a PHB; and six months later to assess outcomes from patients' perspectives. Single semi-structured interviews are also being conducted with small samples of women who have had a PHB for maternity, and carers of people who had a PHB for end-of-life care.

Early findings from the three-month interviews found some immediate, positive benefits. However, many interviewees did not know how much their PHB was, and a number were experiencing related delays in obtaining their desired support arrangements.

Publications

Irvine, A., Davidson, J., Glendinning, C., Jones, K., Forder, J., Caiels, J., Welch, E., Windle, K., Dolan, P. and King, D. (2011) *Personal Health Budgets: Early experiences of budget holders: Fourth interim report*, Department of Health, London.

Jones, K., Forder, J., Caiels, J., Welch, E., Windle, K., Davidson, J., Dolan, P., Glendinning, C., Irvine, A. and King, D. (2011) *The Cost of Implementing Personal Health Budgets: [Third interim report]*, PSSRU Discussion Paper, 2804, Personal Social Services Research Unit, University of Kent, Canterbury.

Jones, K., Welch, E., Caiels, J., Windle, K., Forder, J., Davidson, J., Dolan, P., Glendinning, C., Irvine, A. and King, D. (2010) *Experiences of implementing personal health budgets: 2nd interim report*, PSSRU Discussion Paper, 2747/2, Personal Social Services Research Unit, University of Kent, Canterbury.

Jones, K., Caiels, J., Forder, J., Windle , K., Welch, E., Dolan, P., Glendinning, C. and King, D. (2010) *Early experiences of implementing personal health budgets*, PSSRU Discussion Paper, 2726/2, Personal Social Services Research Unit, University of Kent, Canterbury.

Personalisation and carers: the roles of carers in assessment, support planning and managing personal budgets

Ongoing project
National Institute for Health Research, School for Social Care Research
January 2011 to December 2012
Wendy Mitchell, Caroline Glendinning, Jenni Brooks

Personalised adult social care emphasises the aspirations and preferences of service users. Carers have also secured rights to assessments and support but these developments have occurred separately and may overlook relationships between service users and their carers. This study examines how far current social care practice recognises and balances the needs and interests of disabled service users, especially those with communication or cognitive impairments, and their carers.

The study's aims are to:

- describe social care practice in relation to carers' roles in the assessment, support planning and management of personal budgets
- examine how far personalised assessment and support planning processes recognise and balance the respective needs and wishes of service users and carers
- examine the respective views of service users with communication or cognitive impairments and their carers on the role that each wants carers to play in personalisation processes.

The study is organised into three stages. The first is a survey of adult social care departments in two English regions exploring how carers are involved in personalisation processes. Three departments will be selected for the subsequent stages of research.

Stage two comprises interviews with personalisation and carers' leads in local authorities as well as focus group interviews with front-line staff working with older people and people with learning disabilities. Interviews will further explore policies and practice.

For the third stage older people and young adults with communication or cognitive impairments and their carers will be interviewed. We will use verbal and symbol-based research methods, as appropriate, with service users. Interviews will explore service users' and carers' own experiences and their evaluations of personalisation.

Insights from comparing local authority policies and practice with service users' and carers' own experiences will inform guidance on personalisation processes that more accurately reflect both service users' and carers' wishes.

Personalisation of home care for older people using managed personal budgets

Ongoing project
National Institute for Health Research, School for Social Care Research
January 2011 to December 2012
Parvaneh Rabiee, Kate Baxter, Susan Clarke, Caroline Glendinning

Personal budgets (PBs) are a mechanism for facilitating personalisation of social care services where service users have an allocated amount of money to buy the services that they want. PBs are being rolled out to all adults in England who are eligible for social care. They can be taken as a cash direct payment, but funds can also be held in local authority or other accounts, by service providers, these are known as 'managed personal budgets'. People can also have a mixture of the two. It is important that people using managed PBs are not excluded from receiving personalised and flexible support, or having control over that support, merely because they do not wish to manage their own budget.

The study aims to explore factors helping or hindering the delivery of personalised support to older service users who opt for managed personal budgets. To achieve this, the study will:

- review innovative practices in local authority commissioning and in the contracts for managed personal budgets, and explore managers' views on how effective these changes are in enabling choice, control and flexibility
- examine the roles played by support planners as intermediaries in shaping the expectations that PB holders have and the demands they make on providers
- explore home care provider responses to changes in contracts and user demand
- assess how effective new contracting and support planning arrangements have been in creating opportunities for choice and control, from the perspectives of older managed PB holders.

A range of qualitative methods of data collection and analysis from the three study sites in England will be used. These include documentary analysis; semi-structured interviews with commissioning or contracts managers, home care agency managers and service users; and focus group discussions with support planners.

This study aims to generate evidence to inform practice about the most effective ways in which commissioning or contracts managers, agency managers and support planners can enable choice and flexibility of social care support for people opting not to manage their own PBs.

The study findings will be available in late 2012.

Choice and change: extending choice and control over the lifecourse: a qualitative longitudinal panel study

Completed project
Department of Health, Policy Research Programme
May 2006 to February 2011
Caroline Glendinning, Hilary Arksey, Kate Baxter, Parvaneh Rabiee, Alison Wilde

This study examined disabled people's experiences of making choices about services in the context of changing circumstances in their lives. This included changes in health or in other circumstances. The study's longitudinal perspective enabled the examination of the outcomes of earlier choices (including the responses of service providers); the impacts of choices on perceived independence and quality of life; and anticipated future choices.

The study involved two groups likely to experience changes in their needs for services:

- adults and older people with fluctuating support needs
- adults and older people who had experienced the sudden onset of a disabling condition.

Participants were interviewed at regular intervals over three years. The interviews tracked changes in individuals' circumstances and explored in depth the choices that interviewees made in response to these. Interviews were also conducted with professionals and/or family members who had been heavily involved in specific recent choices.

Key findings from the study included:

- the difficulty of identifying and delimiting choices - choice is a process; even after a preferred option has been identified, protracted difficulties may be experienced in realising that option
- choices are highly variable: they may be (un)avoidable; high/low risk; (ir)reversible; or have unanticipated outcomes
- choices are often made in the context of a very limited range of feasible options
- having information is a precondition both for identifying that a choice might be possible and then for framing that choice
- choice can bring intrinsic emotional benefits but also incur significant emotional and psychological costs
- choices are made in social contexts: family members and professionals provide information and support; and choices are made with an awareness of the implications for others.

The Choice and Change study forms the core of the programme of research carried out for the Department of Health within the Policy Research Programme undertaken at SPRU between 2006-2011 (see a programme review on page 6). Young people with degenerative conditions and their parents were the third service user group included in the Choice and Change study. This research was carried out by our experts in the Children and Families Team and more information about this work can be found on page 31. The study was positively reviewed by independent peer reviewers. On this basis DH funded preparation of the data so that it can be lodged with the Timescapes Qualitative Longitudinal Data Archive (part of the UK Data Archive) during 2012.

Publications

Arksey, H. and Baxter, K. (2012) Exploring the temporal aspects of direct payments, *British Journal of Social Work*, 42, 1, 147-164.

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.

Baxter, K., Rabiee, P. and Glendinning, C. (2011) Choice and change: disabled adults' and older people's experiences of making choices about services and support, *Research Works*, 2011-04, Social Policy Research Unit, University of York, York.

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.

Glendinning, C. (2008) Increasing choice and control for older and disabled people: a critical review of new developments in England, *Social Policy and Administration*, 42, 5, 451-469.

Home care for the elderly and disabled in foreign countries

Completed project
Ministry of Health, Welfare and Sports, France
January 2010 to March 2011
Caroline Glendinning, Alison Wilde, SPRU;
Tine Rostgaard, National Centre for Social Research, Denmark (co-ordinator) / Cristiano Gori, Personal Social Services Research Unit, London School of Economics / Teppo Kröger, Department of Social Sciences, University of Jyväskylä, Finland / August Österle, Institute for Social Policy, Vienna University of Economics, Austria / Marta Szebehely, Department of Social Work, University of Stockholm, Sweden / Virpi Timonen, School of Social Work and Social Policy, Trinity College Dublin, Ireland / Mia Vabø, NOVA, Oslo, Norway

The study aimed to identify how European countries have reformed their home help and home care systems in order to achieve:

- high quality care which meets increasingly diversified and individualised needs
- effective and efficient services
- stronger user orientations in the provision of care
- an optimal balance of responsibility between formal and informal care
- the best way of attracting and retaining home care workers.

Key areas of interest included:

- drivers/pressures for reform
- boundaries of home care
- arrangements for organisation, funding, provision and regulation of home care
- home care workforce
- quality assessment
- impacts on users.

Each participating researcher contributed a report on developments in her/his own country, written to a common structure, but emphasising particular unique national features where relevant. All participating researchers contributed to a concluding comparative chapter.

The English contribution draws on SPRU's extensive body of research into the funding, organisation and delivery of personalised home care services and will inform debates within France about the reform of these services.

The final report was presented to the French Ministry of Health, Welfare and Sports in May 2011. The contributions to the project will form the basis for a special issue of *Health and Social Care in the Community*, to be published during 2012.

Publication
Rostgaard, T. with Glendinning, C., Gori, C., Kroger, T., Osterle, A., Szebehely, M., Thoebald, H., Timonen, V., Vabo, M. (2011) *Livindhome: Living independently at Home: Reforms in home care in 9 European countries*, SFI - Danish National Centre for Social Research, Copenhagen.

Department of Health Programme, 2006-2010: Choice and independence across the lifecourse

Completed research programme
Department of Health, Policy Research Programme
January 2006 to February 2011
Programme leader: Caroline Glendinning;
Hilary Arksey, Kate Baxter, Bryony Beresford, Jane Madison, Wendy Mitchell, Parvaneh Rabiee, Alison Wilde

Please see page 6 for a review of the programme and its achievements.

Details of the projects in the programme and all its outputs are available here:

http://www.york.ac.uk/inst/spru/research/summs/DHProgramme.html

and are also detailed in the overview report:

C. Glendinning ... [et al.] (2012) *Choice and Independence over the Lifecourse. Final Report to the Department of Health*, Social Policy Research Unit, University of York, York.

Research review of risk and adult social care: focused update

Completed project
Joseph Rowntree Foundation
August 2011 – October 2011
Wendy Mitchell, Kate Baxter, Caroline Glendinning

In 2007, SPRU conducted a review of research evidence on perceptions and management of risk amongst users of adult social care services. In order to inform a new programme of *work on Risk, Regulation, Rights and Responsibilities*, the Joseph Rowntree Foundation (JRF) commissioned a focused update of this review to identify more recently published research.

The updated review identified completed, empirical research and, to a limited extent, research currently in progress. It identified recent evidence on:

- social care service users' and carers' (paid and unpaid) experiences and perspectives on risk, including perspectives on the balances between taking risks and protection from risk
- the effectiveness of mechanisms to prevent or reduce risk
- experiences, incidence and the management of risk arising from more personalised approaches to delivering adult social care.

Social policy databases and relevant web-sites were searched. The study's criteria were that the literature was derived from research produced as a result of an experiment or observation, which was published from 2007 onwards and had been conducted in the UK. Literature produced by government agencies or academic institutions that had not been formally published was also identified. Some ongoing studies were included. The relevance of each reference was cross-checked by at least two researchers. Literature falling within the scope was read and summarised.

Thus the review identified the scope of existing literature on this subject which included emerging themes and issues and also highlighted prominent gaps. Recent research has focused mainly on the effectiveness of new measures to identify and reduce risk; and on new challenges in managing risk raised by the increasing availability of personal budgets in social care.

Recent studies repeatedly highlight the dilemmas of professionals in balancing positive approaches to risk-taking against professional and statutory duties to protect service users. Interest in the effectiveness of new measures to manage risk mean that practitioners' and managers' perspectives have dominated recent research. Although robust evidence on mechanisms such as the Protection Of Vulnerable Adults list and the use of Criminal Records Bureau checks is limited, the evidence available does suggest that they could reduce risks. However, safeguarding and other procedures are recognised by both practitioners and users to be potentially disempowering. Little evidence was found of good practice in balancing rights and protection.

These key themes in the literature were used to help inform the *Risk, Regulation, Rights and Responsibilities* programme of work.

Publication
Mitchell, W., Baxter, K. and Glendinning, C. (2012) Updated Review of Risk and Adult Social Care in England, JRF Programme Paper, Joseph Rowntree Foundation, York.

Methods for accessing the 'voice' of older people with dementia in research

Ongoing doctoral project
Economic and Social Research Council, White Rose Studentship
October 2011 to September 2014
Katie Sworn, Gillian Parker (supervisor), Stuart Parker (supervisor, University of Sheffield)

This project will look at the increasing numbers of people who live with impaired cognition or communication. These groups have traditionally been without 'voice' in research and therefore health services and policy makers require a deeper understanding their lives and needs.

One main group of methods to elicit views from people with impaired cognition or communication is the non-verbal techniques generally referred to as augmented and alternative communication (AAC). However, there is little methodological research about *how* these alternatives have been tested and applied and whether they do, indeed, increase 'voice'. The focus of the project will be the emergence of AAC methods in research across a number of groups of people with cognitive impairment, with a particular emphasis on people with dementia.

This studentship will systematically review the literature on AAC methods in research. Findings will be used to understand the contribution of such methods for capturing and analysing the views of participants. Comparison of diverse populations will create greater knowledge of when the methods can be applied and the different meanings that may be attached to them.

Greater understanding of the contribution of AAC methods, including how they have been tested and applied and the data generated, will lead to the creation of 'good practice' guidelines for the use of such methods in research.

Older people's access to public and private services

Ongoing doctoral project
Economic and Social Research Council, White Rose Studentship
October 2011 to September 2014
Charlotte Hamilton, Gillian Parker (supervisor), Mary Godfrey (supervisor, University of Leeds)

There have been radical changes within the last 20 years in the ways in which both public and private sector services are provided and positioned. Local shops and post offices have closed, retail outlets have conglomerated 'out-of' or 'on the edge of' towns, patterns of car ownership and public transport have changed, the internet can be used for shopping and renewal of licences, and primary and secondary health care provision has altered (again, with a trend to conglomeration and movement away from the local). There have been periodic reports on the impact of changes in public services on older people. However, there appears to be little research that systematically examines and tracks these changes, explores the possible impact on older people's ability to live independently in the community, or examines the ways in which they interact with poor health, impairment or general frailty. At a time of far-reaching changes to both public and private sector services, the need to explore these interactions is urgent.

In this research we aim to:

- identify and track change in the UK in the provision and positioning of public and selected private services, drawing on both published research and primary data sources
- hypothesise about the ways in which these changes might have affected the ability of older people to maintain independence while living in the community
- explore these hypotheses, via in-depth, qualitative research with older people
- set the acquired knowledge within a social policy context.

The project will explore the views of older people through the use of focus groups and one-to-one interviews to gain an insight into how access to services affects their lives. More broadly, the study aims to contribute to debates around the changing nature of public and private services as experienced by older people.

Meaning of independence for older people

Ongoing doctoral project
SPRU, Sally Baldwin Studentship
January 2008 to March 2012
Alison Allam, Caroline Glendinning (supervisor)

This is a PhD study funded by the Sally Baldwin Studentship. Taking a qualitative approach, the study aims to develop an understanding of the meaning and perceptions of independence for older people.

As part of the study a scoping literature review and a review of relevant policy have been completed. Informed by these findings, a first round of semi-structured interviews has been conducted with a small sample of older people. Analysis of the interviews will shape the focus of a subsequent round of interviews, in line with the principles of grounded theory.

The aim of the interviews is to gain insights into older people's subjective views of independence and the factors that shape these views. At a wider level, this research aims to contribute to the ongoing conceptual and policy debates surrounding independence and ageing.

Children and Young People's Social Work

The Children and Young People's Social Work Team is led by Professor Nina Biehal. Its research focuses on children in and on the edge of care, abuse and neglect, leaving care, family support, family reunification, adoption, young offenders and asylum seeking children.

Research undertaken during 2011

Corporate parenting: making the difference?

Ongoing project
The Big Lottery Fund
July 2010 to June 2014
Jo Dixon and Mike Stein in collaboration with the National Care Advisory Service (NCAS) and Catch 22

In England around 60,000 young people are looked after in care at any one time. For those who need to remain in the care system there is a legal duty on local authorities to support them and prepare them for the transition to adulthood. Alongside this statutory framework is the concept of corporate parenting, founded on the principle that a local authority should offer the kind of support that any good parent would provide for their own children.

Despite the legislative duties to support young people and the theoretical framework of corporate parenting, young people from care tend to have poorer outcomes than their same age peers. They are over-represented in indicators of social exclusion such as low educational achievement, contact with the criminal justice system, poor health, homelessness and unemployment.

The research will focus on how corporate parenting is being interpreted and delivered across local authorities in England to support young people in and from care. It will aim to identify the key elements of effective corporate parenting. It will examine the impact of corporate parenting policy and practice on the progress and outcomes for young people in, and leaving, care. This will be done from the perspective of the young people and those caring for them. The recommendations arising from the research will be used to inform further policy and practice developments.

The study will employ both qualitative and quantitative methods and will include a policy survey and an annual snapshot survey of young people in and from care. There will be a follow-up study of a sub-sample of young people from the year one snapshot. Annual reviews of local and national statistics will also be undertaken. Importantly, young people will be central to the research, as participants, members of the research steering group and as peer researchers. The peer researcher approach will involve training care-experienced young people in a range of research skills including sample recruitment, data collection, analysis and dissemination.

Findings from the research will be used in inform policy and practice via practitioner conferences and workshops. They will also be used by participating local authorities and the NCAS Benchmarking Forum, which represents almost one-third of all English local authorities. The findings will also inform the further development of NCAS training materials and workshops, which are available to professionals working with young people in and from care.

Feasibility study on research into the maltreatment of looked-after children

Completed project
National Society for the Prevention of Cruelty to Children (NSPCC)
September 2011 to November 2011
Jim Wade, Parvaneh Rabiee, Nina Biehal

Today 70 per cent of looked-after children are placed in foster care. Strategies designed to reduce admissions to care through provision of preventive services to families have also meant that children who do enter care tend to have higher levels of emotional and behavioural difficulties.

Little is known about the nature and incidence of maltreatment in foster care and we need to know much more, including the ways in which agencies identify these problems and respond to them. To do this, however, we needed to discover what kinds of information agencies collect on these issues to establish whether a large-scale study would be feasible.

This short study assessed whether relevant agencies across the UK hold information that:

- could provide reliable estimates of the numbers of children and carers involved in (a) allegations and (b) confirmed cases of maltreatment
- would enable cases to be separated according to whether they concern (a) abuse or neglect or (b) poor standards of care
- could identify the nature and severity of alleged/confirmed cases of maltreatment and the range of responses made by agencies to these cases
- identifies where this information is likely to be held (central agency records, carers' files, children's files or records held in children's homes)
- and, where this varies for children placed in different settings, identifies the kinds of data likely to be available for different sub-groups.

Structured telephone interviews and online questionnaires collected information from a range of key informants in each agency (local authorities, independent fostering providers, private and voluntary children's homes). In addition to these interviews, a focus group discussion was held with foster carers to gather their views on the key issues that a full study in this area should address.

The report for the NSPCC describes the range of information currently collected by these agencies and identifies some key issues for inclusion in further research. It is hoped that a full-scale research project can be undertaken in the future to provide data on this neglected area, for the benefit of future children in the care system and for those who provide their care. A summary of key findings will be made available to each participating agency, since it will be helpful for agencies to know the strengths and limitations of current arrangements for recording allegations.

Evaluation of the Social Pedagogy Pilot Programme in residential children's homes

Completed project
Department for Education
September 2009 to October 2011
Nina Biehal and Manuel Palomares in partnership with David Berridge, Eleanor Lutman and Lorna Henry (University of Bristol)

Concerns have long been expressed about the functioning and low status of children's residential care in England. In contrast, an established, higher status, more coherent, professional approach to children's services is evident in several other European countries in the form of social pedagogy.

Social pedagogy generally emphasises the child as a whole person and provides support for the child's overall development. It has a particular focus on building relationships through practical engagement with children using skills such as art or music or outdoor activities. In residential care for children, it provides a particular expertise in working with groups and using the group as a support for individual children.

This study compared the quality of care and outcomes for children and young people placed in 18 homes served by social pedagogues (SPs) with those for children in 12 comparison homes which did not employ pedagogues.

Key findings were:

- Two-thirds of the 114 residents of the homes had entered care at the age of 11 years or over and most were in their mid-teens.
- Observation visits to 12 of the homes, including both Pilot and comparison homes, revealed that the quality of care was uneven. Only half of these homes appeared to provide a consistently warm and caring environment.
- Most Pilot homes employed just one or two SPs. It cannot be said, therefore, that social pedagogy had been implemented in the Pilot homes.
- The SPs working in homes were usually expected to undertake the same duties as other residential workers, rather than a role that reflected their specialist training. In about half the homes observed we saw no major differences in how SPs spent their time compared with other staff.
- SPs generally valued the support they received but wished for more central backing and clearer direction concerning their role. A third had no prior experience of residential care and just over a third of them left their residential homes prematurely.
- Some residential staff and managers envied the status, expertise and professional autonomy of SPs compared with the English equivalent staff posts. These features seem desirable to help improve standards of residential care in England, whether under the guise of social pedagogy or any other model.
- There was a high turnover of residents as 61 per cent had lived in their current residential home for less than a year and 42 per cent moved on during the seven-month follow-up period.
- Among those who remained, there was no evidence that positive change was any more likely among residents of the Pilot homes than among those in the comparison homes.

Publications

Berridge, D., Biehal, N., Lutman, E., Henry, L. and Palomares, M. (2011) *Raising the Bar? Evaluation of the Social Pedagogy Pilot Programme in Residential Children's Homes*, Department for Education Research Report, DFE-RR148, Department for Education, London.

Berridge, D., Biehal, N., Lutman, E., Henry, L. and Palomares, M. (2011) Raising the bar? Evaluation of the Social Pedagogy Pilot Programme in residential children's homes, *Research Brief*, DFE-RB148, Department for Education, London.

Living in children's residential homes

Completed project

Department for Education

April to October 2011

Nina Biehal, in collaboration with David Berridge and Lorna Henry (University of Bristol)

Recent years have seen significant changes in the nature, use and purpose of children's residential care. However, there has been little recent research into this sector. Today, children's residential care is used for only a small proportion of looked-after children, mostly over the age of 12, many of whom have moved there either from home or from foster care as a result of their challenging behaviour, although a substantial minority have experienced abuse or neglect.

This short study provided an insight into the nature of children's residential homes, the characteristics and circumstances of the young people who live in them and the short-term outcomes for these young people. It built on our recent research for the Department for Education (DfE) *Raising the Bar? An Evaluation of the Social Pedagogy Pilot Programme in Children's Residential Homes* (http://php.york.ac.uk/inst/spru/pubs/2050/)

The aims of the study were to:

- describe the characteristics, purpose and staffing of a sample of residential units
- describe the characteristics and histories of the residents of the children's homes
- investigate short-term outcomes for individuals living in the homes (the 'stock' of residents at a single point in time)
- investigate placement patterns and key outcomes for all residents placed in the homes over an 18-month period (the 'flow' of residents over this period)
- explore the social world of staff and residents to improve understanding of day-to-day life in the homes
- explore the views of young people living in the homes.

The study drew a sub-sample of 16 children's residential homes from the 30 homes in the earlier study. It collected new data on these homes and their residents, and re-analysed data gathered in the earlier research to explore the themes above.

The final report on this study will be published online by the Department for Education early in 2012.

Fostering unaccompanied asylum-seeking and refugee children

Ongoing project

Big Lottery Fund

June 2009 to February 2012

Jim Wade, Ala Sirriyeh (SPRU); John Simmonds (British Association for Adoption and Fostering); Ravi Kohli (University of Bedfordshire)

The Big Lottery funded the British Association for Adoption and Fostering (BAAF), in partnership with Universities of York and Bedfordshire, to carry out research into the fostering experiences of unaccompanied children and their foster carers. The study describes these experiences, identifies specific features of the fostering task in the context of the broad resettlement needs of these children, appraises the support provided to placements by children's services and assesses the factors that facilitate or constrain the making of placements for this group of children.

The project was undertaken in four contrasting local councils and involved a number of phases:

- A census study provided a profile of all unaccompanied children and young people looked after in these councils on a given census date (n=2,113). It described their characteristics, their care and immigration status, identified the range of placements being used for this group of young people and examined how these care arrangements may have changed over recent years.
- A postal survey was conducted with all foster carers (n=133) who, on a given census date, were providing a foster placement to an unaccompanied child. The survey provided information on the characteristics and history of the child in their care, an assessment of the child's progress, the background and fostering experience of carers, their perceptions of key aspects of the fostering role and their experiences of the training and support provided by children's services.
- Depth interviews were conducted with 21 young people and 23 foster carers to provide a deeper understanding of their experiences and the support provided to them from different sources.
- Alongside this work, a policy study was conducted in each area involving practitioner and young people's focus groups, key informant interviews and analysis of relevant documents.
- The final stage of the project involves the preparation of practice guidance to support the development of effective fostering policies and practice with unaccompanied children and young people. The report and guidance will be published later in 2012 by BAAF.

Evaluation of Multi-dimensional Treatment Foster Care for looked-after children and young people (MTFC-A)

Completed project
Department for Children, Schools and Families
December 2004 to April 2010
Nina Biehal, Jo Dixon, Elizabeth Parry and Ian Sinclair in collaboration with the Department of Psychiatry, University of Manchester

This study evaluated the effectiveness of Multidimensional Treatment Foster Care for Adolescents (MTFC-A), an innovative, evidence-based form of fostering for looked-after children (age 11-16 years) with complex needs, which was implemented by 18 English local authorities. This is only the second independent study of MTFC[1] in this country and is the first to evaluate its use with older children in the care system. It investigated whether placement in MTFC-A results in improved outcomes, relative to the usual care placements, and which children are most likely to benefit from it. The evaluation studied 219 young people (63 per cent of all those who entered the MTFC-A programme during the study period).

The study had two components: a small randomised controlled trial embedded within a larger quasi-experimental study. It compared outcomes for two groups of young people:

- those who entered treatment foster care placements
- those who entered the other types of care placement usually available to this group of young people, including both foster and residential care.

Outcomes were assessed one year after baseline. Most of the young people had experienced considerable placement instability, nearly all had experienced abuse or neglect and two-thirds had mental health difficulties.

Over half had statements of special educational needs and 36 per cent had recently committed a recorded offence. The study found that:

- For the sample as a whole, placement in MTFC-A showed no statistically significant benefit over the usual care placements. This was true for all the outcomes studied including overall social adjustment, education outcomes and offending.
- In a subgroup of the sample with serious antisocial behaviour problems, MTFC-A showed improved reduction in these behaviour problems over usual care and also in overall social adjustment.
- The young people who were not anti-social did significantly better if they received a usual care placement.
- Young people's engagement was a key issue. Some were reluctant to 'buy in' to the structured nature of the programme. However, development of strong relationships with foster carers facilitated engagement.
- MTFC-A foster carers found the displacement of discipline on to a 'points and levels' system to be helpful, and valued the training and intensive support provided by the MTFC-A teams.

Publication

Biehal, N., Dixon, J., Parry, E., Sinclair, I., Green, J., Roberts, C., Kay, C., Rothwell, J., Kapadia, D. and Roby, A. (2012) The Care Placements Evaluation (CaPE) Evaluation of Multidimensional Treatment Foster Care for Adolescents (MTFC-A), *Research Brief*, DFE-RB194, Department for Education, London.

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[1] The previous study is the Evaluation of the Youth Justice Board's Intensive Fostering Scheme. See, Biehal, N., Ellison, S. and Sinclair, I. (2011) Intensive fostering: an independent evaluation of MTFC in an English setting, *Children and Youth Services Review*, 33, 2043-2049.

Transitions to adulthood of young people leaving public care. International research group (INTRAC) (representatives from 16 countries)

Ongoing network
Department for Children, Schools and Families (start-up funding)
2003 onwards
Co-ordinators: Mike Stein (SPRU); Harriet Ward and Emily Munro (Loughborough University)

A growing body of international research findings has revealed the poor outcomes for looked-after children, in comparison to children who have not been in care, especially in relation to their education, health and well-being. These findings have also shown the high risk of social exclusion of young people making the transition from care to adulthood: they were far more likely than young people who had not been in care to have poorer educational qualifications, be younger parents, be homeless, and have higher levels of unemployment, offending behaviour and mental health problems.

In 2003, a seminar brought together, for the first time, researchers from Europe, the Middle East, Canada and the United States, to begin to explore in depth the issues underpinning these research findings. From 2003, representatives from 16 countries have continued to meet and their work led to the first comparative publication in the field (Stein and Munro, eds., 2008).

In 2011, the annual meeting of INTRAC was held at the University of Goteborg, Sweden. Major work carried out during 2011 included the publication of a special edition of Children and Youth Services Review (Special Issue Editors, Mike Stein, Harriet Ward and Mark Courtney) containing 17 international research papers on transitions from care to adulthood. Comparative research work on this area is also being developed in 12 post-communist societies through links with SOS Children's Villages. This has included the publication of the first comparative report, *Ageing Out of Care: from care to adulthood in European and Central Asian Societies*, published in December 2010.

It is intended that sharing international research, policy and practice in respect of young people during their journey from care to adulthood, will contribute to a substantial comparative evidence base to underpin improvements in outcomes for this very vulnerable group of young people.

Publications

Stein, M. and Dumaret, A-C. (2011) The mental health of young people aging out of care and entering adulthood: exploring the evidence from England and France, *Children and Youth Services Review*, 33, 12, 2504-2511.

Stein, M., Ward, H. and Courtney, M. (2011) Editorial: International perspectives on young people's transitions from care to adulthood, *Children and Youth Services Review*, 33, 12, 2409-2411.

Lerch, V. with Stein, M. (eds.) (2010) *Ageing Out of Care: From care to adulthood in European and Central Asian societies*, SOS Children's Villages International, Innsbruck, Austria.

Stein, M. (2010) Conclusion: From care to adulthood in European and Central Asian societies, in V. Lerch with M. Stein, (eds.) *Ageing Out of Care: From care to adulthood in European and Central Asian societies*, SOS Children's Villages International, Innsbruck, Austria, pp.129-134.

Stein, M. and Munro, E. (2010) Young people's transitions from care to adulthood, the challenges of making international comparisons, in Knorth, E.J., Kalverboer, M. and Knot-Dickscheit, J. (eds.) *Inside Out, how interventions in child and family care work, An international source book*, Garant, Apeldoorn, pp. 67-69.

Further publications, back to 2005, available from:
php.york.ac.uk/spru/research/summs/caretransitions.php

Children and Families

The Children and Families Team is led by Professor Bryony Beresford. We conduct research to inform policy and practice relating to the health and social welfare of children, young people and young adults with disabilities and/or chronic or life-limiting conditions and their families, including service delivery and organisation issues. In addition, we have a growing interest in the impact on staff of working in difficult and stressful settings.

Research undertaken during 2011

Supporting health transitions for young people with life-limiting conditions: researching positive practice: the STEPP project

Ongoing project
Big Lottery Fund Research Programme
April 2010 to July 2012
Bryony Beresford, Mairi Harper, Suzanne Mukherjee, Lucy Stuttard, Gemma Spiers (SPRU) with Jennifer Beecham (Personal Social Services Research Unit, University of Kent)
Project partners: Together for Short Lives, Help the Hospices, National Council for Palliative Care

Advances in the treatment of many life-limiting paediatric conditions mean that children are living longer and many now survive into adulthood. In terms of health care, two key implications of this are:

- the need for systems and processes to plan and manage the transfer from paediatric to adult health care
- the need for adult health services to be ready and able to receive, and appropriately care for, a population they might not have previously encountered.

The uncertain trajectory of many of these conditions also means it can be necessary to 'parallel plan' active condition management and palliative care. Some conditions (for example, cystic fibrosis and congenital heart disease) have grappled with these issues for many years. For others, improvements in life expectancy are more recent. There is a growing body of evidence that this period of health care transitions is a time of high risk of non-adherence, lack of attendance and deterioration.

The aim of this project is to identify and describe 'what works' in setting up and delivering positive condition management transitions for young people with life-limiting conditions. The project is unusual in that it is investigating this issue across a number of conditions. We are using a case study approach to investigate five condition-management pathways which have successfully overcome the barriers to positive health transitions. The conditions represented include:

- renal disease
- cystic fibrosis
- Duchenne muscular dystrophy
- spinal muscular atrophy
- profound neurological impairment (cerebral palsy or metabolic conditions).

In each case study site we are interviewing young people who have experienced the transfer to adult health care, their parents, their clinicians, and other practitioners working in the paediatric and adult health services. Data to produce cost estimates of the pathways is also being collected.

The project will generate guidance and resources for clinics and services wishing to improve their services and/or practice. There will also be specific outputs for young people and parents. A range of focused, practical, web-based, multi-media resources will be produced for these different groups. Consultation with key professional groups and organisations, towards the end of the project, will ensure that the research findings have application beyond the condition groups directly represented in the study.

Stress, burnout and well-being in staff working in health care settings

Ongoing project
University of York, Anniversary Lectureship
October 2011 to June 2012
Suzanne Mukherjee

Suzanne Mukherjee has been awarded an Anniversary Lectureship from the University of York to support the development of a programme of research on stress, burnout, and well-being of staff working in health care settings.

Over the past four years Suzanne Mukherjee has been funded by Cancer Research UK and CLIC Sargent to carry out research on this topic, with a focus on the paediatric oncology workforce. This anniversary lectureship will allow her to develop and extend this work. During this period she will be:

- conducting further analysis on existing project datasets and publishing the findings
- consolidating and developing links with clinicians, other practitioners and researchers in the UK and overseas with interests/expertise in this area
- preparing an application for funding a large-scale, multi-disciplinary research project.

Throughout the course of the award there will be a focus on developing this area of research in such a way that supports the development of evidence-based interventions to support staff.

Transition to adult services and adulthood for young people with autistic spectrum conditions

Ongoing project
Department of Health
November 2009 to January 2012
Nicola Moran, Bryony Beresford, Linda Cusworth, Wendy Mitchell, Gemma Spiers, Kath Weston (SPRU); Jennifer Beecham (Personal Social Services Research Unit, University of Kent)

This project complements another we previously worked on for the Department of Health on multi-agency transition services for young people with complex health needs. Here we are focusing on another group of young people: those with autistic spectrum conditions, including those with Higher Functioning Autism and Asperger Syndrome. It is important that the research represents the entire autistic spectrum because the issues associated with service transfer and transitioning to adulthood differ according to the young person's abilities and needs. For example, those with Asperger Syndrome or Higher Functioning Autism may have very limited access to statutory adult services, yet may still need support to make successful transitions from childhood to adulthood. For those with more severe forms of autism, planning and preparation around leaving school and successfully transferring from children's to adult services can be very challenging.

The purpose of this project is to describe and understand good practice in transition support and services for this group of young people. We are carrying out the research in five case study sites, each of which have established multi-agency transition planning processes and autism-specific strategies and/or services. The research team is carrying out qualitative interviews with young people, parents, managers and practitioners in order to explore and understand:

- how multi-agency transition planning for young people with autistic spectrum conditions was developed, is delivered and sustained
- the development and delivery of autism-specific strategies and services, including, where relevant, the interface between statutory and third sector provision
- young adults' access to service and support, including those not typically eligible for support from statutory adult social care
- young people's and parents' experiences of planning for leaving school and transferring to adult services, and making the transition from childhood to adulthood.

Data about the costs of services are also being collected from each site to allow us to cost typical transition pathways according to the type of autism.

This research will describe components of good practice that are associated with more positive experiences and outcomes for young people with autism spectrum conditions during the transition period. Features of transition planning systems and processes which support positive outcomes will also be identified. Areas where further developments in transition support are required will also be highlighted. The evidence generated by this research will therefore both support policy and service development at local and national levels, and be an important resource for practitioners.

Researching the lives of disabled children and young people, with a focus on their perspectives: ESRC seminar series

Completed project
Economic and Social Research Council
January 2010 to May 2011
Kirsten Stalker (University of Strathclyde) (project leader); Bryony Beresford (SPRU); David Abbott and John Carpenter (University of Bristol); Roy McConkey (University of Ulster); Nick Watson (University of Glasgow)

Professor Bryony Beresford is part of a UK-wide team which ran an ESRC-funded seminar series on researching the lives of disabled children and young people. The series, lead by Professor Kirsten Stalker (University of Strathclyde), provided a forum for applied social science researchers as well as key individuals within the policy and third sectors to consider ways forward in terms of researching the lives of disabled children.

Each seminar took a different focus:

- theoretical perspectives
- methodological approaches
- policy developments
- substantive issues in disabled children's lives
- planning for the future.

A key outcome of this series has been the decision to create a network of researchers doing work which relates to the lives of disabled children and their families, with that network holding an annual meeting. The seminar organisers are also co-editing a special issue of *Children and Society*.

Publication
Selected papers from the seminar series will be published in a special issue of the *Children and Society* journal in 2012.

Choice and change: extending choice and control over the lifecourse: a qualitative longitudinal panel study

Completed project
Department of Health, Policy Research Programme
May 2006 to February 2011
Bryony Beresford, Jane Maddison, Wendy Mitchell, Tricia Sloper, Jan Heaton

The Choice and Change Project is a longitudinal study of service users' experiences of making choices regarding their care and support. Young people with degenerative conditions and their parents were one of the three service user groups under investigation. Researchers in the Children and Families Team lead on this aspect of the study.

Most previous research on service users and decision-making had focused on the interface between the service user and practitioners or clinicians. The Choice and Change project took a different approach. It was concerned with the entire decision-making process including:

- how and why decisions regarding services, care and support arose
- the processes by which families, or individuals within families, came to a decision
- the outcomes and consequences of the decision
- individuals' reflections and satisfaction with decisions.

Young people and parents who took part in the study were interviewed up to three times over a two-year period. Families chose to discuss a wide range of situations where significant decisions were required, including: leaving school, surgery and other health care interventions, and social care support. Over 30 families participated in this project. We used visual tools to facilitate the interviews with young people with learning disabilities and/or those who do not use speech to communicate.

Key implications arising from this work concern:

- the involvement of parents in decisions being made by young adults
- supporting families when they are making significant decisions, including meeting their information needs
- the support needs of families as decisions are implemented
- the involvement of young people with learning disabilities in decision-making.

A summary of the findings is available in Choice and change: how disabled young people with degenerative conditions and their parents make choices about care and services, Research Works, 2011-05.

The Choice and Change study forms the core of the programme of research carried out for the Department of Health within the Policy Research Programme undertaken at SPRU between 2006-2011 (see a programme review on page 6). Two other groups of people were included in the Choice and Change study: adults and older people with fluctuating conditions; and those who experienced the sudden onset of a disabling condition. This research was carried out by our experts in the Adults, Older People and Carers Team and more information about this work can be found on page 18. The study was reviewed positively by independent peer reviewers. On this basis DH funded preparation of the data so that it can be lodged with the Timescapes Qualitative Longitudinal Data Archive (part of the UK Data Archive) during 2012.

Publications

Maddison, J. and Beresford, B. (forthcoming) Decision-making around moving on from full-time education: the roles and experiences of parents of young people with life-limiting conditions, *Health and Social Care in the Community*.

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*.

Mitchell, W. (forthcoming) Making choices about medical interventions: the experiences of disabled young people with degenerative conditions, *Health Expectations*.

Mitchell, W. (forthcoming) Perspectives of disabled young people with degenerative conditions on making choices with parents and peers, *Qualitative Social Work*.

Mitchell, W., Maddison, J. and Beresford, B. (2011) Choice and change: how disabled young people with degenerative conditions and their parents make choices about care and services, *Research Works*, 2011-05, Social Policy Research Unit, University of York, York.

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.

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.

Beresford, B. and Sloper, P. (2008) *Understanding the Dynamics of Decision-Making and Choice: A scoping study of key psychological theories to inform the design and analysis of the Panel Study*, Social Policy Research Unit, University of York, York.

The effectiveness, cost-effectiveness and costs of behavioural approaches to the management of sleep and behaviour problems among disabled children: the SPaR project

Completed project
Centre for Excellence in Outcomes in Children and Young People's Services (C4EO)/ Department for Education
August 2008 to October 2011
Bryony Beresford, Lucy Stuttard, Susan Clarke, Tricia Sloper (SPRU); Jennifer Beecham (Personal Social Services Research Unit, University of Kent)

Disabled children are at greater risk of developing sleep and/or behaviour problems compared to their non-disabled peers. The impact on child and family well-being and outcomes can be considerable. Parents report high levels of unmet need in the skills to manage day and night-time sleep problems.

There is, however, very little robust evidence on what works to help parents manage their child's sleep or behaviour in a more effective way. This project is investigating interventions or programmes that have been designed specifically to help parents of disabled children, including those with autistic spectrum conditions, to improve their ability to manage these behaviours.

The evidence produced in this project will be of direct use to clinicians, other practitioners and service commissioners in making decisions about the provision of parenting support for parents of disabled children.

Two rapid evidence reviews have been carried out and published on:

- the effectiveness of behavioural approaches to managing sleep problems in disabled children
- the effectiveness of parent training in behavioural approaches to managing behaviour problems among disabled children.

In addition there is a large-scale programme of work on the effectiveness and costs of four sleep-management and four behaviour-management interventions (or programmes). These are currently being delivered to parents of disabled children by Child and Adolescent Mental Health Services (CAMHS), schools and/or voluntary sector organisations. A controlled trial design is being employed with standardised measures as well as parent-set goals as outcome measures. Interviews with parents and professionals are exploring issues such as take-up and engagement with interventions, factors affecting effectiveness, and the experiences of receiving or delivering such interventions.

The findings from the project will be published by the Department of Education in March 2012.

Publications
Beresford, B., Stuttard, L., Clarke, S., Maddison, J., Beecham, J. (forthcoming) *Managing Behaviour and Sleep Problems in Disabled Children: An investigation into the effectiveness and costs of parent-training interventions*, Department for Education, London.

Beresford, B. (2009) *The Effectiveness of Behavioural Interventions Which Involve Parents in the Management of Behaviour Problems Among Disabled Children: A rapid review*, Social Policy Research Unit, University of York, York.

McDaid, C. and Sloper, P. (2009) *Evidence on Effectiveness of Behavioural Interventions to Help Parents Manage Sleep Problems in Young Disabled Children: A rapid review*, Social Policy Research Unit, University of York, York.

The 'Life in Paediatric Oncology Project' (LIPOP): the development and validation of measures of work-related stressors and rewards

Completed project
Cancer Research UK
February 2009 to January 2011
Suzanne Mukherjee, Bryony Beresford (SPRU); Alan Tennant (University of Leeds)

This project has developed psychometric measures of work-related stressors and work-related rewards for staff working in paediatric oncology (see references below). It arose from a desire to research the processes by which exposure to work-related stressors does, or does not, result in burnout, or psychiatric morbidity, among staff working in settings with a high emotional load. In order to carry out this work, robust measures of these stressors and rewards were required.

We developed the measures using an established method. First, over 30 members of multi-disciplinary paediatric oncology teams were interviewed. We used these interviews to compile an extensive list of short statements (or 'item pool') which described either a work-related stressor or a work-related reward. These item pools were used as the basis of the first draft of the work-related stressors and work-related rewards measures. A large-scale survey, including these draft measures, was completed by over 200 staff. This survey also contained existing measures of burnout and work environment. We used the RASCH model to analyse and test how staff had completed the draft measures and identified the items which should comprise the final versions of each measure. Further statistical analysis tested the validity of the newly created measures by comparing scores on these measures with scores on the measures of burnout and work environment.

The team has been collaborating with researchers and paediatric oncology staff in Canada who are currently testing whether these measures can be used with staff in that country. We are also collaborating with a local children's hospice with a view to producing an adapted version for children's hospice settings.

As well as being used in future research, these measures have clinical or practical applications: for example, informing the focus of preventive staff support interventions at a team or individual level, and investigating the effectiveness of such interventions.

Publication

Mukherjee, S., Beresford, B. and Tennant, A. (forthcoming) *The Development and Validation of the Work -Stressors Scale and Work Rewards Scale for Paediatric Oncology: A technical report*, Social Policy Research Unit, University of York, York.

Mukherjee S., Beresford, B. and Tennant A. (2012) *The Work Stressors Scale - Paediatric Oncology (WSS-PO)*, Social Policy Research Unit, University of York, York.

Mukherjee S., Beresford, B. and Tennant A. (2012) *The Work Stressors Scale - Paediatric Oncology (WSS-PO): Scoring guidance notes*, Social Policy Research Unit, University of York, York.

Mukherjee S., Beresford, B. and Tennant A. (2012) *The Work Rewards Scale - Paediatric Oncology (WRS-PO)*, Social Policy Research Unit, University of York, York.

Mukherjee S., Beresford, B. and Tennant A. (2012) *The Work Rewards Scale - Paediatric Oncology (WRS-PO): Scoring guidance notes*, Social Policy Research Unit, University of York, York.

Translation of the Strengths and Difficulties Questionnaire into British Sign Language

Ongoing project
NIHR, Health Services Research Programme
January 2011 to February 2014
Dr Sophie Roberts and Dr Barry Wright (National Deaf CAMHS, York) (Lead researchers)
Dr Andrew Holwell and Dr Maria Gascon Ramos (National Deaf CAMHS, London); Dr Sarah Kent (National Deaf CAMHS, Dudley); Professor Alan Tennant (University of Leeds); Dr Victoria Allgar (Hull York Medical School, University of York); Professor Bryony Beresford (SPRU)

British Sign Language (BSL) is the preferred language for some deaf children and young people. Where this is the case, lower levels of English literacy compared to their peers is to be expected. Consequently, English versions of self-completed measures or scales which measure mental health cannot be reliably used in research or clinical practice with this group. This project is translating a widely-used measure of child mental health (Strengths and Difficulties Questionnaire (SDQ), Goodman (1996)) into British Sign Language. It will be used by clinicians and researchers to capture self-reported mental health among children and young people who use BSL as their first language. As well as improving the monitoring of deaf individuals for clinical purposes, this tool will assist with epidemiological and service audit/evaluation research. In this way levels of mental ill health should be more accurately comprehended and the effectiveness of services to help deaf children and young people will be assessed more accurately, leading to improvements in their care.

A strict protocol of translation and 'back-translation' is being followed. A computer-administered version will be created and completed by a sample of children and young people. Scores obtained using the newly created BSL version of the SDQ will then be tested against scores on other measures of child mental health.

Professor Beresford is a member of the multi-disciplinary research team for this project. It is being led by clinical psychologists based in York who work for the national specialist Mental Health Service for Deaf Children and Adolescents.

Welfare and Employment

The Welfare and Employment Team is led by Professor Roy Sainsbury. Its research focuses on employment; welfare to work policy; health, work and well-being; sickness and disability; families and children; and social security.

Research undertaken during 2011

Evaluation of the Work Programme

Ongoing project
Department for Work and Pensions
December 2011 to December 2014
Roy Sainsbury, Anne Corden, Jacqueline Davidson, Katharine Weston in collaboration with Institute for Employment Studies, National Institute of Economic and Social Research, Centre for Social and Economic Inclusion and GfK NOP

The Work Programme is the Coalition Government's flagship welfare to work programme for benefit claimants, replacing previous programmes such as Flexible New Deal and Pathways to Work. It was implemented in summer 2011. Distinctive features of the Work Programme include contracting out delivery to prime contractors in the private and third sectors and an innovative 'Payment by Results' funding model.

A consortium of research organisations, including SPRU, will be evaluating the Work Programme over a period of three years. The evaluation will comprise a number of complementary strands:

- a 'commissioning strand' to investigate how the novel method of commissioning services affects the provider market and the decision-making of the Work Programme providers
- a 'provider strand' to explore how providers deliver their services in their local labour markets
- a 'claimant strand' to explore the end-to-end experience of the Work Programme from initial recruitment to, it is to be hoped, sustained employment.

A range of research methods will be employed including surveys, analysis of management information, in-depth qualitative studies and documentary analysis. Data collection will commence in early 2012.

The evaluation package will test the success of the Work Programme as a novel method of delivering welfare to work services. Findings will be used to inform the evolution of the Work Programme as it progresses, by generating lessons about what works, for whom and in what circumstances. The findings will be used by other government departments to inform decisions about the commissioning of other public services beyond welfare to work.

Health, Work and Well-being Co-ordinators and the Challenge Fund

Ongoing project
Department for Work and Pensions
January 2010 to June 2012
Roy Sainsbury, Anne Corden, Linda Cusworth, Annie Irvine, Katharine Weston and Michael Hirst in collaboration with Ipsos MORI

In 2008 a review was published by Dame Carol Black of the health of Britain's working age population, *Working for a Healthier Tomorrow*. Among its recommendations was the appointment of Health, Work and Well-being Co-ordinators in the nine English regions and in Scotland and Wales. The 11 co-ordinators, working with Regional Directors of Public Health (and their equivalents in Scotland and Wales) were given the task of promoting action on health, work and well-being in a number of ways, including:

- acting as a catalyst for action, developing and encouraging partnerships between employment, health and other relevant networks within their area
- administering the Challenge Fund (see below)
- recognising and promoting best practice and innovation within firms on health, employment and skills.

The Health Work and Well-being Challenge Fund was a grant scheme open to small and medium enterprises and local partnerships to improve workplace health and well-being through innovative initiatives. One-off awards were made in 2009.

The ongoing research being carried out by SPRU aims to evaluate the impact and effectiveness of the Co-ordinators and the Challenge Fund. The evaluation programme has been running since January 2010 and has comprised:

- a survey of businesses and organisations with whom co-ordinators have contact
- a survey of Challenge Fund winning organisations
- in-depth case studies of a sub-sample of Challenge Fund winners
- collection and analysis of quantitative data on the work of the co-ordinators
- a series of qualitative interviews with co-ordinators, Directors of Public Health and key policy makers.

At the end of 2011 all data collection had been completed and analysis was ongoing. A final report to DWP will be submitted in April 2012 and published in the summer. The findings will inform decisions about future policy and will generate examples of effective practice that can inform the development of health and well-being services across the UK.

Evaluation of the Fit for Work Services Pilots: Focused study of GP involvement with Fit for Work Services

Completed project
Department for Work and Pensions and Department of Health
January 2011 to July 2011
Jacqueline Davidson and Roy Sainsbury

Fit for Work Services (FFWS) are designed to provide support to help people stay in work or return to work more quickly after developing a health condition or disability. An initial pilot began operating in 11 areas in 2010.

GPs can be a vital source of information about the FFWS during consultations about health problems and the patient's ability to continue to work. Emerging findings from the evaluation of the FFWS suggested that pilot sites had varied experiences in engaging GPs in the FFWS. Some GPs informed their patients about the FFWS, while others did not.

The main aim of the focused study with GPs was to generate findings about the barriers and facilitators to GP involvement with FFWS. A total of 31 GPs across the 11 pilot sites were interviewed by telephone, 22 of whom had referred patients to the service and nine who had made no referrals.

This study is part of a larger evaluation of the Fit for Work Service Pilots involving the Institute for Employment Studies, National Institute for Economic and Social Research, the University of Liverpool and GfK NOP. The study findings will form part of the final report for the whole evaluation, which is due for completion in 2012. They will help the Department for Work and Pensions and the FFWS to be more effective in engaging GPs and increasing the flow of appropriate referrals to the service.

Evaluation of the Fit for Work Services Pilots: Qualitative longitudinal study of service users' experiences

Ongoing project
Department for Work and Pensions and Department of Health
January 2011 to April 2012
Roy Sainsbury, Katharine Weston, Anne Corden and Jacqueline Davidson in collaboration with the University of Liverpool

This study is part of a larger evaluation of the Fit for Work Services (FFWS) Pilots involving the Institute for Employment Studies, National Institute for Economic and Social Research, the University of Liverpool and GfK NOP. Fit for Work Services are designed to provide support to help people stay in work or return to work more quickly after developing a health condition or disability. An initial pilot began operating in 11 areas in 2010.

This qualitative, longitudinal study is focused on service users' experiences. We interview participants twice, with an interval of six months in between. These interviews explore the factors affecting people's behaviour and decision-making about work, examining in particular the contribution of the FFWS. The study also aims to understand the reasons why people seek help from the FFWS, and to learn about their experiences of receiving the support offered.

The study involves over 60 service users from four pilot sites. At the time of recruitment to the study, some people were recent recruits to the FFWS and some had returned to work. This mix of knowledge and circumstances will help us to learn about people's experiences of engaging with a Fit for Work Service. We will understand more about how returns to work are achieved as well as whether, and how, work is sustained.

The study findings will help to address questions about effective practice and inform policy thinking about the future of the FFWS. The study findings will form part of the final report for the whole evaluation, which is due for completion in 2012.

York Fairness Commission

Completed project
City of York Council and the Joseph Rowntree Foundation
September 2011 to April 2012
Jacqueline Davidson, Roy Sainsbury (SPRU); Dr Anna Barford (Equality Trust); Nicky Denison and Les Newby (Yorkshire Forward)

The York Fairness Commission is an independent body set up to advise the City of York Council on ways it can increase fairness and reduce inequality in York. The Commission is sponsored by the Archbishop of York and chaired by Ruth Redfern from Yorkshire Forward. The other members of the Commission are: John Kennedy (Director of Care Services, Joseph Rowntree Housing Trust); John Lister (Finance Director, Aviva Life UK) and the co-directors of the Equality Trust, Professor Kate Pickett and Professor Richard Wilkinson.

The City of York Council has requested that the Fairness Commission provide independent advice on how to prioritise its spending and influence its partners to address deprivation, exclusion and inequality in the city, so as to create a fairer York for all residents. SPRU was commissioned to analyse the evidence from a consultation exercise with the public of York and employees of the City Council.

In the consultation exercise people were specifically asked for their views about:

- the different ways that people in York experience inequality and disadvantage in their everyday lives
- ideas about how to improve people's lives.

The public consultation was concluded in November 2011 and a report on findings submitted by SPRU to the Commission.

The Commission will continue its work in 2012 and publish a report in the spring. More information on the York Fairness Commission can be found at:

www.yorkfairnesscommission.org.uk

UK expert on EU Expert Group on Social Inclusion

Ongoing project
European Commission
January 2003 onwards
Jonathan Bradshaw; Fran Bennett (University of Oxford)

In 2003 we were asked by the European Union to perform the role of UK National Experts for the Network of Independent Experts on Social Inclusion. The Network was established to provide an independent report on the National Action Plans for Social Inclusion. These are prepared by the member states every two years. This process is part of the Open Method of Coordination which was established by the European Commission following the Lisbon Council in 2000.

Every year we write three 'Semester Reports' for the Commission and a coordinating team writes a synthesis report. In 2011 we wrote three reports:

- Jonathan Bradshaw and Fran Bennett (2011) UK: *Assessment of progress towards the Europe 2020 objectives: A Study of National Policies.*
- Jonathan Bradshaw and Fran Bennett (2011) UK: *Assessment of policy developments in 2011.*
- Gary Craig (2011) UK: The Roma: *A Study of National Policies.*

Publications
Not all the reports are published but some are made available by the EU on this website:
http://www.peer-review-social-inclusion.eu/network-of-independent-experts

Unit information

Widespread and effective dissemination of the results of our research is central to SPRU's purpose. Our work often communicates the needs and desires of hard-to-reach groups in society, and as such makes a distinctive contribution to policy, practice and public debate. To these ends we write and disseminate research reports, summary findings and good practice guides as well as engage with the media on issues of public interest.

We also advance academic debate via articles in peer-reviewed journals, chapters in academic books and by presenting our work at relevant national and international conferences. We arrange a series of public seminars on topical subjects with eminent external speakers (page 11) and host visiting scholars from around the world.

SPRU invests heavily in the training of its staff to help them achieve their full potential. As well as undertaking their research work, our staff members are engaged in many external activities, such as peer-reviewing articles for prominent journals in the field, advising on external research projects, membership of the boards of charitable and government organisations. These activities enhance our role in the wider community and make the best use of our expertise to make a positive difference.

SPRU **Staff 2011**

Director

Professor Gillian Parker

Adults, Older People and Carers Team

Research Director - Professor Gillian Parker

Fiona Aspinal
Kate Baxter
Sylvia Bernard
Jenni Brooks
Professor Caroline Glendinning
Kate Gridley
Parvaneh Rabiee
Alison Wilde
PhD Student - Alison Allam
PhD Student - Charlotte Hamilton
PhD Student - Katie Sworn

Children and Families Team

Research Director - Professor Bryony Beresford

Susan Clarke
Mairi Harper
Wendy Mitchell
Nicola Moran
Suzanne Mukherjee
Gemma Spiers
Lucy Stuttard
PhD Student – Julie Bruce
PhD Student – Jo Nicholson

Children and Young People's Social Work Team

Research Director - Professor Nina Biehal

Jo Dixon
Manuel Palomares
Visiting Associate - Gwyther Rees
Emeritus Professor - Ian Sinclair
Research Professor - Mike Stein
Ala Sirriyeh
Jim Wade

Welfare and Employment Team

Research Director - Professor Roy Sainsbury
Associate Director - Professor Jonathan Bradshaw

Anne Corden
Linda Cusworth
Jacqueline Davidson
Annie Irvine
Katharine Weston

Support Staff Team

Unit Manager – Jeanette Whalley (until May 2011)
Information Assistant - Ruth Dowling
Research Support Administrator - Teresa Frank
Finance Officer - Simon Johnson
Information Officer - Rachel McAllister
Office Manager and PA to the Director - Sally Pulleyn
Research Support Administrator - Dawn Rowley
Research Support Administrator – Lisa Southwood
Administration Assistant - Rebecca Thompson / Heather Milnes

SPRU Publications

Journal Articles

2011

Arksey, H. and Baxter, K. (forthcoming) Exploring the temporal aspects of direct payments, *British Journal of Social Work* (Available online from April 2011).

Aspinal, F., Gridley, K., Bernard, S. and Parker, G. (forthcoming) Promoting continuity of care for people with long-term neurological conditions: the role of the neurology nurse specialist, *Journal of Advanced Nursing.*

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.

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.

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.

Beresford, B. (forthcoming) Working on well-being: a researcher's experiences of a participative approach to understanding the subjective well-being of disabled young people, *Children & Society.*

Biehal, N. (forthcoming) Parent abuse by young people on the edge of care: a child welfare perspective, *Social Policy and Society*, 11, 2.

Biehal, N., Ellison, S. and Sinclair, I. (2011) Intensive fostering: an independent evaluation of MTFC in an English setting, *Children and Youth Services Review*, 33, 2043-2049.

Bradshaw, J. (2011) Child benefits in the European Union, *Poverty*, 139, 13-16.

Bradshaw, J. (forthcoming) The case for family benefits, *Children and Youth Services Review* (Available online from 14 October 2011).

Bradshaw, J. and Bennett, F. (2011) Editorial: National Insurance: past, present, future?, *Journal of Poverty and Social Justice*, 19, 3, 207-209.

Bradshaw, J. and Keung, A. (2011) Trends in child subjective well-being in the UK, *Journal of Children's Services*, 6, 1, 4-17.

Bradshaw, J., Keung, A., Rees, G. and Goswami, H. (2011) Children's subjective well-being: international comparative perspectives, *Children and Youth Services Review*, 33, 4, 548-556.

Clarke, S., Sloper, P., Moran, N., Cusworth, L., Franklin, A. and Beecham, J. (2011) Multi-agency transition services: greater collaboration needed to meet the priorities of young disabled people with complex needs as they move into adulthood, *Journal of Integrated Care*, 19, 5, 30-40.

Corden, A. and Hirst, M. (2011) Partner care at the end-of-life: identity, language and characteristics, *Ageing & Society*, 31, 2, 217-242.

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.

Gridley, K., Aspinal, F., Bernard, S. and Parker, G. (2011) Services that promote continuity of care: key findings from an evaluation of the national service framework for long-term neurological conditions, *Social Care and Neurodisability*, 2, 3, 147-157.

Gridley, K., Spiers, G., Aspinal, F., Bernard, S., Atkin, K. and Parker, G. (forthcoming) Can general practitioner commissioning deliver equity and excellence? Evidence from two studies of service improvement in the English NHS, *Journal of Health Services Research & Policy.*

Irvine, A. (forthcoming) Am I not answering your questions properly? Clarification, adequacy and responsiveness in semi-structured telephone and face-to-face interviews, *Qualitative Research.*

Irvine, A. (2011) Duration, dominance and depth in telephone and face-to-face interviews: a comparative exploration, *International Journal of Qualitative Methods*, 10, 3, 202-220.

Irvine, A. (2011) Fit for work? The influence of sick pay and job flexibility on sickness absence and implications for presenteeism, *Social Policy & Administration*, 45, 7, 752-769.

Irvine, A. (2011) Something to declare? The disclosure of common mental health problems at work, *Disability & Society*, 26, 2, 179-192.

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 personalization of care services and the early impact on staff activity patterns, *Journal of Social Work* (Available online from 6 July 2011).

Jones, K., Netten, A., Fernandez, J-L., Knapp, M., Challis, D., Glendinning, C., Jacobs, S., Manthorpe, J., Moran, N., Stevens, M. and Wilberforce, M. (forthcoming) The impact of individual budgets on the targeting of support: findings from a national evaluation of pilot projects in England, *Public Money & Management.*

Kirkley, C., Bamford, C., Poole, M., Arksey, H., Hughes, J. and Bond, J. (2011) The impact of organisational culture on the delivery of person-centred care in services providing respite care and short breaks for people with dementia, *Health and Social Care in the Community*, 19, 4, 438-448.

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.*

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.*

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.

Meyer, D. R., Skinner, C. and Davidson, J. (2011) Complex families and equality in child support obligations: a comparative policy analysis, *Children and Youth Services Review*, 33, 10, 1804-1812.

Mitchell, W. (forthcoming) Making choices about medical interventions: the experiences of disabled young people with degenerative conditions, *Health Expectations.*

Mitchell, W. (forthcoming) Perspectives of disabled young people with degenerative conditions on making choices with parents and peers, *Qualitative Social Work.*

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.

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).

Moran, N., Glendinning, C., Stevens, M., Manthorpe, J., Jacobs, S., Wilberforce, M., Knapp, M., Challis, D., Fernandez, J-L., Jones, K. and Netten, A. (2011) 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.

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.*

Oldfield, N. and Bradshaw, J. (2011) The costs of a child in a low-income household, *Journal of Poverty and Social Justice*, 19, 2, 131-143.

Parker, G., Corden, A. and Heaton, J. (2011) Experiences of and influences on continuity of care for service users and carers: synthesis of evidence from a research programme, *Health and Social Care in the Community*, 19, 6, 576-601.

Parker, G., Spiers, G., Cusworth, L., Birks, Y., Gridley, K. and Mukherjee, S. (forthcoming) Care closer to home for children and young people who are ill: developing and testing a model of service delivery and organization, *Journal of Advanced Nursing* (Available online from 6 December 2011).

Parker, G., Spiers, G., Gridley, K., Atkin, K., Birks, Y., Lowson, K. and Light, K. (forthcoming) Systematic review of international evidence on the effectiveness and costs of paediatric home care, *Child: care, health & development.*

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.

Spiers, G., Parker, G., Gridley, K. and Atkin, K. (2011) The psychosocial experience of parents receiving care closer to home for their ill child, *Health and Social Care in the Community*, 19, 6, 653-660.

Spiers, G., Parker, G., Gridley, K., Cusworth, L., Mukherjee, S., Heaton, J., Atkin, K., Birks, Y., Light, K., Lowson, K. and Wright, D. (forthcoming) Understanding models of 'care closer to home' for children and young people who are ill: a mixed methods study, *Nursing Children & Young People.*

Stein, M. (2011) Let's not forget interventions in later years, *Public Health Today*, June, 14.

Stein, M. and Dumaret, A-C. (2011) The mental health of young people aging out of care and entering adulthood: exploring the evidence from England and France, *Children and Youth Services Review*, 33, 12, 2504-2511.

Stein, M., Ward, H. and Courtney, M. (2011) Editorial: International perspectives on young people's transitions from care to adulthood, *Children and Youth Services Review*, 33, 12, 2409-2411.

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.

Wade, J. (2011) Preparation and transition planning for unaccompanied asylum-seeking and refugee young people: a review of evidence in England, *Children and Youth Services Review*, 33, 12, 2424-2430.

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.

Books and Reports

2011

Berridge, D., Biehal, N., Lutman, E., Henry, L. and Palomares, M. (2011) *Raising the Bar? Evaluation of the Social Pedagogy Pilot Programme in Residential Children's Homes*, Department for Education Research Report, DFE-RR148, Department for Education, London.

Bradshaw, J. (ed.) (2011) *The Well-being of Children in the UK*, 3rd ed., The Policy Press, Bristol.

Bradshaw, J. and Mayhew, E. (2011) *The Measurement of Extreme Poverty in the European Union*, European Commission, DG Employment, Social Affairs and Inclusion, Brussels.

Davidson, J. (2011) *A Qualitative Study Exploring Employers' Recruitment Behaviour and Decisions: Small and medium enterprises*, Department for Work and Pensions Research Report, no. 754, Department for Work and Pensions, Sheffield.

Irvine, A., Davidson, J., Glendinning, C., Jones, K., Forder, J., Caiels, J., Welch, E., Windle, K., Dolan, P. and King, D. (2011) *Personal Health Budgets: Early experiences of budget holders: Fourth interim report*, Department of Health, London.

Jones, K., Forder, J., Caiels, J., Welch, E., Windle, K., Davidson, J., Dolan, P., Glendinning, C., Irvine, A. and King, D. (2011) *The Cost of Implementing Personal Health Budgets*: *[Third interim report]*, PSSRU Discussion Paper 2804, Personal Social Services Research Unit, University of Kent, Canterbury.

Newbronner, L., Chamberlain, R., Bosanquet, K., Bartlett, C., Sass, B. and Glendinning, C. (2011) *Keeping Personal Budgets Personal: Learning from the experiences of older people, people with mental health problems and their carers*, Adults' Services Report, 40, Social Care Institute for Excellence, London.

Parker, G., Spiers, G., Gridley, K., Atkin, K., Birks, Y., Lowson, K., and Light, K. (2011) *Evaluating Models of Care Closer to Home for Children and Young People who are Ill: A systematic review*, NIHR Service Delivery and Organisation programme, Southampton.

Parker, G., Spiers, G., Gridley, K., Atkin, K., Cusworth, L., Mukherjee, S., Birks, Y., Lowson, K., Wright, D., and Light, K. (2011) Evaluating Models of Care Closer *to Home for Children and Young People who are Ill: Main report*, NIHR Service Delivery and Organisation programme, Southampton.

Rees, G., Stein, M., Hicks, L. and Gorin, S. (2011) *Adolescent Neglect: Research, policy and practice*, Jessica Kingsley Publishers, London.

Rostgaard, T. with Glendinning, C., Gori, C., Kroger, T., Osterle, A., Szebehely, M., Thoebald, H., Timonen, V., Vabo, M. (2011) *Livindhome: Living independently at Home: Reforms in home care in 9 European countries*, SFI - Danish National Centre for Social Research, Copenhagen.

Stein, M. (2011) *Care Less Lives*, National Care Advisory Service, London.

Wade, J., Biehal, N., Farrelly, N. and Sinclair, I. (2011) *Caring for Abused and Neglected Children: Making the right decisions for reunification or long-term care*, Jessica Kingsley, London

Contributions to books

2011

Biehal, N. (2011) Demystifying evidence in child welfare, in A. N. Maluccio, C. Canali, T. Vecchiato, A. Lightburn, J. Aldgate and W. Rose (eds.) *Improving Outcomes for Children and Families: Finding and Using International Evidence*, Jessica Kingsley Publishers, London, pp.30-40.

Bradshaw, J. (2011) Child poverty, in N. Yeates, T. Haux, R. Jawad and M. Kilkey (eds.) *In Defence of Welfare: The impacts of the Spending Review*, Social Policy Association, pp.17-19.

Bradshaw, J. (2011) Child poverty and deprivation, in J. Bradshaw (ed.) *The Well-being of Children in the UK*, 3rd ed., The Policy Press, Bristol, pp.27-52.

Bradshaw, J. (2011) Conclusion, in J. Bradshaw (ed.) *The Well-being of Children in the UK*, 3rd ed., The Policy Press, Bristol, pp.261-270.

Bradshaw, J. (2011) Demography of childhood, in J. Bradshaw (ed.) *The Well-being of Children in the UK*, 3rd ed., The Policy Press, Bristol, pp.13-25.

Bradshaw, J. (2011) Hands off child benefit!, in B. Knight (ed.) *A Minority View: What Beatrice Webb would say now*, Alliance Publishing Trust, London, pp.59-69.

Bradshaw, J. (2011) Introduction, in J. Bradshaw (ed.) *The Well-being of Children in the UK*, 3rd ed., The Policy Press, Bristol, pp.1-11.

Bradshaw, J. (2011) Poverty, in A. Walker, A. Sinfield and C. Walker (eds.) *Fighting Poverty, Inequality and Injustice: A manifesto inspired by Peter Townsend*, Policy Press, Bristol, pp.91-110.

Bradshaw, J. and Attar-Schwartz, S. (2011) Fertility and social policy, in N. Takayama and M. Werding (eds.) *Fertility and Public Policy: How to reverse the trend of declining birth rates*, MIT-Press, Cambridge MA and London UK, pp.183-202.

Bradshaw, J. and Bloor, K. (2011) Physical health, in J. Bradshaw (ed.) *The Well-being of Children in the UK*, 3rd ed., The Policy Press, Bristol, pp.53-88.

Bradshaw, J. and Chzhen, Y. (2011) Lone parent families: poverty and policy in comparative perspective, in E. Almeda Samaranch and D. Di Nella (eds.) *Las Familias Monoparentales a Debate II: Bienestar, Proteccion Social y Monoparentalidad*, Tiifamo-Copolis, Barcelona, pp.25-45.

Bradshaw, J. and Keung, A. (2011) Subjective well-being and mental health, in J. Bradshaw (ed.) *The Well-being of Children in the UK*, 3rd ed., The Policy Press, Bristol, pp.89-109.

Brooks, J. (forthcoming) It's like having a friend around, in M. Davies (ed.) *Social Work with Adults: From policy to practice*, Palgrave Macmillan, London.

Gridley, K. (forthcoming) A good arrangement - now under threat, in M. Davies (ed.) *Social Work with Adults: From policy to practice*, Palgrave Macmillan, London.

Irvine, A. (2011) Common mental health problems and work, in S. Vickerstaff, C. Phillipson and R. Wilkie (eds.) *Work, Health and Wellbeing: The challenges of managing health at work*, Bristol, The Policy Press, pp.39-58.

Rees, G. and Stein, M. (2011) Children and young people in and leaving care, in J. Bradshaw (ed.) *The Well-being of Children in the UK*, 3rd ed., The Policy Press, Bristol, pp.175-190.

SPRU International presentations 2011

SPRU researchers gave a wide range of public presentations to diverse audiences in 2011. The events at which we spoke included: international and national conferences on the major topics of our time; local government practice workshops; academic association conferences; Making Research Count workshops; invited University lectures; campaigning organisations'/charities' workshops and report launch events. In total, we spoke at over 115 events that were open to the public. We also speak formally to many advisory groups and to the funders of our work about what our research is revealing and the implications of this for policy and practice. We list the main international presentations below.

Aspinal, F. (2011) **Integrated community teams: promoting continuity of care for people with long-term neurological conditions?**, *Recent Developments and Future Challenges of Integrated Care in Europe and Northern America, 11th International Conference on Integrated Care,* University of Southern Denmark, Odense, Denmark, 31 March-1 April 2011.

Biehal, N. (2011) **Randomised controlled trials in children's services: challenges and strategies**, *Randomised Controlled Trials on Family Programmes: Experiences from Neighbouring Countries Conference*, Copenhagen, Denmark, 31 March 2011.

Biehal, N. (2011) **Permanency planning: reunification or long-term care? Research, policy and practice in England. Keynote**. *The Family's Right to Their Child Conference,* Warsaw, Poland, 28 April 2011.

Biehal, N. (2011) **Implementing evidence-based programmes in the real world: challenges and issues. Invited**. *International Association for Outcome-Based Evaluation and Research (IAOBER) 11th International Research Seminar,* Fondazione Zancan, Malosco, Italy, 27-28 June 2011.

Biehal, N. (2011) **Reunifying children in care with their families: using research in practice. Invited plenary**. *Integrating Evidence-Based Practices in Child and Family Services: Lessons Learned from Different Countries Conference,* University of Bolzano, Italy, 29 June 2011.

Biehal, N. (2011) **Contact in long-term foster care. Keynote**. *5th International Network Conference on Foster Care Research,* University of Graz, Graz, Austria, 19-21 September 2011.

Biehal, N. (2011) **Permanence, progress and belonging in long-term foster care. Keynote**. *Fostering in Today's World - Permanency, Progress and Belonging Conference,* Dublin, Ireland, 13 October 2011.

Bradshaw, J. (2011) **The case for universal child benefits,** *Comparative Child and Family Policy: A Conference in Honor of Sheila Kamerman,* Columbia University, New York, United States of America, 12 May 2011.

Bradshaw, J. (2011) **The case for 'and' rather than 'or' in dimensions of poverty measurement in the European Union,** *Measuring Poverty in the European Union: A Debate,* University College Dublin, Dublin, Ireland, 19 May 2011.

Bradshaw, J. (2011) **Where to go with research on subjective well-being of children?**, *Centre for Welfare Research Seminar, Centre for Welfare Research,* University of Turku, Finland, 26 May 2011.

Bradshaw, J. (2011) **An analysis of generational equity over recent decades in the OECD and UK, Growth, Social Protection and Inequality**, *Foundation for International Studies on Social Security, Eighteenth International Research Seminar on Issues in Social Security : Growth, Social Protection and Inequality,* Sigtuna, Sweden, 10 June 2011.

Bradshaw, J. (2011) **Guaranteeing minima to children - the CEE/CIS experience: the failure of a model?,** *Anti-Poverty Programs in a Global Perspective: Lessons from Rich and Poor Countries Seminar,* Social Science Research Center, Berlin, Germany, 21 June 2011.

Bradshaw, J. (2011) **Child poverty and subjective well-being,** *New Families, New Politics Conference,* International University Menéndez Pelayo, Barcelona, Spain, 4 October 2011.

Bradshaw, J. (2011) **The subjective well-being and mental health of children,** *All Well in the Welfare State? Mental Well-being and the Politics of Happiness Conference,* Helsinki, Finland, 24 October 2011.

Bradshaw, J. (2011) **Lone parents in comparative perspective,** *Tiifamo Lone Parent Families International Symposium,* University of Barcelona, Barcelona, Spain, 27 October 2011.

Bradshaw, J. and Holmes, J. (2011) **Generational equity in the income distribution in the UK and the OECD**, *Growing Inequalities' Impacts Workshop WP6,* University of Antwerp, Antwerp, Belgium, 14 November 2011.

Bradshaw, J. and Van Mechelen, N. (2011) **The structure and value of the child benefits package for working families in the European Union**, *Growing Inequalities' Impacts Workshop WP6,* University of Antwerp, Antwerp, Belgium, 14 November 2011.

Bradshaw, J., Redmond, G. and Holmes, J. (2011) **A comparative analysis of generational equity in the Australian and UK welfare states,** *The Well-being of Children in Australia Workshop,* Social Policy Research Centre, University of New South Wales, Sydney, Australia, 6-7 April 2011.

Glendinning, C. (2011) **Paying for informal care: autonomy, independence or interdependence?**, *Does Europe Care? European Conference on Long-term Care and Diversity,* University of Amsterdam, The Netherlands, 28-29 April 2011.

Glendinning, C. (2011) **Caring for people at home: developments in paid and unpaid care**. **Invited.** *Social Experimentation to Develop Innovative Home Care Solutions: Best Practice Workshop,* European Commission, Brussels, Belgium, 12 September 2011.

Glendinning, C. (2011) **Personalisation and personal budgets in England: achievements and challenges. Invited.** *National Disability Authority Seminar,* Dublin, Ireland, 12 October 2011.

Glendinning, C. (2011) **People with disabilities making choices about their services and support**. **Keynote.** *National Disability Conference,* Dublin, Ireland, 13 October 2011.

Glendinning, C. (2011) **What works for carers? Invited.** *Assessing the Impact of ICT-Based Solutions for Caregivers on the Sustainability of Long-Term Care in an Ageing Europe Seminar,* European Commission, Brussels, Belgium, 21-22 November 2011.

Parker, G. (2011) **Research on costs and effectiveness of carer support: searching for a new paradigm?** *Social Policy in a Complex World, Australian Social Policy Conference,* University of New South Wales, Sydney, Australia, 6-8 July 2011.

Parker, G. (2011) **Conducting systematic reviews. Workshop.** *Research Driving Change in Policy and Practice, School of Social Work and Human Services Annual Research Symposium,* School of Social Work and Human Services, University of Queensland, Brisbane, Australia, 12 July 2011.

Parker, G. (2011) **The relationship between evidence and policy making. Keynote.** *Research Driving Change in Policy and Practice, School of Social Work and Human Services Annual Research Symposium,* School of Social Work and Human Services, University of Queensland, Brisbane, Australia, 12 July 2011.

Stein, M. (2011) **The mental health of young people ageing out of care. Keynote.** *International Transitions from Care to Adulthood Research Seminar (INTRAC),* University of Gothenburg, Gothenburg, Sweden, 9 September 2011.

Stein, M. and Lerch, V. (2011) **Leaving care: from care to adulthood in European and Central Asian societies. Keynote.** *Quality in Alternative Care International Conference,* Prague, Czech Republic, 4-6 April 2011.

Weston, K. (2011) **Service user responses to UK labour market activation policies aimed at sick or disabled people**, *Re-forming Activation: A New Turn in Policy? Conference,* University of Hamburg, Hamburg, Germany, 24-25 March 2011.

External advisory positions and activities

Kate Baxter

Member, Advisory Group, The Bristol TARA Project on Homeless Women

Proposal refereeing

National Institute for Health Research, School of Social Care Research

Economic and Social Research Council

The Netherlands Organisation for Health Research and Development (ZonMw)

Bryony Beresford

Member, Research Advisory Group, University of Stirling

Member, Research Advisory Group, University of Manchester

Member, Disability Thematic Advisory Group, Centre for Excellence and Outcomes (C4EO)

External Examiner, University of Sydney, Australia

Academic Reviewer, International Society for Child Indicators 2011 Conference

Proposal refereeing

National Institute for Health Research Programme Grant

Nina Biehal

Member, Research Group Advisory Committee, British Association of Adoption and Fostering

Member, International Association for Outcome-Based Evaluation and Research on Child and Family Services (iaOBERfcs)

Member, Research Project Advisory Group, At Home in Care, Queen's University, Belfast

Consultant, Evaluation of the Children's Commissioning Support Resource (CCSR), Welsh Assembly Government

Jonathan Bradshaw

UK Expert, European Union Expert Group on Social Inclusion

Chair, Scientific Advisory Board, Nordic Centre of Excellence Programme on Welfare Research 2007-2011

Honorary Research Fellow, South African Human Sciences Research Council

Chair, Management Committee, York Welfare Benefits Unit

Member, Research Committee of the International Social Security Association (ISSA)

Honorary Fellow, Faculty of Public Health

Academician, Learned Societies for the Social Sciences

Fellow, British Academy

Trustee, Social Research Unit, Dartington

Board Member, Child Poverty Action Group

Board Member, International Society for Child Indicators

Board Member, Foundation for International Studies in Social Security (FISS)

Member, Research Advisory Group, Cost of a Child, Joseph Rowntree Foundation

Member, Research Advisory Group, National Evaluation of the Healthy Start Scheme

Honorary Visiting Professor, Oxford Institute of Social Policy, University of Oxford

Anne Corden

Member, Bereavement Advisory Group for Money Advice Service, Financial Services Authority

Member, Steering Group for Research on Socio-economic Impact of Bereavement in Scotland

Consultant, Down to Earth Project on supporting people dealing with funerals in East London, Quaker Social Action

Member, Strategic Alliance in East London (support in death and bereavement)

Event Organiser, Bereavement Round Table, convened by Dame Carol Black, Department for Work and Pensions

Proposal refereeing

Economic and Social Research Council

The Leverhulme Trust

BUPA

Jacqueline Davidson

Member, White Rose Partnership on Welfare to Work for Claimants of Disability Benefits

Jo Dixon

Member, Starting Blocks Working Group, York Cares

Proposal refereeing

Nuffield Foundation

Caroline Glendinning

Chair, UK Social Policy Association, 2008-2011

Academician, Academy of Learned Societies in the Social Sciences

Associate Director, NIHR School for Social Care Research

Founder Member, Eurocarers: European Organisation on Informal Care

Member, Nordic Network for Research on Marketisation in Eldercare

Trustee, Thalidomide Trust

External Examiner, Professional Doctorate, University of Sussex

Proposal refereeing

The Netherlands Organisation for Health Research and Development (ZonMw)

Book proposal, The Policy Press

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Group facilitator, Bereavement Round Table, convened by Dame Carol Black, Department for Work and Pensions

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Shadow Awards Officer, Executive Committee, Social Policy Association

Member, Seminars Competition Commissioning Panel, Economic and Social Research Council

Gillian Parker

Member, Consultation Group on Methods for Developing Social Care Guidance, National Institute for Health and Clinical Excellence (NICE)

Clinical Specialty Lead, Age and Ageing, North & East Yorkshire & Northern Lincolnshire Comprehensive Local Research Network (NEYNL CLRN)

Proposal refereeing

Nuffield Foundation

National Institute for Health Research, Service Delivery and Organisation Programme

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Member, Advisory Panel on Intergenerational Worklessness, Joseph Rowntree Foundation

Member, White Rose Partnership on Welfare to Work for Claimants of Disability Benefits

International Adviser, Social Regulation in the Nordic Countries Project, Norwegian Social Research Institute, Oslo

Event Organiser, Bereavement Round Table, convened by Dame Carol Black, Department for Work and Pensions

Expert Witness, Welfare Reform Public Bill Committee, House of Commons

Expert Witness, Proposal to replace DLA with Personal Independence Payment, House of Commons Work and Pensions Select Committee

External Examiner, Stirling University

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Joint co-ordinator, Transitions from Care to Adulthood International Research Group (INTRAC) (16 Countries)

Member, Professional Advisory Group, The Children Act 1989 Guidance and Regulations, Vol. 3: Planning Transition to Adulthood for Care Leavers, Department for Education

Member, Children & Youth Programme Advisory Board, UNESCO

Member, Research Liaison Group, Department for Education

Member, Learning from Serious Case Reviews Advisory Group, Department for Education

Chair, Research Advisory Group, Department for Education Evaluation of the ‘Staying Put 18 Plus’ Pilot

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Consultant, Commissioning, Delivery and Perceptions of Emergency Accommodation for Young Runaways Project, The Children's Society

Member, International Research Network on Leaving Care (INTRAC)

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Member, Network for Research on Children, Young People and Families, co-ordinated by the NSPCC

Member, Home Office/Nuffield Foundation Advisory Group, Evaluation of a Pilot Family Drug and Alcohol Court (FDAC) Project

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Journal of Poverty and Social Justice - editor of the Research Round-up

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Australian Journal of Social Issues

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European Journal of Social Security

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