SPRU ANNUAL REPORT 2005

S|P|R|U

SOCIAL POLICY RESEARCH UNIT

THE UNIVERSITY *of York*

Contents

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The Social Policy Research Unit (SPRU) is a research centre based within the Department of Social Policy and Social Work 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's work is particularly focused on people who are vulnerable because of poverty, unemployment, ageing, disability or chronic sickness.

Research within the Unit is organised around three research teams, each of which is led by an Assistant Director:

1.
Children and Families Team
(led by Professor Tricia Sloper)

2.
Community Care for Adults Team
(led by Professor Caroline Glendinning)

3.
Social Security and Living Standards Team
(led by Dr Roy Sainsbury)

Professor Peter Kemp

Introduction by the Director

INTRODUCTION BY THE DIRECTOR

The year 2005 was another busy and productive one for SPRU. During the year we worked on thirty-four research projects and engaged in a wide spectrum of related activities, including policy advice to government and presentations at academic, policy and practice conferences and seminars.

A major landmark during 2005 was the successful completion of our five-year, Department of Health funded research programme on the outcomes of social care. We also created the framework and vision for our new DH research programme, which is focused on choice and independence over the lifecourse, further details of which are on pages six and seven.

Towards the end of the year we were commissioned to evaluate the new individual budgets scheme for older people, adults and children with additional support needs. This is being piloted in 13 local authority areas for up to two years. This is a potentially path-breaking initiative in social care and related services and we are delighted to have this opportunity to contribute to its development. We will be working on the evaluation in collaboration with the two other Department of Health funded social care research units.

Other highlights during 2005 include the completion of a research report on the cost and effectiveness of different models of key worker services for disabled children. We hope that this research, which was funded by the Department of Health, Department for Education and Skills, HM Treasury and the National Assembly for Wales, will make an important contribution to the development of national policy in this area. As the report shows, key workers can make a vital contribution to the delivery of joined up services for chronically sick and disabled children and their families (page 19).

Among the many research projects underway during the year was a qualitative study, funded by the Department for Work and Pensions, of routes onto Incapacity Benefits. Although there is a growing body of research evidence on the impact of various policy initiatives that encourage Incapacity Benefit recipients to move into work, relatively little is known about how people end up claiming the benefit in the first place. This project has shed new light on a subject that has gained much media and policy attention in recent years (page ten).

The year also saw a stream of publications emerging from an ESRC-funded research project on the use of verbatim quotations in qualitative research. Several of these outputs, including a particularly fascinating one on the views of research participants about how their words are used in research reports, are available for downloading from our website (page 16).

Another important highlight for us during the year was the great success of our two-day conference in memory of the late Professor Sally Baldwin, which was held on the theme of cash and care. Sponsored by the Department of Health and the Economic and Social Research Council, with additional support from the UK Social Policy Association, the conference was a fitting tribute to Sally. See page five for further details.

I am delighted to report that Professor Jonathan Bradshaw, Associate Director of SPRU, received a CBE for services to child poverty in the Queen's Birthday Honours List. This is a well-deserved, public recognition of the important contribution that Jonathan has made to our knowledge and understanding of poverty, social security and related topics over many years.

None of our activities would have been possible without the funding that we have received from a wide range of organisations. These included the Department for Education and Skills, the Department of Health, the Department for Work and Pensions, the Economic and Social Research Council, the Joseph Rowntree Foundation, and the Social Care Institute for Excellence. We are grateful to them all.

Finally, this is my last introduction to the Unit's annual reports, as I am moving to the University of Oxford in April to take up the Barnett Professorship in Social Policy. I should like to thank the research and support staff in SPRU for making working in the Unit such an enjoyable experience. I have been greatly impressed by their professionalism, expertise and commitment. The Unit will be ably led by the assistant directors – Caroline, Roy and Tricia – in the interregnum between my departure and the new director taking office later in the year.

Peter Kemp

Cash and Care:

Understanding the Evidence Base for Policy and Practice

The conference held in memory of Sally Baldwin in April 2005 was a marked success and fitting tribute to Sally's distinguished career in social policy research at the University and as director of SPRU.

The conference focused on the themes that featured most prominently in Sally's research: care and caring, chronic illness and disability, money and gender – and particularly the relationship between them.

Over 30 papers were presented, including talks by a distinguished list of keynote speakers: Professor Ian Diamond, Andrew Cozens, Sue Duncan and Malcolm Wicks, (then Minister for Work and Pensions). Researchers and policy makers gathered with service users and PhD students to discuss leading edge research in a convivial atmosphere.

The conference dinner was held in the medieval Merchant Adventurers' Hall in York, where members of Sally's family joined delegates, many of whom had been friends and colleagues of Sally throughout her career. Saul Becker gave a speech remembering Sally and her impact on those who worked with her and those who had been influenced by her work.

The conference was sponsored by the Department of Health and the Economic and Social Research Council, with additional finance support from the Social Policy Association.

Money raised from the conference has been channelled into creating a PhD studentship in Sally's name to be held at the University of York. A book based on a selection of the papers presented at the conference is due to be published in September 2006 by The Policy Press.

DH Research Programme 2006-2010

Choice and Independence Across the Lifecourse

Extending greater choice to the users of public sector services, including social care services, is at the heart of current government policy. In 2005 a raft of policy proposals was announced aimed at increasing choice and control by users of social care services. Moreover, reflecting the focus of SPRU's previous DH-funded research programme, social care services are now expected to support users in maintaining their independence and quality of life.

These policies are mirrored in academic debates about the role of consumerism and choice in publicly-funded welfare services: some advocate that increased choice is consistent with rising expectations in post-modern, individualistic societies; others question whether theories and practices developed in the context of private consumption are applicable to the public sector. Several of these arguments will be examined in the course of the DH research programme.

SPRU's new DH-funded research programme will examine the exercise of choice by disabled children, young people, adults and older people; the information and other support they need to do so; and the consequences of making choices for independence and well-being. Both the concept and the practice of choice may be highly problematic for many such people. For example, there may be very few opportunities for choice over scarce specialist services, while changing needs may necessitate repeated choices about services and support arrangements. The programme will address the following questions:

- What kinds of choices over social care and related services are important to disabled and chronically ill young people, adults and older people and their families or carers, and why; how do these vary between different groups; and how do they relate to concepts of independence?
- What opportunities do disabled and chronically ill young people, adults and older people and their families or carers have to make choices that are important to them; what information and other support is needed to facilitate choice?
- What roles do carers play in supporting choice and what are the implications for their own choices?
- What are the consequences of choice on the part of disabled and chronically ill young people, adults and older people and their families or carers?
- How far are service providers able to respond to (increased choice)?

Qualitative longitudinal panel study
This will form the core of the programme. It will examine the realities of choice in the context of changing circumstances, whether arising from changes in illness or disability or from other social transitions. It will enable us to examine the consequences of past choices,

including the responses of service providers, and the impact on perceived independence.

The panel study will include people likely to experience considerable change in their support needs:

- young people with degenerative or progressive conditions
- adults with fluctuating conditions
- older people experiencing the sudden onset of severe disability.

Respondents will be interviewed at regular intervals over two to three years. Complementary interviews may be carried out with key professionals and/or family members who have been heavily involved in specific recent choices. As well as tracking changes in individual circumstances and responses to these, cross-cutting themes will examine issues such as:

- the role of carers in supporting choice
- finding an acceptable balance between choice and responsibility
- the perceived response of service providers to user choice
- the impact of choices on independence.

The panel study is currently being designed; we expect fieldwork to begin in summer 2006.

Scoping studies

We will conduct two scoping studies:

- understanding the dynamics of decision-making and choice about social care and related services
- the application of literature on welfare consumerism to social care and related services for disabled and chronically ill young people, adults, older people and carers.

The scoping studies will:

- critically appraise existing research
- identify gaps in evidence
- contribute to theoretical debate about choice
- inform the development of the panel study.

The scoping studies will be conducted between January and July 2006.

Other studies in the DH programme under development include:

Providers' responses to choice – barriers and opportunities. This study will examine, from the perspectives of social care providers, the barriers to and opportunities for responding to increases in user choice through mechanisms such as direct payments, individual budgets and private purchase of services.

Out-of-area placements and the transition to adult services. Choice and change are particularly problematic for the minority of severely disabled young people who attend residential schools outside their local authority area. This study will examine transition planning, choice and their outcomes in terms of achieved independence.

Choice and change – exploration of large-scale data sets. This will complement the panel study by providing, where possible, larger-scale perspectives on the same questions.

Finally, SPRU is collaborating with the two other DH-funded social care research units (the Social Care Workforce Research Unit at King's College London and the Personal Social Services Research Unit at the Universities of Manchester, LSE and Kent) to evaluate the individual budget pilot projects which were announced in November 2005. This evaluation, which will inform decisions about the long-term roll-out and sustainability of individual budgets, will also complement SPRU's core DH-funded programme and we will aim to achieve maximum interaction and synergy between the two strands of research.

Visit of Work and Pensions Select Committee

In November 2005, SPRU hosted a two-day visit by the House of Commons Select Committee on Work and Pensions.

During the visit, the Committee was briefed on a range of policy issues by researchers from SPRU and elsewhere. Topics covered included child poverty, housing benefit, incapacity benefit and pensions.

SPRU directors were among the experts making presentations to the Committee: Jonathan Bradshaw spoke on child poverty and child support; Peter Kemp spoke on housing benefit and the Social Fund; and Roy Sainsbury gave a briefing on employment issues. The visit also included a dinner hosted by the Joseph Rowntree Foundation.

The Select Committee
(back row, left to right) Michael Jabez Foster, Natascha Engel, Greg Mulholland, Terry Rooney, Joan Humble, John Penrose (front row, left to right) Justine Greening, Jenny Willott, Harry Cohen

SPRU and the UK's Presidency of the EU

During the UK's Presidency of the European Union in 2005, the Government hosted a number of events and meetings to explore key issues including raising employment rates and helping economically inactive people move into the labour market.

UK
PRESIDENCY
OF THE EU
2005

As part of the UK Presidency, Professor Jonathan Bradshaw from the Unit's Social Security and Living Standards Team chaired a workshop on Families and Children at a Round Table on Social Inclusion, which was held in Glasgow on 17-19 October. The Round Table provides a forum for discussion and sharing of good practice between Governments and organisations with an interest in social inclusion across Europe.

Dr Roy Sainsbury spoke at an EU Presidency conference on Economic Inactivity and Ill-health, which was held in Cardiff on 23-24 November. The conference focused on the UK's approach to tackling the problem of incapacity benefit and long-term sickness and the wider implications for the EU. Roy's paper examined the Government's anticipated proposals for reform of incapacity benefits.

The Social Security and Living Standards Team is led by Dr Roy Sainsbury. Its research focuses on poverty, income maintenance and employment.

The main streams of work being undertaken by the researchers within the Team are: the living standards of children and families; social security and the labour market, especially welfare to work policies in relation to people on incapacity benefit and other groups on the margins of employment; employment policies for disabled people; housing benefit; and the administration and delivery of benefits and tax credits, including the issue of social security fraud.

Recently, we have begun to develop research on pensioner poverty, which complements our existing expertise in child poverty.

The Team has a long track record of international comparative research.

Dr Roy Sainsbury

Social Security and Living Standards Team

Evaluation of the incapacity benefit pilots

On-going project

Department for Work and Pensions

September 2003 to March 2007

Roy Sainsbury, Anne Corden, Katharine Nice (in collaboration with the Policy Studies Institute, the National Centre for Social Research, the Institute for Fiscal Studies, and Mathematical Policy Research Inc., USA)

The incapacity benefit pilots (also known as the 'Pathways to Work' pilots) commenced in October 2003 in three locations in Great Britain and were extended to a further four locations in April 2004. The aim of the pilots is to extend help to new incapacity benefit claimants from Jobcentre Plus offices in order to encourage and facilitate a return to employment. Innovations include the introduction of personal advisers to work with all new incapacity benefit claimants, a series of up to six work-focused interviews, access to health condition management, and financial help through the Return To Work Credit. The pilot was extended in February 2005 to people in receipt of incapacity benefits for between one and three years.

The wider evaluation of the pilots comprises surveys, analysis of administrative data, a cost benefit analysis and a qualitative process evaluation element (to which SPRU is contributing). In 2004 the first cohort of a longitudinal qualitative study of incapacity benefit recipients' experiences was completed and will be reported in 2005. Two further cohorts started in November 2004 and March 2005. The research design also includes separate studies of different aspects of the pilots including the work of incapacity benefit personal advisers and other Jobcentre Plus staff, the impact of the Return to Work Credit, and the workings of the health condition management programmes.

The evaluation will be expanded in 2006 to cover 14 new pilot areas in which Pathways to Work is being introduced.

Interim reports will be presented to the DWP over the course of the evaluation and a final report submitted in March 2007.

Publication

Corden, A., Nice, K. and Sainsbury, R. (2005) *Incapacity Benefit Reforms Pilot: Findings from a longitudinal panel of clients*, Department for Work and Pensions Research Report, vol. 259, Corporate Document Services, Leeds

Routes onto incapacity benefits

On-going project

Department for Work and Pensions

October 2004 to December 2006

Roy Sainsbury, Jacqueline Davidson, Angela Meah, Naomi Finch, Peter Kemp

Little is known about the routes by which people become recipients of an incapacity benefit. SPRU is conducting a two-stage study into the employment and health experiences of people before they make a claim for incapacity benefit. The study aims to explore the circumstances of claimants in the period leading up to claiming, whether their employment and benefit histories influence the decision to claim, and the roles played by key actors such as GPs and other health professionals, Jobcentre Plus staff, other advisers, and family and friends. It is hoped that greater understanding of the factors leading to a claim will inform developments in disability and Welfare to Work policies.

The first stage was begun in 2005 and comprised a qualitative study of 60 new claimants of incapacity benefit interviewed initially in March/April and subsequently in October. The follow-up interviews aimed to investigate people's exits from incapacity benefit in relation to their routes on to the benefit. The second stage is a large-scale survey, which will be carried out in 2006.

The report from the first stage of the study is due for publication in the Spring of 2006.

Trends in disability benefit recipiency rates

Completed project

International Social Security Association and Department for Work and Pensions

January 2003 to October 2005

Peter Kemp, Patricia Thornton

Like Britain, many economically advanced nations have experienced substantial, long-term growth in the number of people receiving incapacity benefits (disability benefit or disability insurance). The aim of this study was to examine and attempt to explain the trends in incapacity benefit in six countries – Denmark, Great Britain, Israel, the Netherlands, Sweden and the USA – over the past 20 years.

It was found that as well as the well-documented rise of incapacity amongst older male workers in manufacturing and mining areas of the country, new trends are also apparent. These include the rise of women claiming incapacity benefit due to their greater inclusion in the workforce in recent decades. There is also an increase in mental health problems leading to claims. Raised levels of incapacity claims seem to be linked to the high levels of stress and anxiety associated with the processes of 'downsizing' and the increased work intensity that are characteristic of the post-industrial economy.

A complex and diverse pattern of factors emerges to show the pressures that have led to the upward trend in disability claims across the developed world.

Publication

Bakker Tauritz, B., Kemp, P. A. and Sunden, A. (eds) (forthcoming) *Sick Societies? Trends in Disability Benefits in Post-industrial Welfare States*, Geneva: International Social Security Association

Evaluation of the Job Retention and Rehabilitation Pilots

On-going project

Department for Work and Pensions

April 2003 to April 2006

Roy Sainsbury, Anne Corden, Patricia Thornton, Katharine Nice (in collaboration with the National Centre for Social Research)

The Job Retention and Rehabilitation Pilots (JRRP) commenced in April 2003 and operated for two years until March 2005. The aim of the pilots was to test methods to help people who have been out of work because of sickness or disability for between six and 26 weeks to return to employment as soon as possible. The pilots used random assignment techniques to measure the impact of different 'interventions'. Voluntary participants were allocated to one of three treatment groups (to receive health interventions, workplace interventions or a combination of both) or to a control group. Four organisations independent of DWP delivered the JRRP in six locations in Great Britain. SPRU contributed to the qualitative process evaluation element of the wider evaluation.

In 2003 the first cohort of a longitudinal qualitative study of clients following their experiences was carried out over a period of six months, and a study of the workings of the JRRP providers was undertaken. Further work has included two more cohorts in the client longitudinal study, and separate studies of the roles of GPs and employers in relation to sickness management and working with the pilot.

Publication

Nice, K. and Thornton, P. (2004) *Job Retention and Rehabilitation Pilot: Employers' Management of Long-Term Sickness Absence*, DWP Research Report 227, Social Research Division, Department for Work and Pensions, London

Available online at:
http://www.dwp.gov.uk/asd/asd5/rports2003-2004/rrep227.pdf

Evaluation of the New Deal for Disabled People National Extension

On-going project

Department for Work and Pensions

August 2001 to February 2006

Roy Sainsbury, Anne Corden, Patricia Thornton, Angela Meah (in collaboration with the Universities of Loughborough and Sussex, the National Centre for Social Research, the Urban Institute, Washington, and Abt Associates, USA)

The New Deal for Disabled People (NDDP) is delivered through a network of 'job broker services' by a mix of organisations from the public, private and voluntary sectors. Job brokers have the freedom to decide how they deliver services to help people move towards and into work and are funded according to the results they achieve. The research design incorporates a range of quantitative and qualitative techniques, including surveys of participants, non-participants and employers, the analysis of administrative data to measure the cost-effectiveness of the programme, and a programme of qualitative work with participants, job broker staff and employers.

In 2004 a second wave of qualitative research was carried out to explore experiences of delivering and using NDDP services from the perspectives of clients, job broker staff and staff from Jobcentre Plus offices. The results were published in 2005. Using the survey of people eligible to participate in NDDP as a sampling frame, a qualitative follow-up study was carried out of people identified from the survey as being knowledgeable about job broker services. The findings from the follow-up study will be published in the survey report in 2006.

Publication

Lewis, J., Corden, A., Dillon, L., Hill, K., Kellard, K., Sainsbury, R. and Thornton, P. (2005) *New Deal for Disabled People: An in-depth study of Job Broker service delivery*, Department for Work and Pensions Research Report, vol. 246, Corporate Document Services, Leeds

Housing benefit payment methods: claimant perspectives

On-going project

Joseph Rowntree Foundation

September 2005 to August 2006

Peter Kemp, Annie Johnson

The Government is currently testing, in a number of pathfinder areas, a Local Housing Allowance (LHA) to replace Housing Benefit (HB) for private tenants. In due course, the LHA is expected to be extended to include local authority and housing association tenants on HB. The most controversial feature of the LHA is that it is normally paid to claimants rather than landlords.

The aims of this project are to examine HB recipients' understanding, experiences and views of different payment methods (payment to the tenant versus payment to the landlord). This topic is being examined in relation to their household budgeting, beliefs and behaviours about debt and paying the rent, and their perceptions about the relative risks and benefits of moving into paid work under the two different payment regimes.

Semi-structured interviews are being conducted with HB recipients renting from local authorities, housing associations and private landlords in four localities. The sample is being purposively selected to comprise three household types: families with children, single people under 25, and pensioners.

Area variations in the take-up of means-tested benefits/tax credits

On-going project

Neighbourhood Renewal Unit,
Office of the Deputy Prime Minister

November 2005 to October 2006

Jonathan Bradshaw and Dominic Richardson

The Income Domain in the Index of Multiple Deprivation 2004 uses administrative data on benefit receipt. However it does not take account of variations in take-up. There is some evidence that benefits such as Pension Credit and tax benefits such as Child Tax Credits might vary with the characterisitcs of the population of an area or might vary by the type of area. If take-up does vary in these ways then ideally an index of deprivation should adjust for it. Otherwise an area with low take-up will be losing out doubly – in unclaimed means-tested benefits and in the allocation of central resources to local areas using the Index of Multiple Deprivation.

The Neighbourhood Renewal Unit agreed to undertake further research on this problem in time for the next Index of Multiple Deprivation. It will be based on the secondary analysis of the Family Resources Surveys 2003/4 and 2004/5.

The work will seek to:

- identify the characteristics of eligible non-claimants of Pension Credit and Tax Credits
- build predictive models of propensity to claim
- investigate whether this leads to siginificant spatial variations in claiming, and/or
- whether there are significant spatial variations in claiming independently of the characteristics of the population.

The project will end with a recommendation to the Neighbourhood Renewal Unit on whether spatial variation in take-up can and should be taken into account in the Index of Multiple Deprivation or whether it can be ignored.

Disability Services Research Partnership

Completed project

Jobcentre Plus

April 2000 to March 2005

Patricia Thornton, Michael Hirst, Anne Corden, Roy Sainsbury, Hilary Arksey, Angela Meah

The Disability Services Research Partnership carried out research to inform employment programmes and services for disabled people. The Partnership was set up as a way of improving the quality of its research and its utilisation and as a means of accessing external knowledge and advice on policy and operations. In addition to undertaking evaluations of specific programmes, the Partnership worked with the Department for Work and Pensions to review needs for information and research as a basis for planning and innovation.

This new way of working offered scope to work more closely with policy customers to identify the questions they wanted answering and to feed findings into the policy development cycle. Experiences on both sides were very positive.

There were many projects during the lifetime of the Partnership including:

- A Study of Providers New to WORKSTEP
- Review of Results-based Funding in Supported Employment
- The added value of the Supported Employment Programme
- Evaluation of the impact of Access to Work
- Good practice in Work Preparation
- Study of the feasibility of evaluating Access to Work and WORKSTEP using a comparison group methodology
- Users' views of Access to Work.

The final project was, Desirable Outcomes from WORKSTEP: User and Provider Views.

Final publication

Meah, A. and Thornton, P. (2005) *Desirable Outcomes of WORKSTEP: User and provider views*, Department for Work and Pensions Research Report, vol. 279, Corporate Document Services, Leeds

Self-employed: working and saving for retirement

On-going project

Department for Work and Pensions

October 2005 to May 2006

Roy Sainsbury, Anne Corden, Naomi Finch

The UK 's ageing population and its implications for future pension provision is recognised as a key area of social policy concern. Self-employed people are unique in two respects: first, because they are not entitled to the second state pension (it is largely left to the individual to plan financially and save for retirement); and secondly, because they are more likely to work beyond state pension age.

However, we do not have a clear understanding of the decision-making processes by self-employed people when planning for retirement, or the factors that influence their decisions. Nor do we have sufficient understanding of how self-employment can play a part in extending people's working lives. To explore these issues further, the Department for Work and Pensions has commissioned the research with self-employed people.

Qualitative research will be carried out in November/December 2005 in outer London and North Yorkshire. In-depth interviews will be undertaken with 40 people aged 40 and over who are currently self-employed, including some who are working beyond state retirement age.

The key objectives for the research are to:

- explore, among self-employed people, feelings about and expectations of financial security at the end of working life
- explore the perceived role of pensions, savings and earned income at the end of working life
- understand more about the behaviour of self-employed people in relation to financial planning towards retirement and/or extending working life.

The research will contribute to the development of Government policies on saving for retirement and the promotion of flexible retirement and extending working life. A research report will be published in late 2006.

Which pensioners do not spend their incomes and why?

Completed project

Department for Work and Pensions

March 2005 to September 2005

Naomi Finch, Peter Kemp, Julie Williams

Research by the Pensions Commission found that older pensioners, on average, spend substantially less of their income than young pensioners. Meanwhile research by Saunders et al. (2002) has shown that pensioners are more likely to be 'expenditure poor' than 'income poor' when compared with the general population. This has significant implications for the Government's strategy for tackling pensioner poverty.

The aim of this project was to examine which pensioner households do not spend their income and why that might be. The research involved secondary analysis of existing datasets, principally the Expenditure and Food Survey and its predecessor the Family Expenditure Survey. In addition, analysis was undertaken with the British Household Panel Survey and the English Longitudinal Survey of Ageing.

Publication

Finch, N. and Kemp, P.A. (forthcoming) *Which Pensioners do not Spend their Income and Why?*, Department for Work and Pensions Research report, Leeds: Corporate Document Services

Welfare policy and employment in the context of family change

Completed project

Nordic Council of Ministers

May 2002 to April 2005

Jonathan Bradshaw, Naomi Finch and Anne Skevik (Nova, Norway) and national rapporteurs

This was a comparative study of the interactions between changing family forms, the labour market and related social policies in Sweden, Denmark, Finland and Iceland – and Germany, the Netherlands and the UK. The aim was to compare patterns of family change, changes in the labour market and the impact of these in reconciling work and family life, and explore how social policies are responding to these changes. National reports were prepared on the three topics. Each member of the collaborating team has also undertaken at least one comparative sub-study on the following areas: family change; labour market patterns; policy overview; parental rights and obligations; child-care and parental leave; family policy packages; individualisation of family life; education, employment and family formation; lone parents and poverty; child poverty in the EU; mothers' and fathers' time use; first births; men and (their) families; and fertility rates in Europe.

The project will result in one book and a conference. The national working papers and tables of income and benefits can be viewed at: *http://www.york.ac.uk/inst/spru/research/summs/welempfc.htm*

Publication

Bradshaw, J. and Hatland, A. (2006) *Social Policy, Employment and Family Change in Comparative Perspective*, Edward Elgar, Cheltenham

Child poverty in large families

On-going project

Joseph Rowntree Foundation

October 2004 to September 2006

Jonathan Bradshaw, Emese Mayhew, Naomi Finch, Christine Skinner, Veli-Matti Ritakalio

In 2003, 32 per cent of dependent children lived in a large family (defined as a family containing three or more children) in Great Britain. At the same time, children from large families represent 43 per cent of all poor children. Children in large families have a poverty risk more than twice as high as children in small families. The objective of this project is to bring together evidence from a variety of sources using secondary analysis and review to bring the issue of child poverty in large families onto the policy agenda.
This will be done by:

- establishing the current extent of child poverty within large families in the UK
- comparing how different countries treat families of different sizes in their tax benefit packages
- examining how this relates to the relative child poverty rates of large and small families in different countries.

Publications

Bradshaw, J. (2005) Child poverty in larger families, in G. Preston (ed) *At Greatest Risk: The children most likely to be poor*, Child Poverty Action Group, London

Bradshaw, J., Finch, N., Mayhew, E., Ritakallio, V.M. and Skinner, C. (forthcoming) *Child Poverty in Large Families*, Joseph Rowntree Foundation, York

The well-being of children in the UK

On-going project

Save the Children UK

March 2001 to March 2006

Jonathan Bradshaw and Emese Mayhew (co-editors) with contributions from all sections of SPRU and the Social Policy and Social Work Department

The project aims to provide a comprehensive picture of how children are doing, how their well-being varies within the countries of the UK and by gender, age, ethnicity, family type and level of income. The impact of poverty is another focus of this project.

This project draws on the expertise that exists in the wider Social Policy and Social Work Department at the University of York on children. The second volume of the book was published this year containing 14 chapters covering different aspects of the physical, cognitive, behavioural and emotional well-being of children.

For more details of this edition see *http://www.york.ac.uk/inst/spru/wellbeing.html*

Publication

Bradshaw, J. and Mayhew, E. (eds.) (2005) *The Well-being of Children in the UK*, 2nd ed., Save the Children, London

COST Action 19: children's welfare in ageing Europe

On-going project

European Union

September 2001 to June 2006

Jonathan Bradshaw and Bryony Beresford, Emese Mayhew,Tess Ridge, Emma Uprichard

COST Action 19 is a comparative project involving 13 countries that seeks to understand children's welfare in ageing societies. The

project explores the interplay of material, social and institutional forces through emphasising theoretical and methodological approaches to children's welfare. Three areas of welfare are highlighted:
- Children's economic and social welfare
- Children's access to space and use of time
- Children's rights and discourses.

The research team has produced a report for the UK covering these topics, published in January 2005.

June 2006 will see the concluding conference of the COST Action 19 programme, in which researchers in the field will come together to discuss the outcome of the programme in the context of other relevant research. It is intended that this will lead to further development of the field of childhood studies, theoretically and empirically. The conference is to be held in Denmark, 16-17 June, 2006.

Publication

Mayhew, E., Uprichard, E., Beresford, B., Ridge, T. and Bradshaw, J. (2004) Children and childhood in the United Kingdom, in Jensen, An-Magritt et al. (eds), *Children's Welfare in Ageing Europe*, Volume 1, Norwegian Centre for Child Research, Trondheim, pp.410-457

Verbatim quotations in applied social research: theory, practice and impact

Completed project

Economic and Social Research Council

November 2002 to June 2005

Anne Corden and Roy Sainsbury

In presenting findings from applied social research, one technique is to include respondents' verbatim quotations within the author's written text. However, in most research methods texts, more attention has been paid to data collection and analysis than to writing up findings. This study has helped to redress this imbalance. The study aimed to:
- review conceptual and theoretical arguments for using verbatim quotations
- explore current beliefs and practice among social researchers
- investigate the views of those who speak the words presented
- test accessibility, acceptability and impact of different ways of including quotations in written outputs.

The research has been conducted in stages:
- a review of what the theoretical and methodological textbooks say about using quotations
- a review of selected recent social research texts, to examine different ways of using quotations
- two series of depth interviews with researchers and research users (policy makers, funders, other researchers) to explore preferences about using and reading quotations
- testing the impact of different approaches, with alternative versions of a report from a small study of people taking part in a volunteering project.

The study is funded as part of the ESRC Research Methods Programme.

Fieldwork is complete, and dissemination of findings continues. During 2005 there were ESRC funded dissemination seminars in London and York. Completed working papers from the study are posted on the SPRU website, to which four more will be added during 2006.

Publications

Corden, A. and Sainsbury, R. (forthcoming) Quality enhancement: using verbatim quotations in reporting qualitative research, *International Journal of Social Research Methodology*

Corden, A. and Sainsbury, R. (2005) Verbatim quotations: whose views count?, *Qualitative Researcher*, 1, 4-6

Corden, A. and Sainsbury, R. (2005) *Research participants' views on use of verbatim quotations*, Social Policy Research Unit, University of York, York

Corden, A. and Sainsbury, R. (2005) *The Impact of Verbatim Quotations on Research Users: Qualitative exploration*, Social Policy Research Unit, University of York, York

Corden, A. and Sainsbury, R. (2005) *Volunteering for Employment Skills: A qualitative research study*, Social Policy Research Unit, University of York, York

The Children and Families Team is led by Professor Tricia Sloper. The main focus of our work is on support relating to illness and disability in children and younger adults. Our work encompasses support from the many different agencies involved with chronically ill or disabled people: social services, health services, education and housing. We are particularly concerned to investigate ways in which such support takes account of the family context, and the ways that carers and others in the family respond to and are affected by the care needs of the ill or disabled person. Central to this process is the issue of multi-agency working. Our past research has shown that lack of co-ordination of services is a recurring problem for families. Recently, we have investigated the factors within multi-agency services that lead to better outcomes for disabled children and their families.

In the past, work on the needs of disabled or chronically ill children and their families has largely concentrated on the accounts of adults, particularly parents. Yet, research has also shown that children's and adults' views differ, and adults cannot be used as proxies for children's views. Recognising this gap in knowledge, much of our research has focused on the views of children about their needs and experiences and the support they receive from services.

Professor Patricia Sloper

Children and Families Team

DEPARTMENT OF HEALTH OUTCOMES PROGRAMME

Priorities and perceptions of disabled children and young people and their families regarding outcomes of social care

Completed project

Department of Health

October 2001 to December 2005

Tricia Sloper, Bryony Beresford and Parvaneh Rabiee

Building on both the Looked After Children assessment framework and SPRU's programme of work on outcomes for disabled adults and older people, this project was concerned with outcomes for disabled children and their families. It focused specifically on four groups of children: those with autistic spectrum disorders, communication impairments, complex health needs, or degenerative conditions.

The aims were:

- to identify desired outcomes of support services from the perspectives of disabled children and their parents
- to explore managers' and practitioners' perspectives on outcomes
- working with local authority staff and parents to develop tools by which outcome information can be collected in practice
- to pilot and evaluate these tools.

Working in three local authority areas, interviews and focus groups with disabled children and parents, and participatory workshops with key stakeholders amongst staff, were used to investigate views of outcomes. Using the research findings, the research team worked with local steering groups of staff and parents in two sites to develop tools by which information about outcomes for parents and children could be collected in practice. One site developed a tool to support outcome-focused assessment within the core assessment process. The other site developed an outcomes-focused tool looking at parental well-being. These tools were piloted by practitioners, with researchers in SPRU conducting an independent evaluation of the tools from practitioner and parent perspectives.

Publications to date

Beresford, B., Tozer, R., Rabiee, P. and Sloper, P. (2004) Developing an approach to involving children with autistic spectrum disorders in a social care research project, *British Journal of Learning Disabilities*, 32, 180-185

Rabiee, P., Sloper. P. and Beresford, B. (2005) Desired outcomes for children with complex health care needs, and children who do not use speech for communication, *Health and Social Care in the Community*, 13(5), 487-487

Rabiee, P., Sloper, P. and Beresford, B. (2005) Doing research with children and young people who do not use speech for communication, *Children and Society*, 19, 385-396

Beresford, B., Tozer, R., Rabiee, P. and Sloper, P. (in press) Desired outcomes for children and adolescents with autistic spectrum disorders, *Children and Society*

OTHER RESEARCH PROJECTS

An evaluation of a national specialist mental health service for deaf children

On-going project

Department of Health

December 2005 to September 2007

Bryony Beresford, Veronica Greco, Sue Clarke, Lesley Jones (Hull York Medical School)

Prior to 2004 the only specialist inpatient and outpatient mental health service for deaf children in England was in London. In 2004 the National Specialist Commissioning Advisory Group (NSCAG) of the Department of Health set up a three-year pilot project to extend this service and thereby increase access to specialist mental health services by deaf children and young people. The pilot project involves specialist Child and Adolescent Mental Health teams in York and Dudley linking closely with the London service. An innovative part of this service is to utilise telemental health technology (TMH), with video-conferencing between the three teams being used for therapeutic, case management, supervision and training purposes.

This research will evaluate the pilot project in terms of: changes in the population accessing specialist deaf mental health services; outcomes for service users; and the impact of the service on referring agencies. In addition, it will describe the impact of TMH on the way services are provided and the experiences of using TMH in this setting.

Changes in access to the service will be obtained from data routinely collected by the services. The outcomes and experiences of using the service will be explored using standardised assessment tools and qualitative interviews with the children and their parents at the time of referral and on discharge. Specialist interviewers skilled in using BSL will conduct the interviews with the children. Staff from the specialist teams will be interviewed on two occasions to capture their views of developing and providing the service. A questionnaire will obtain the views of referring professionals.

Key worker services for disabled children: effectiveness and costs

Completed project

Department of Health, Department for Education and Skills, HM Treasury, the National Assembly for Wales

October 2002 to January 2005

Tricia Sloper, Veronica Greco, Rosemary Webb, Jennifer Beecham

Evidence indicates that families with disabled children report difficulties in negotiating access to services through the different agencies, and understanding the responsibilities of the different professionals. Parents express the need for a single point of contact with services by means of a key worker. Previous research has shown that, in general, families with a key worker service are likely to have better outcomes than families without.

This study aimed to compare the implementation and operation of different models of key worker services, in relation to outcomes for families and costs of the services.

The study had three stages:

- A UK-wide survey, to determine which areas had key worker services, and details of the service models
- Seven areas with differing models of key worker services were identified for further investigation in case studies, and interviews were carried out with 87 managers and staff in each of the services
- Investigation of the effectiveness of the services in providing co-ordinated care and in meeting families' needs, through questionnaires completed by 205 parents and 30 children who received the services and interviews with a sub-sample of 68 parents and nine children.

Findings from the study have been published in the Department for Education and Skills research reports.

Publications

Greco, V. and Sloper, P. (2004) Care co-ordination and key worker schemes for

disabled children: results of a UK wide survey, *Child: Care, Health and Development*, 30, 1: 13-20

Greco, V., Sloper, P. and Barton, K. (2004) Care co-ordination and key worker services for disabled children in the UK, *Research Works*, 2004-01, Social Policy Research Unit, University of York, York

Greco, V., Sloper, P., Webb, R. and Beecham, J. (2005) *An Exploration of Different Models of Key Worker Services for Disabled Children: Effectiveness and Costs*, Department for Education & Skills, Research Report 656, DfES Publications, Sheffield

Greco, V., Sloper, P., Webb, R. and Beecham, J. (2005) *An Exploration of Different Models of Key Worker Services for Disabled Children: Effectiveness and Costs*, SDepartment for Education & Skills, Research Brief RB 656, DfES Publications, Sheffield

Sloper, P., Greco, V., Beecham, J. and Webb, R. (2006) Key worker services for disabled children: what characteristics of services lead to better outcomes for children and families?, *Child: Care, Health and Development*, 32, 2, 147-157

Children, young people's and parents' access to and use of Patient Advice and Liaison Services (PALS)

On-going project

Community Fund and Department of Health, in conjunction with Carnegie Young People Initiative (CYPI)

January 2003 to March 2006

Janet Heaton and Patricia Sloper

In the project we are examining the extent to which NHS Patient Advice and Liaison Services (PALS) have enabled children, young people and parents to access and use this service, which provides information and advice to people of all ages on healthcare issues. This multi-stage project has so far involved: a national survey of all PALS in acute trusts, primary care trusts and children's hospitals across England; discussion groups and interviews with children, young people and parents, who have experience of using health services, to establish their views on emerging models of PALS; a survey of parents and young people who have used PALS; and telephone interviews with PALS advisers. Young people and parents have contributed to the design of the research and the project as a whole has benefited from the advice of a steering group composed of young people, practitioners, policy makers, and researchers interested in the study and its implications.

Publications

Heaton, J. and Sloper, P. (2004) National Survey of Patient Advice and Liaison Services (PALS) in England: Children, young people and parents' access to and use of PALS, *Child: Care, Health and Development*, 30, 5, 495-501

Heaton, J. and Sloper, P. (2003) Access to and use of Patient Advice and Liaison Services (PALS) by children, young people and parents – a national survey, *Research Works*, 2003-04, Social Policy Research Unit, University of York, York

Participation of disabled children and young people under Quality Protects

Completed project

Department for Education and Skills Quality Protects Research Initiative

April 2003 to Oct 2005

Anita Franklin and Tricia Sloper

Developing children's participation is a key component of the Quality Protects programme. This reflects the growing importance attached to involving young service users in decisions about their own care and/or wider service planning. However, while in general children are increasingly involved in decision-making, growth is slower for involving disabled children. Consequently there is little evidence about the specific factors which could promote disabled children's participation, or about the impact of disabled children's participation on service planning and/or individual care packages. This research seeks to address these gaps.

The project focused on four groups of disabled children who have been identified by service providers as being especially 'difficult to reach': children with complex health needs; autistic spectrum disorders; communication impairments; or degenerative conditions.

The aims were to:
- identify participation work which includes disabled children
- establish factors which can support and promote disabled children's effective participation.

The research had three stages:
In stage one, Year 4 QP Management Action Plans (MAPs) were analysed to identify participation work with disabled children and provide a summary of the range and types of participation.

Stage two was a survey of all Social Services Departments in England to identify and describe current work concerning disabled children's participation in decisions on their own care and in service development.

Stage three was qualitative research with children (using verbal and non-verbal methods to facilitate communication), parents and staff in a sample of seven local authorities to find out 'what works' in respect of the processes and outcomes of disabled children's participation.

Publications

Franklin, A. and Sloper, P. (2004) 'Participation of disabled children and young people in decision-making within social services departments in England', *Research Works*, 2004-02, Social Policy Research Unit, University of York, York

Franklin, A. and Sloper, P. (2004) *Participation of Disabled Children and Young People in Decision-making Within Social Services Departments in England*, Social Policy Research Unit, University of York, York

Franklin, A. and Sloper, P. (2005) Listening and responding? Children's participation in health care within England, *International Journal of Children's Rights*, 13, 11-29

Franklin, A. and Sloper, P. (2005) Participation of disabled children and young people in decision-making within social services departments: A survey of current and recent activities in England, *British Journal of Social Work*, doi: 10.1093/bjsw/bch306

Evaluating the Integrated Children's System: specific study in relation to children with a disability

On-going project

Department for Education and Skills and the National Assembly for Wales

October 2004 to February 2006

Wendy Mitchell and Tricia Sloper

The Integrated Children's System (ICS), as part of a wider Government programme to re-shape local services for children and their families, especially children in need, aims to redress some of the problems in previous recording systems and connect with other systems currently being implemented. However, there are many questions surrounding how the ICS will work with, and its relevance to, different groups of children. This project (part of a broader evaluation of ICS) will explore implementation outcomes for disabled children and their families.

Key aims of the project are:

- To examine the application and use of ICS for disabled children and their families, in particular, parents, children's and practitioners' views and experiences of information gathering, participation within and outcomes of the process
- To compare parents and disabled children's own understanding of the information they are given and services they expect to receive with the actual information recorded in the ICS system and the services received.

The study will draw upon a purposive sample of disabled children and their families from four pilot sites (two English local authorities and two Welsh local authorities). The sample will encompass a range of ages, impairments and children at different stages of the assessment process.

Individual interviews will be conducted with approximately 20 parents and at least 10 children (aged 10 years plus). The children's interviews will draw upon a variety of verbal and non-verbal methods. Individual telephone interviews will also be conducted with social workers working with the disabled children in the sample. These telephone interviews will explore social workers' views on the application and suitability of ICS for disabled children and their families.

A qualitative study of the experiences of teenagers and young adults when faced with possible or actual fertility impairment following cancer treatment

On-going project

Candlelighters

June 2003 to May 2006

Marilyn Crawshaw (Dept of Social Work), Tricia Sloper (SPRU), Adam Glaser (St James's University Hospital Leeds), Juliet Hale (Institute of Child Health, Newcastle), Bernadette Brennan (Royal Manchester Children's Hospital)

Treatment for cancer can lead to fertility impairment. The effects of this on a young person's emotional and sexual health, identity and well-being, and on their relationships are not known. Neither is it known what effect the experience of coping with potential or actual impairment has on young people as they enter adulthood and are faced with related decisions, including whether and when to have their fertility status tested (where appropriate) and, if they are contemplating parenthood at some stage, whether to opt for assisted conception treatment (where appropriate) or adoption or another route. As growing numbers of young people survive treatment for cancer, and as advances in fertility preservation open up new possibilities for future treatments, it is crucial that more information is gathered about the experiences of patients themselves.

The aim of this study is to identify the needs for services that teenagers and young adults have in relation to this aspect of their cancer experience. This will inform staff involved with these patients and those responsible for planning and commissioning cancer services, fertility impairment services and other services as appropriate.

The study involves:

- Interviews with up to 20 teenagers and 20 adults in their twenties (both males and females) diagnosed in their teens about the impact of possible or actual fertility impairment following treatment for cancer
- Multi-disciplinary focus groups with staff from paediatric oncology and assisted conception units to discuss professional experiences and the appropriate knowledge and skills base for this work across age groups.

The study will also develop written materials for patients and their parents, where appropriate.

Evaluation of Big Lottery Cardiac Rehabilitation programme

On-going project

Big Lottery Fund (BLF), in conjunction with British Heart Foundation (BHF)

July 2004 to June 2008

Janet Heaton (SPRU) with Prof Bob Lewin and Corinna Petra (Dept of Health Sciences, University of York)

The Big Lottery Fund has funded the Department of Health Sciences and the Social Policy Research Unit (SPRU) at the University of York to undertake an evaluation of cardiac rehabilitation schemes based in primary health care in England. The schemes were set up through the British Heart Foundation (BHF) with funding from the Big Lottery.

The Cardiac Rehabilitation Programme has two main aims:

- to increase the uptake of cardiac rehabilitation services, particularly among groups of people who currently make low use of existing services, and
- to drive sustainable improvements in the quality of services on offer to patients.

As part of its commitment to evaluate this and other programmes it funds, the Big Lottery has commissioned the research to examine to what extent the programme has met its overall aims and how far individual schemes have achieved their goals. This includes examination of how effective services have been at improving access, involving patients, impacting on outcomes, improving quality of life and addressing inequalities.

Various qualitative and quantitative methods will be used as part of the evaluation. These will include: a survey of the schemes, case studies of a selection of schemes (including interviews with staff, patients and carers), and quantitative analysis of audit data kept by the schemes.

Integrating Services for Disabled Children Consultancy Project

Completed project

City of York Children's Trust

October 2004 to May 2005

Sue Clarke, Bryony Beresford, Tricia Sloper

This piece of consultation was commissioned by the City of York Children's Trust. The aim of the consultation was to identify changes that can be made to improve the outcomes of disabled children, young people and their families in York. Parents, children and young people, and professionals from the statutory and voluntary sectors were involved in the consultation. Different methods were used to ensure the participation of all stakeholders including focus groups, questionnaires and individual interviews. Special tools were developed to facilitate accessing the views of disabled children and young people. The consultation report also included relevant key findings from reviews of evidence on 'what works' in services for disabled children, young people and their families.

Publication

Beresford, B., Clarke, S. and Sloper, P. (2005) *Integrating Services for Disabled Children, Young People and Their Families in York: Consultation project*, Social Policy Research Unit, University of York, York

The Community Care for Adults Team is led by Professor Caroline Glendinning. Research carried out within the team focuses on the individual and collective views and experiences of adults and older people coping with disability or chronic illness and their families. Much of the research currently carried out by team members forms part of the Department of Health funded research programme; over the past year other research has been funded by the Social Care Institute for Excellence, the Department of Work and Pensions and the NHS Health Technology Assessment Programme.

Although the primary focus of the Community Care for Adults Team's work is on their experiences and evaluations of public services, patterns of support are changing and there are increasing opportunities for individuals to receive publicly-funded support in the form of cash payments. This option has been explored in the comparative research into different countries' arrangements for funding long-term care; and it will form an important element of the choice options to be explored in the new DH programme to begin in 2006.

We are delighted to have had the opportunity during 2005 to work with the two other DH-funded social care research units (the Personal Social Services Research Unit at the Universities of Manchester, Kent and LSE and the Social Care Workforce Research Unit at King's College London) on preparations for the evaluation of the Individual Budget Pilot projects. The evaluation, funded by the DH, will formally begin during 2006.

Professor Caroline Glendinning

Community Care for Adults Team

DEPARTMENT OF HEALTH OUTCOMES PROGRAMME

Department of Health Outcomes Programme 2001-2005

Completed project

Following the successful scientific review of this programme in autumn 2004, the emphasis this year has been on completing the three main projects and pulling together some of the main issues and themes that the programme addressed.

The DH-funded Outcomes Programme aimed to:

- Identify the outcomes of receiving services that are valued and desired by different groups of service users
- Through development work with local service managers and front-line staff, devise outcomes-focused approaches to social care services that can be integrated into local contexts and practices.

Two of the three projects in the programme, on Outcomes for Disabled Service Users (see below) and Flexible Person-Centred Home Care for Older People (see below) came to an end during 2005. Work for these projects has focused on writing final reports and papers for academic and other publications. The final stages of the third project, on Priorities and Perceptions of Disabled Children and Young People and their Families Regarding Outcomes of Social Care, are described on page 18.

In addition, we have taken advantage of the opportunities offered by programme funding to pull together some of the work carried out under the programme. For example, during the course of the programme separate pieces of work have been carried out on the outcomes valued by carers of adults and disabled people, and disabled children and young people respectively. We are now comparing these outcomes to identify common and contrasting features and consider their relevance to the current policy contexts for adults and children's services. Another project, carried out jointly with the Social Care Institute for Excellence (see page 28), has examined the extent to which social services departments across England and Wales have developed outcomes-focused approaches to older people's services, the nature of these approaches and the barriers and opportunities that have been experienced. This project has shown that the *Outcomes into Practice Resource Pack* (2004) produced by SPRU as part of the Outcomes Programme has been very influential in effecting local change. However some significant organisational and policy barriers remain to be addressed, if the ambitions of the 2005 Green Paper on Adult Social Care Services to focus services on user outcomes are to be met.

Outcomes for Disabled Service Users

Completed project

Department of Health Outcomes Programme

January 2002 to May 2005

Jennifer Harris, Michele Foster,
Karen Jackson (Hannah Morgan)

Often disabled people of working age require support that is more flexible, or of a different type, than social services can offer. The aim of this project was to work with staff in two social services teams to introduce a focus on the outcomes that service users wanted to achieve into the routine assessment and review activities of these staff. The project then evaluated the processes of change and their impact on professionals. The study concluded that most professionals found the outcomes-focused approach to be useful and workable; service users valued it because they had more choice and control over the assessment process. However a focus on outcomes involved some professionals in helping users access services they were unfamiliar with, particularly in relation to education, training and employment. This suggests that an outcomes-focused approach may have training implications for some social services staff.

Publications

Harris, J., Foster, M., Jackson, K. and Morgan, H. (2005) *Outcomes for Disabled Service Users*, Social Policy Research Unit, University of York, York

Morgan, H. and Harris, J. (2005) Involving service users in research; barriers and challenges, in L. Lowes and I. Hulatt (eds)

Service Users' Involvement in Health and Social Care Research, Routledge, London

Foster, M., Harris, J., Jackson, K., Morgan, H. and Glendinning, C. (2006) Personalised social care for disabled adults: A problematic concept for frontline practice, *Health and Social Care in the Community*, 14, 2, 125-135

Flexible, person-centred home care for older people

Completed project

Department of Health Outcomes Programme

October 2001 to March 2005

Charles Patmore

This project aimed to identify the factors that enable home care services to help older people in a flexible, person-centred way.

Stage One of the project involved a review of recent research on home care and the delivery of individualised services.

Stage Two involved a series of in-depth telephone interviews with independent sector and social services in-house providers of home care services in 12 contrasting local authority districts.

Stage Three examined the factors affecting the commissioning and delivery of services from six of these providers. First, interviews were carried out with older people receiving services from these providers to identify examples of flexible, individualised home care services. Next, interviews were conducted with the front-line home care staff in the study providers; with their managers; and with care managers and senior commissioning managers in the local authority social services department. At each level, the interviews sought explanations of the factors that contributed to or inhibited the delivery of flexible, person-centred home care.

Publications

Patmore, C. and McNulty, A. (2005) *Making Home Care for Older People more Flexible and Person-Centred*, Social Policy Research Unit, University of York, York

Patmore, C. and McNulty, A. (2005) Flexible, person-centred home care for older people, *Research Works*, 2005-04, Social Policy Research Unit, University of York, York

Patmore, C. and McNulty, A. (2005) Power of the purchaser, *Community Care*, 6-12 October 2005

Patmore, C. and McNulty, A. (2005) That little bit extra, *Community Care*, 13-18 October 2005

Measuring and understanding social services outputs

Completed project

Department of Health Outcomes Programme

March 2004 to May 2005

Michael Hirst, Jennifer Harris and Caroline Glendinning (in collaboration with the Personal Social Services Research Unit, University of Kent)

The Office for National Statistics is conducting a review of the future development of government output, productivity and associated price indices. As part of this review, the Department of Health funded work to improve the measurement and understanding of personal social services (PSS) output and productivity. SPRU contributed to this work, which is led by PSSRU at the University of Kent, by examining PSS activity in relation to working age disabled people and informal carers. The first stage involved reviewing the literature and collating information on the outcomes valued by these groups of service users; the second stage identified the practical and conceptual challenges of measuring PSS outputs for carers of disabled and older people.

Three components of a welfare index being developed by PSSRU researchers to measure the outputs of PSS expenditure were examined: the quantity of PSS outputs delivered to carers; the extent to which carers rely on PSS to look after the person they are caring for and/or to sustain their caring roles; and carers' views about the quality of PSS provision. As well as recommending improvements to routinely collected data on carer assessments and services to carers, the review considered different approaches to assessing carers' capacity to benefit from PSS output and identified the criteria required to evaluate the quality of the support they receive.

Publications

Glendinning, C., Hirst, M. and Harris, J. (2005) *Understanding and Measuring Personal Social Services Outputs Relating to Disabled Adults and Carers*, Social Policy Research Unit, University of York, York

Hirst, M. (2005) *Measuring and understanding social services outputs in relation to carers*, Social Policy Research Unit, University of York, York

Netten, A., Hirst, M. and Glendinning, C. (2005) *Developing a measure of PSS outputs: interim report*, Discussion Paper 2234, Personal Social Services Research Unit, University of Kent, Canterbury

Carers' outcomes – knowledge synthesis

Completed project

Department of Health Outcomes Programme

August to December 2005

Veronica Greco, Hilary Arksey, Bryony Beresford, Tricia Sloper

Over the past ten years SPRU has conducted a number of studies into the outcomes of services valued by different groups of carers. This small project aimed to bring together the evidence on the outcomes valued by people caring for disabled adults and older people (typically their spouses or parents) and the outcomes valued by parents caring for disabled children and young people. Areas of similarity and difference were identified and the implications for current social care policy and practice discussed.

OTHER RESEARCH PROJECTS

Knowledge review on outcomes-focused services for older people and their carers

On-going project

Social Care Institute for Excellence (SCIE) and Department of Health Programme

April 2005 to February 2006

Caroline Glendinning, Inna Kotchetkova,
Jan Heaton, Sue Clarke,
and Liz Newbronner, Philippa Hare,
Jane Maddison (Acton Shapiro)

This knowledge review has three strands. First, a review was conducted of research evidence on the outcomes that older people and their carers value and aspire to achieve from their contacts with social care services; and on the development of outcomes-focused practice in social care, including the factors that facilitate or inhibit the commissioning, organisation and delivery of outcomes-focused services to older people and carers. Secondly, following extensive screening, a postal survey was conducted of all social services departments in England and Wales that were known to be developing outcomes-focused approaches to any aspect of their services for older people and carers. As well as revealing the extent and variety of approaches being developed, the postal survey also enabled us to identify six localities for in-depth case studies. This third

stage involves interviews with key managers, front-line staff and service users and carers.

The knowledge review will strengthen the evidence base on how to deliver outcomes-focused services for older people and carers. It will form the basis of practice guidance to be published by SCIE to support the implementation of proposals in the forthcoming health and social care White Paper.

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

On-going project

National Co-ordinating Centre for Health Technology Assessment

March 2005 to February 2006

Hilary Arksey and Caroline Glendinning (SPRU); Joy Adamson and Karen Spilsbury (Department of Health Sciences); Mike Drummond, Anne Mason, and Helen Weatherly (Centre for Health Economics); Su Golder (Centre for Reviews and Dissemination)

The last 40 years has seen an increasing proportion of older people in the UK population. Most disabled and elderly people live in the community; the care they receive is almost wholly provided by family, friends or neighbours. Providing informal care for frail older people can adversely affect carers' quality of life. Respite care is regarded as one of the key interventions to alleviate the stress of caring, and is a service that carers have identified as critical to their caring efforts. Paradoxically, respite and short-term breaks are known to have low utilisation rates. The aim of this study is to identify service models that provide effective and cost-effective breaks for frail older people and their carers. This will be achieved by systematic review of the national and international effectiveness and cost-effectiveness literature on community-based respite care for frail older people and their carers. Consumers are involved in the research through an 'Expert Reference Group', who are being consulted throughout the review. The Group will meet together for a one-day workshop, to help the researchers interpret the findings for policy and practice and explore the implications for further research.

Carers' aspirations and decisions around work and retirement

Completed project

Department for Work and Pensions

May 2004 to September 2005

Peter A Kemp, Caroline Glendinning, Hilary Arksey, Inna Kotchetkova and Rosemary Tozer

There are an estimated 6.8 million people in Britain looking after a relative or friend in need of support because of age or frailty, physical or learning disability or illness. The Government aims to support carers in their caring role, and enable them to continue care-giving for as long as that is their wish. However, many carers will be working when the need to care arises, and most wish to carry on working. Paid employment can be important for carers' well-being and can help protect against poverty in later life. This research aimed to determine what can be done to assist carers to remain in, or find, work, during or after an episode of caring, and to shed light on the main factors that influence carers' decisions about work, retirement and caring.

The first stage of the study was a review of literature published in the UK to identify existing evidence on carers' employment and retirement issues. This was followed by interviews with 80 carers with substantial caring responsibilities. Finally, focus groups were held with front-line professionals from Jobcentre Plus, social services departments and carers organisations who worked with carers to provide advice or support.

Publication

Arksey, H., Kemp, P., Glendinning, C., Kotchetkova, I. and Tozer, R. (2005) *Carers' Aspirations and Decisions around Work and Retirement*, Department for Work and Pensions Research Report No 290, Corporate Document Services, Leeds

Available from the following weblink: *http://www.york.ac.uk/inst/spru/pubs/ccatreps.htm*

Double discrimination? Gender and disability in access to the graduate labour market

On-going project

European Social Fund (Higher Education: Research into Gender Discrimination)

June 2005 to August 2006

Dr Gillian Pascall and Dr Nicola Hendey (School of Sociology and Social Policy, University of Nottingham), Professor Gillian Parker (Social Work Research and Development Unit, University of York), with Michael Hirst

Both government and disabled people see paid work as the best route out of poverty and social exclusion, yet disabled people are less likely than their non-disabled peers to take up or retain paid employment, and more likely to occupy poorly paid, low status jobs. Disabled women often fare worse than both disabled men and non-disabled women. Access to higher education can boost employment opportunities, sustain career development, and increase occupational choice. This project aims to understand how disabled women's experiences at university translate into good quality, sustainable, career opportunities in professional, managerial and senior official roles. It will identify their support needs, investigate the role of careers guidance and planning, and suggest practical strategies to enhance occupational success.

The study is predominantly qualitative, including group discussions and case studies of disabled women and men in their final university year and following graduation. The project is committed to using emancipatory methods and the topics explored will be largely determined by the participants themselves rather than the researchers. Existing literature and official statistics will also be reviewed to understand how disabled graduates currently fare in the labour market. SPRU will contribute a review and analysis of existing datasets, including administrative sources, for evidence of disabled graduates' labour market position and working patterns following graduation. Employment outcomes of disabled women and disabled men will be compared using both cross-sectional and longitudinal data.

Funding long-term care

On-going project

Unfunded

August 2003 onwards

Caroline Glendinning

This work originated with a project commissioned by the Joseph Rowntree Foundation and conducted in collaboration with the Personal Social Services Research Unit at LSE, to investigate the lessons that could be learned from other countries' approaches to the organisation and funding of long-term care for older people. The research culminated in a major international seminar organised by JRF and held in Edinburgh in April 2005, at which the results of the research were presented. The aim of the seminar was to prompt discussion and debate across the UK, particularly with the Wanless Review of social care funding under way.

Subsequent work has built on this foundation and has involved detailed comparisons of arrangements in the UK and Germany; further analyses of policy options for the UK; and evaluations of different approaches to paying family care-givers.

Publications

Glendinning, C. (forthcoming 2007) Developing a sustainable approach to funding long-term care in the UK, *Social Policy and Society*

Glendinning, C. and Igl, G. (forthcoming 2006) Long-term care, in C. Naegele and A. Walker (eds) *Social Policy in Ageing Societies: Britain and Germany Compared*, Palgrave Macmillan, Basingstoke

Keefe, J., Fancey, P. and Glendinning, C. (forthcoming) Compensating family members to provide care; policy approaches and debates, in A. Martin-Matthews and J. Phillips (eds) *Blurring the Boundaries: Ageing at the Intersection of Work and Home Life*, Laurence Erlbaum, Mahwah, NJ

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 and practice.

To achieve this, we write and disseminate research reports, summary findings and good practice guides. We regularly engage in academic debate via articles in peer-reviewed journals, chapters in academic books and by presenting our work at relevant conferences. We also arrange a series of public seminars on topical subjects with eminent external speakers.

SPRU invests heavily in the training of our research and support staff to help them achieve their full potential. As well as their research, our staff are engaged in many external activities, such as peer-reviewing articles for academic journals and contributing to 'Chatham House rules' seminars with policy makers. These activities enhance their role in the social policy community.

Unit Information

Research staff profiles

Hilary Arksey took forward her earlier research on carers and employment in a study exploring the factors that influenced carers' decisions about work, retirement and care-giving, work. This has particular significance in the light of the Carers (Equal Opportunities) Act 2004 which aims to enhance carers' opportunities in relation to training, education, work and leisure activities. Hilary was awarded one of the University's Anniversary Lectureships which enabled her to spend time writing about the roles and visibility of carers in current Government policies.

Bryony Beresford has been working on a number of projects over this year including research on defining outcomes for disabled children and their families and a piece of consultation work on services for disabled children living in York. Towards the end of the year she began work on a project which is evaluating a specialist mental health service for deaf children. All these projects are highly relevant in informing the way national bodies and local authorities respond to the priorities and actions outlined in the Every Child Matters, the Children's National Service Framework and the Strategy Unit's 'Life Chances for Disabled People' report. Bryony's on-going interests include developing methodologies for research with children and the issues and processes surrounding the implementation of research findings into practice.

Kate Baxter trained as a health economist and has worked most recently on evaluations of primary care-related health policy. She was based previously at the University of Bristol where her research included evaluations of total purchasing pilots and commissioning by primary care groups. In addition she has been involved in systematic reviews and economic evaluations of health care interventions, and a study of the costs and outcomes of non-infant adoptions. She has both qualitative and quantitative skills but concentrates on qualitative research. Since moving to SPRU in September 2005 Kate has been developing proposals within the DH-funded programme on choice and independence across the life-course. She has been concentrating in particular on: the longitudinal panel study which will explore how people exercise choice about social care and how this affects their independence; a scoping review to map the availability and accessibility of information about adult social care services; and a forthcoming study on responses by home care providers to increased user choice.

Jonathan Bradshaw has been Associate Director of SPRU since 1994 and is a member of the Social Security and Living Standards Team. He is Head of Department of Social Policy and Social Work at the University of York. His research interests include social security policy; family policy; poverty and living standards; comparative social policy; demography and social policy; well-being of children. Highlights of his year include being awarded the CBE for services to child poverty and the publication by Save the Children of the second biennial report of the Well-being of Children in the UK, which he edits. Currently his research includes child poverty in large families; welfare policy and employment in the context of family change; COST Action 19 Child Well-being; the multi-national project measuring and monitoring children's well-being and work on the area variations in the take-up of means tested benefits.

Sue Clarke has developed her interest in both quantitative and qualitative research during 2005, working on projects in social care and health. This includes a consultation project on improving services for disabled children and their families living in the City of York, and a project looking at outcomes-focused services for older people in England and Wales. Both projects tie into recent national policy developments, such as the Children Act and Children's National Service Framework, and the Green Paper on Adult Social Care. Based in the Children and Families Team, Sue is responsible with Bryony Beresford for organising and developing the team's user consultation groups of parents and young people.

Anne Corden's interests in qualitative methodology have continued this year, in her exploration of theoretical and practical issues in using verbatim quotations from research participants in reporting social research. In this area she also organised and presented at a London workshop about the analysis of data from longitudinal, qualitative social research. Anne has also continued working in a number of large, government-commissioned evaluations of labour market programmes for disabled people. Findings will be immediately relevant to the Government's commitment to 'welfare to work' and the proposed major changes to incapacity benefits. She has returned to some work in the area of low-income self-employment, a topic in which SPRU had a long programme of research during the 1990s.

Jacqueline Davidson joined SPRU in July 2005 and is currently working on all aspects of the issue of incapacity benefit and job rehabilitation. Her work looks at how people find themselves on incapacity benefits and evaluating projects to help new applicants for incapacity benefit get back to work. Jacqueline's research interests include comparative social policy; the understanding and perceptions of human need; and poverty, social security issues and the labour market.

Naomi Finch has skills and experience of both quantitative and qualitative data collection and analysis, but is mainly a quantitative researcher. She has undertaken research focusing on issues of poverty, living standards, employment and family policy. Naomi's work over the last year has focused on pensioner poverty. Her research has included quantitative analysis exploring which pensioners do not spend all of their income and why, a question with important implications for the government's strategy of tackling pensioner poverty. She has also undertaken a qualitative study with self-employed people about financial planning for retirement and working beyond state pension age. This is an important area of exploration given the ageing population and its implications for future pension provision. In addition to research surrounding pensioner poverty, in the last year Naomi has also undertaken comparative analysis using the Luxembourg Income Study on how different welfare states treat large families.

Anita Franklin has been able to combine her interest in the research of children and young people's participation with her current study examining the participation of disabled children and young people in decision-making within social services. This study identified specific factors which could promote disabled children's participation, and provide evidence on the impact of children's participation on service planning and/or tailoring individual care packages. Recent policy such as the National Service Framework (NSF) has given increased prominence to involving children and young people in decision-making, it is hoped that the findings from this study will contribute to current debates about how the participation of disabled children can be implemented effectively. Anita left SPRU at the end of the project, to return to London and is now working at the National Children's Bureau.

Caroline Glendinning had two main priorities in 2005: to pull together the results of the DH Outcomes programme; and to develop the new DH-funded programme beginning in 2006, on Choice and Independence across the Lifecourse. As part of the former priority she has examined the extent to which social services authorities in England and Wales are developing outcomes-focused approaches to their services for older people, and the factors that help and impede them in this process. An exciting opportunity arose during 2005 to collaborate with the other DH-funded social care research units in evaluating the pilot Individual Budget projects. As an alternative to direct payments, individual budgets are being piloted in 13 localities and the evaluation will be watched closely by Ministers. Caroline has also contributed to a DWP study on the employment decisions and aspirations of carers; and a HTA-funded review of respite services for older people, led by the Centre for Health Economics. Caroline has continued to make presentations and publish on comparative approaches to long-term care policy and funding. With Professor Peter Kemp, she helped organise the ‘Cash and Care’ conference held in York in April 2005 to commemorate Professor Sally Baldwin, and is subsequently working with Professor Kemp on an edited book on this topic. The book will be published by Policy Press in autumn 2006.

Veronica Greco’s current research comprises the evaluation of a national specialist mental health service for deaf children and young people. A main feature of this service is the use of videoconferencing, which is used both in direct clinical work and in the training and supervision of professionals who are providing the service. This research project uses both qualitative and quantitative methods and gathers an extensive amount of data from deaf children and young people who are users of the service, their parents and guardians, and the professionals who provide the service. The research comes at a time when attention is being focused on ensuring that the mental health needs of all children and young people are better met. Recent policy initiatives stipulate that all children should have equal access to timely, integrated, high quality mental health services, and that services for low incidence conditions must be co-ordinated on a regional or national basis. The research is important not only in terms of evaluating the specialist service per se, but may also be used to inform the future development of mental health services for other groups of children where specialist national or regional services are necessary.

Jennifer Harris led research within the Department of Health research programme on disabled adults of working age. The project developed and tested a goal-orientated approach to social services assessment and review with disabled people of working age and was successfully completed in 2005. In the summer Jennifer moved to Dundee University to take up the chair of social science there. Jennifer’s research interests are in the fields of cultural deafness, disability studies and qualitative research methods.

Janet Heaton has been involved in three projects this year. One is examining the extent to which NHS Patient Advice and Liaison Services (PALS) have enabled children, young people and parents to access and use this service, which provides information and advice to people of all ages on healthcare issues. She has also contributed to a project looking at outcomes-focused approaches in social care services for older people in England. She is also part of a team (with Health Sciences at the University of York) evaluating the Big Lottery Fund’s Cardiac Rehabilitation programme. These projects reflect her interest in improving access to services, and outcomes for service users and their families.

Michael Hirst has conducted research evaluating policy, the delivery of benefits and services, and outcomes as they affect disabled people and carers. He has considerable experience of quantitative research methods and the analysis of complex datasets. In 2005, Michael completed a scoping study of the practical and conceptual challenges of routinely measuring the contribution of personal social services to achieving the outcomes valued by unpaid carers. Latterly, he began work on a review and analysis of existing datasets for evidence of gender differences in disabled graduates' occupational outcomes following graduation.

Karen Jackson finished her work with Jennifer Harris and Michele Foster on the outcomes for disabled service users project this year. The project developed and tested a goal-orientated approach to social services assessment and review with disabled people of working age. Karen's interests are in service user involvement in the research process and systematic review methods. Karen left SPRU to travel in the Antipodes with her husband.

Annie Johnson joined SPRU's Social Security Team in September 2005, having previously worked for three years in education research, where her work included a focus on vulnerable children. She is currently working on a Joseph Rowntree Foundation funded project, looking at claimant perspectives on Housing Benefit payment methods. Its findings will contribute to a deeper understanding of the potential impacts and implications of the Government's proposed Local Housing Allowance. Primarily drawing on depth interviews, the project is enabling Annie to extend her interest and skills in qualitative methodologies. Annie is also undertaking a part-time MSc in social research methods and plans to explore issues around the housing aspirations of young adults as a dissertation topic.

Peter Kemp has a long-standing interest in the implementation of policy and the outcomes that result from it. Having spent many years studying housing policy, his research is now focused on social security, welfare reform, and welfare to work (especially in relation to hard-to-help groups). He also maintains his long-term research interest in housing benefit. During 2005 he completed a comparative study of trends in incapacity benefits, a study of carers' aspirations and decision-making about work and retirement, and a research project on pensioners' spending. His current research includes a qualitative study of housing benefit recipients. He is also editing a comparative book on housing benefit and co-editing another on cash and care. He moves to the University of Oxford in April 2006 to take up the Barnett Professorship of Social Policy.

Emese Mayhew's main interests are in the fields of child poverty, demography, gender inequality and comparative social policy. Her primary skills include using large-scale surveys and collecting and analysing cross-national data. In the context of the government's target to abolish child poverty by 2020, her most recent project concerned exploring poverty in large families in the UK, from both a historical and a comparative perspective. She also contributed to a project exploring poverty during pregnancy (in the UK) and how it affects health outcomes for both mother and child. Her latest comparative project focused on welfare policy and employment in the context of family change in five Nordic and three European countries. Emese compared the participation rates of various types of families with children in the labour markets of the participating countries. She was also a co-editor of the second edition of *The Well-being of Children in the UK* and contributed to several of the chapters in this volume.

Angela Meah has undertaken research focusing on issues relating to sickness and employment, and supported employment for disabled people funded by the DWP. As a qualitative researcher and a sociologist, she has experience of collecting and analysing data via focus groups and individual interviews and has experience of teaching focus group methodology. She worked on a project that examined claimants' routes onto Incapacity Benefit, one of the aims of which was to identify key transitions points at which current or future interventions may help people toward work or active job seeking. In the spring Angela moved to Manchester University's School of Nursing, Midwifery and Social Work.

Wendy Mitchell is currently completing a project for the Department for Education and Skills and the Welsh Assembly evaluating the pilot programme implementing the Integrated Children's System (ICS) in four local authority Social Service departments. Wendy's work examines the experiences of families with disabled children, via qualitative interviews with both parents and disabled children and the ideas of social workers, via telephone interviews. Wendy's past work has included a study for CLIC-Sargent examining the psycho-social care and support needs of children with cancer and their families. The results of this research were drawn upon by NICE to inform their recent guidance and the development of standards for children's cancer. Wendy's first work with SPRU was to develop a directory and website of services that families with disabled children valued and nominated as 'quality' services. This was done with the Community Fund, the Family Fund and Barnardos.

Katharine Nice has been using qualitative research methods to evaluate Government welfare to work initiatives for sick and disabled people. Her experience and interest in conducting qualitative longitudinal research for policy have developed through her work with service users. Her research on the Pathways to Work pilot, and in particular on people's experiences and views of work-focused interviews and packages of support, has helped to inform current debate about the reform of Incapacity Benefit. Evaluating the Pathways pilot also provided the opportunity to learn about the Condition Management Programme and the new ways of working between Jobcentre Plus and the NHS in rehabilitating people for work. Her interests in support for people who return to work have been enhanced by research on the new Return to Work Credit and the provision of specialist in-work support through Jobcentre Plus. Other work, for the evaluation of the Job Retention and Rehabilitation Pilot, explored provider staff perspectives on the effectiveness of their approaches to helping people retain their jobs.

Charles Patmore's interests are in ways of adjusting social care for older people to reflect individuals' values and aspirations, and ways of supporting morale and quality of life for older people who suffer disability or long-term illness. This year he completed his research project on factors which enable home care for older people to be flexible and person-centred. This was part of the Department of Health research programme. Charles left the Unit to become an independent consultant for community services for older people.

Parvaneh Rabiee is currently working on a research and development project exploring the views of disabled children and young people and their parents on their desired outcomes from Social care and support services. The development phase of the project focuses on developing ways of collecting outcomes information that can be used in practice. Her current project involves children who do not use speech to communicate and one of the main challenges of that project has been to develop a method that facilitated communication with these children and enabled them to participate in the project. Her earlier work in the Centre for Disability Studies at Leeds University included a project exploring disabled children and young people's experiences of leaving care and transition into adulthood, an evaluation of local pilot schemes for school inclusion and a project examining the representation of claims to social inclusion by older people's groups, from a critical disability studies perspective.

Dominic Richardson has skills and experience of quantitative analysis of large data sets, including analysis of comparative survey data. He is undertaking research focusing on issues of child well-being, educational attainment and benefits take-up. Dominic's research on take-up (funded by the Neighbourhood Renewal Unit) will involve analysis of a range of means-tested benefits to understand the area variations in entitled non-recipients. He is exploring the variation in take-up of these benefits through secondary analysis of the Family Resources Survey.

Roy Sainsbury's research interests include social security and the labour market, sickness and disability benefits, housing benefit, and the administration and delivery of benefits, in particular the appeals system and social security fraud. This year Roy has worked on all aspects of the issue of incapacity benefit and job rehabilitation. His work looks at how people find themselves on incapacity benefits; projects to help new applicants for incapacity benefit get back to work; how self-employed people make decision about pensions and the age at which they retire. All these are issues at the heart of recent government concern and action about the rising levels of incapacity benefit claimants and the pension problem. A separate strand of work explores the theoretical and practical issues around using verbatim quotations from research participants in reporting social research.

Tricia Sloper's research interests include the needs of children and young people with chronic illness or disability and their families; stress and coping in children, young people and families affected by illness or disability; developing methods for research with children; and the implementation of research findings in practice. Tricia's background is in psychology and she has long-standing interests in the application of knowledge from developmental and social psychology to issues affecting the lives of disabled children and their families. Current work includes studies of: the effectiveness of different models of key workers for families with disabled children; the outcomes disabled children and their parents aspire to achieve through provision of support services and how these relate to the government's *Every Child Matters* outcomes; disabled children's participation in decisions that affect the services they receive; children and young people's use of Patient Advice and Liaison Services; and evaluation of the implementation of the Integrated Children's System .

Patricia Thornton's research continued in the highly topical policy area of how to support the employment of people on sick leave at risk of leaving employment. Patricia's work on the New Deal for Disabled People and WORKSTEP concluded this year. Patricia left SPRU in the summer, after 18 years with the Unit, to go to Papua New Guinea to work on a project for Voluntary Services Overseas. She is involved in piloting a survey of disabled people in the Highlands region which in turn will become a foundation for a national survey.

CCNUK Staff

Katy Barton's background is in social work with over 25 years experience as a manager and practitioner in both the statutory and voluntary sector. Her interests are in disabled children and their families and her work over the last five years has been a development role to set up an umbrella organisation, Care Co-ordination Network UK, that promotes key working for disabled children and their families.

Caz Byrne is the project administrator for CCNUK and is responsible for the finances, database, website and other administrative work to support the network.

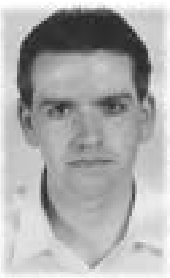
Support staff profiles

Alison McKay is personal assistant to Peter Kemp and Caroline Glendinning and provides secretarial and administrative support to the Main Office. She is responsible for administration of the Senior Management Group and the administration of the Foundation for International Studies on Social Security (FISS) conference that is held annually.

Ruth Dowling is the information assistant in the Publications and Information Office. She deals with publications administration and distribution.

Teresa Frank is personal assistant to Patricia Sloper and provides secretarial and administrative support to the Children and Families Team.

Lisa Goode has moved on to pursue a career as a translator but still works part-time at SPRU providing administrative help to the Main Office whilst she does her MA.



Simon Johnson is the Unit's Finance Officer. He is responsible for the administration of the Unit's general finances and research grants.

Rachel Pitman is the Information Officer at SPRU. Her role includes maintaining the website and publicising the Unit's work. She also works in the Alcuin Research Resource Centre Library and Archive Service.

Sally Pulleyn is personal assistant to Roy Sainsbury and provides secretarial and administrative support to the Social Security and Living Standards Team and the Community Care for Adults Team. Sally is Senior Secretary and is responsible for the overall management of the secretarial staff.

Jeanette Whalley is the Unit Administrator and is responsible for the Unit's finance and personnel issues.

Julie Williams provides statistical assistance with general survey and data analysis, including secondary analysis of large data sets such as the Expenditure and Food Survey. She is involved in the design and development of databases used within SPRU and in supporting computer users.

Staff training and development

SPRU is committed to developing the skills and expertise of its staff as part of a broader contribution to sustaining research capacity in social policy and social care. A real demonstration of this commitment is our ring-fenced budget for staff training. All staff in the Unit, from support staff to professors, can apply for funding. Training needs are an important topic during annual Performance Review discussions and are often discussed between staff and supervisors at other times during the year, especially at the start of new projects.

Courses attended over the past year include training in statistical techniques; courses on survey design and interviewing; and training in communication and supervisory skills. The training budget is also used to fund attendance at specialist conferences and workshops on specific research topics – these can be very useful in helping researchers 'get up to speed' with important issues at the start of a new project, or in establishing contact with wider research networks. In addition, we have organised two training courses ourselves, buying in specialist trainers. These courses, on managing and supervising people and on presentation skills, were attended by all relevant staff in the Unit.

We were pleased that our investment in staff development was recognised this year as two members of staff, Dr Hilary Arksey and Anne Corden, were promoted to Grade 3. In addition, Dr Arksey was awarded a prestigious and highly competitive University of York 40th Anniversary Lectureship. This University funding has enabled her to spend three months synthesising findings from previous research projects into academic journal papers.

Peer reviewing

Adoption and Fostering

Archives of Disease in Childhood

Benefits

British Journal of Psychology

British Medical Journal

Child and Adolescent Mental Health

Child: Care, Health and Development

Childhood

Children and Society

European Journal of Housing Policy

Health & Social Care in the Community

Health Policy

Housing Studies

International Journal of Integrated Care

International Journal of Social Methodology

Journal of European Social Policy

Journal of Social Policy

Population Trends

Psycho-Oncology

Qualitative Social Work: research and practice

Social Policy and Society

Social Policy and Administration

Urban Studies

Member of editorial boards

Caroline Glendinning
Social Policy and Society
Social Policy and Administration
Health Policy
The Policy Press

Roy Sainsbury
Journal of Social Security Law
Benefits

Patricia Sloper
Child: Care, Health and Development

Jonathan Bradshaw
International Social Security Review

Hilary Arksey
Journal of Social Policy

Naomi Finch
Social Policy and Society

Advisory roles and external activities

Jonathan Bradshaw
Advisor to the House of Commons Work and Pensions Committee

UK Expert on the European Union National Action Plans for Social Inclusion

Member of the Department for Work and Pensions Technical Committee on the measurement of child poverty

Member of the Department for Work and Pensions Child Poverty Stakeholders Forum

Member of the Joseph Rowntree Foundation Technical group on the Strategy to abolish Child Poverty

Member of the Foundation for International Studies on Social Security Board

Chair of the Management Committee of the Welfare Benefits Unit (York)

Member of the Family Law Advisory Group (York)

Anne Corden
Committee Member of the Bereavement Research Forum

Joint Organiser of a Workshop on Qualitative Longitudinal Analysis for Policy Research

Caroline Glendinning
Member of Advisory Groups for:
- Health and Social Care Advisory Service 'Evaluation of the Impact of the Modernisation of Social Care on the Development of Direct Payment schemes'

- Nuffield Community Care Studies Unit, University of Leicester ‘Impact of the Health Act flexibilities on Partnership Working and Outcomes for Frail Older People’

Member of Joseph Rowntree Foundation ‘Independent Living’ Single Programme Committee

External Examiner, Health and Social Care MSc Course, City University

Member of Executive Committee, Research Committee 11 Sociology of Ageing, International Sociological Association

Member of ESRC Research Evaluation Committtee

Member of Executive Committee, Eurocarers EU Network to promote policy and research on carers

Member of University of York Research Committee

Advisor, Help the Hospices Research Programme on Carers

PhD Supervisor, University of Manchester

Referee for research proposals for the Department of Health and the Economic and Social Research Council

Jan Heaton

Member of research advisory group for the project: ‘An exploration of children’s and young people’s experiences of being dependent on medical technology’, University of Manchester

Michael Hirst

Member of the Stakeholder Steering Group for *Care 21: The Future of Unpaid Care in Scotland*, commissioned by the Social Work Services Policy Division of the Scottish Executive

Member of the Board of Trustees, Carers UK

Peter Kemp

Department for Work and Pensions’ Housing Benefit Reform Programme Board

Joseph Rowntree Foundation Housing Benefit Reform Forum

Roy Sainsbury

Invited consultant to Margaret Hodge MP, Minister of State, Department for Work and Pensions, on reform of incapacity benefits

Refereed for research proposals for the Economic and Social Research Council, and the Nuffield Foundation

Member of Advisory Board for the Evaluation of the New Opportunities in PE and Sport Initiative (NOPES), Loughborough University

Patricia Sloper

Member of the National Children’s Bureau ‘Meeting Medical Needs in Education’ Project Advisory Group

Member of National Association for Colitis and Crohn’s Disease (NACC) Social, Psychological and Health Services Research Awards Committee

Member of York NHS Local Research Ethics Committee

Research Advisor to Care Co-ordination Network UK

Member of the York Children’s Trust Board (representing University of York)

External examiner for PhD thesis, Monash University, Australia

External examiner for DClinPsych thesis, University of Essex

External supervisor for PhD, University of East London

SPRU seminars 2005

Tuesday 18 January 2005
‘Social Expenditure in the 1990s: Data and Determinants’
Professor Frank Castles, Department of Social Policy, University of Edinburgh

Tuesday 8 February 2005
‘Supporting Parenting in Poor Neighbourhoods: Policy and Practice for Improving Access and Effectiveness of Family Support Services’
Dr Deborah Ghate, Co-Director, Policy Research Bureau, London

Tuesday 8 March 2005
‘The Impact of Institutional Racism in Social Work Practice with Black Children and their Families: with specific reference to the Victoria Climbie Case’
Ratna Dutt, Director, Race Equality Unit, London

Tuesday 22 March 2005
‘Involving Children and Young People Living with and Affected by HIV in Policy and Practice Development’
Magda Conway, Co-ordinator of the Children’s and Young People’s HIV Network, National Children’s Bureau, London

Tuesday 5 April 2005
‘Ethnicity and Families with a Person with Learning Disabilities’
Professor Christopher Hatton, Research Director, Institute for Health Research, University of Lancaster

Tuesday 3 May 2005
‘Well-being in Later Life: The Impact of Inequality Over the Life Course’
Mary Godfrey, Senior Research Fellow, Nuffield Institute for Health, University of Leeds

Tuesday 7 June 2005
‘Where Have All the Old Men Gone? Invisible Men in Day Centre Provision: Policy Implications for the Twenty-First Century’
Dr Kate Davidson, Department of Sociology, University of Surrey

Tuesday 5 July 2005
‘Voices Behind the Statistics: Young People’s Views on Sectarianism in Northern Ireland’
Dr Shirley Ewart, Lecturer in Social Work, School of Sociology and Applied Social Studies, University of Ulster

Tuesday 6 September 2005
‘Disabled Children: Inequalities in Access’
Christine Lenehan, Director, Council for Disabled Children, London

Tuesday 18 October 2005
‘Ethnicity and Families with a Person with Learning Disabilities’
Professor Christopher Hatton, Research Director, Institute for Health Research, University of Lancaster

Tuesday 1 November 2005
‘The Affluence Epidemic: Poverty and Wealth in Britain?’
Professor Daniel Dorling, Department of Geography, University of Sheffield

Tuesday 6 December 2005
‘Converting the Sceptics: The Premises and Boundaries of ‘Engaged’ Social Research’
Dr Colin Clark, Department of Sociology and Social Policy, University of Newcastle

Publications in 2005

Articles in academic journals 2005

Access to health care for people with learning disabilities in the UK: mapping the issues and reviewing the evidence
Alborz, A., McNally, R. and Glendinning, C.
Journal of Health Services Research and Policy, 10, 3, 173-82

Unpaid carers' access to and use of primary care services
Arksey, H. and Hirst, M.
Primary Health Care Research and Development, 6, 2, 101-16

Scoping studies: towards a methodological framework
Arksey, H. and O'Malley, L.
International Journal of Social Research Methodology, 8, 1, 19-32

Deprivation and variations in teenage conceptions and abortions in England
Bradshaw, J., Finch, N. and Miles, J. N. V.
Journal of Family Planning and Reproductive Health Care, 31, 1, 15-19

Is child poverty higher in Wales?
Bradshaw, J. and Mayhew, E.
Wales Journal of Law and Policy, 4, 1, 112-21

Using a model of group psychotherapy to support social research on sensitive topics
Corden, A., Sainsbury, R., Sloper, P. and Ward, B.
International Journal of Social Research Methodology, 8, 2, 151-60

Dependence, independence or inter-dependence? Revisiting the concepts of 'care' and 'dependency'
Fine, M. and Glendinning, C.
Ageing & Society, 25, 4, 601-21

Listening and responding? Children's participation in health care within England
Franklin, A. and Sloper, P.
International Journal of Children's Rights, 13, 1/2, 11-29

Partnerships between health and social care under 'New Labour': smoke without fire? A review of policy and evidence
Glendinning, C., Dowling, B. and Powell, M.
Evidence & Policy, 1, 3, 365-81

Under strain? Exploring the troubled relationship between health and social care
Glendinning, C., Hudson, B. and Means, R.
Public Money and Management, 25, 4, 245-51

Families' experiences of caring for technology-dependent children: a temporal perspective
Heaton, J., Noyes, J., Sloper, P. and Shah, R.
Health and Social Care in the Community, 13, 5, 441-50

Asian carers' perceptions of care assessment and support in the community
Hepworth, D.
British Journal of Social Work, 35, 3, 337-53

Carer distress: a prospective, population-based study
Hirst, M.
Social Science and Medicine, 61, 2005, 697-708

Disabled people in public sector employment, 1998 to 2004
Hirst, M. and Thornton, P.
Labour Market Trends, 133, 5, 189-99

Using pooled budgets to integrate health and welfare services: a comparison of experiments in England and Sweden
Hultberg, E., Glendinning, C., Allebeck, P. and Lonnroth, K.
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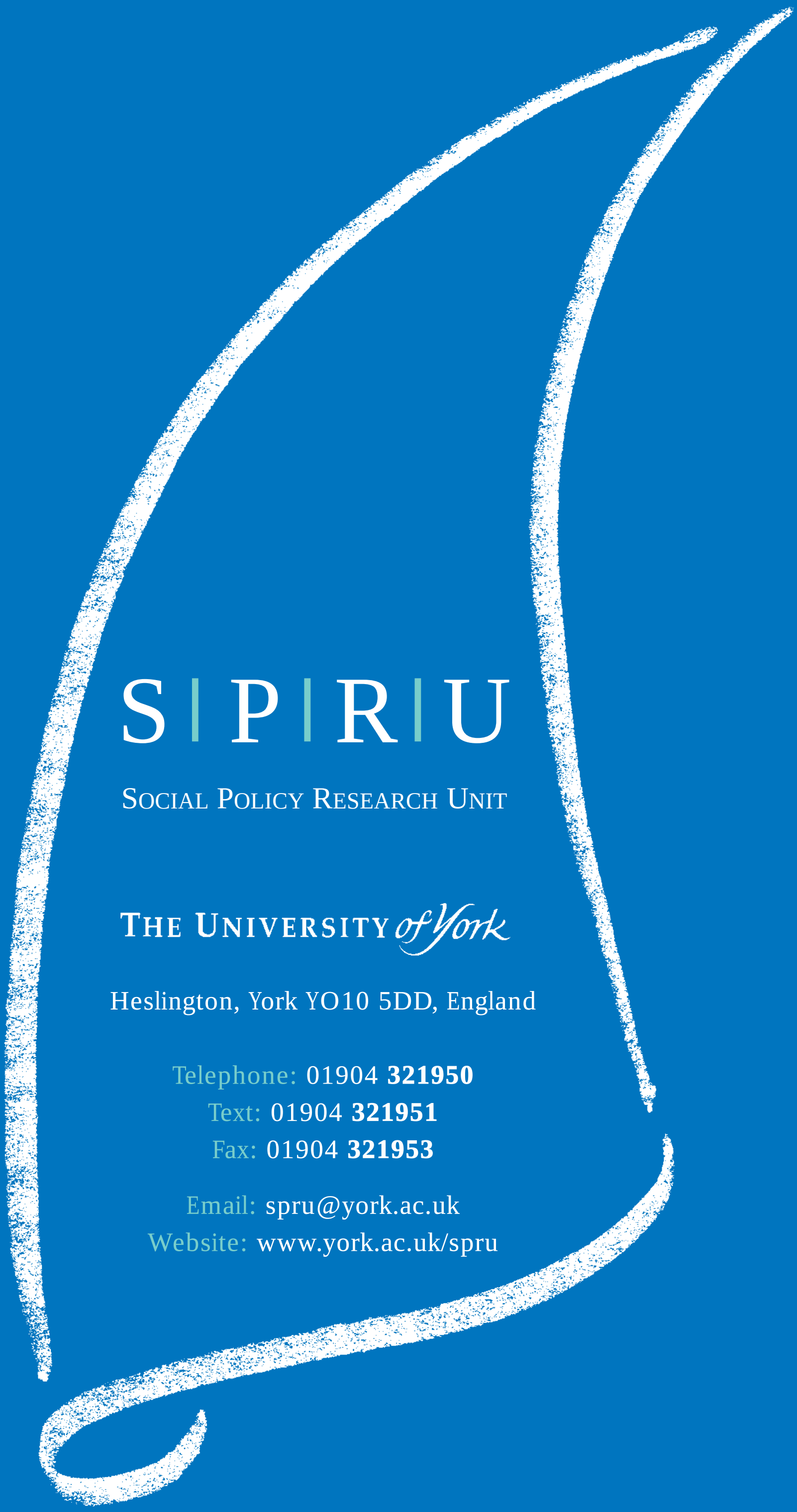

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