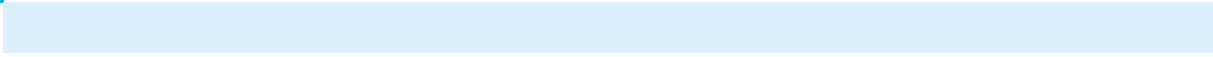


C O N T E N T S

INTRODUCTION BY THE DIRECTOR		3
COMMUNITY CARE FOR ADULTS TEAM	<i>Introduction by Professor Caroline Glendinning</i>	5
	<i>Research projects</i>	7
CHILDREN AND FAMILIES TEAM	<i>Introduction by Professor Patricia Sloper</i>	17
	<i>Research projects</i>	19
SOCIAL SECURITY AND LIVING STANDARDS TEAM	<i>Introduction by Dr Roy Sainsbury</i>	25
	<i>Research projects</i>	27
PUBLICATIONS APRIL 2002 TO DECEMBER 2003	<i>Articles in academic journals</i>	41
	<i>Articles in professional journals</i>	42
	<i>Reports and books</i>	43
	<i>Chapters in books</i>	44
	<i>Research summaries</i>	45
UNIT STAFF AND PROFILES		46



Welcome to the latest annual report of the Social Policy Research Unit (SPRU). It documents our research and publications for the period from April 2002 to December 2003. This is of course a longer period than 12 months, but we are in the process of moving from a financial to a calendar year for the report.



*Professor
Peter Kemp*

SPRU is an autonomous research centre based within the Department of Social Policy and Social Work at the University of York. It is also a constituent member of the Institute for Research in the Social Sciences (IRISS), a constellation of five health and social policy research units within the University.

Our research is particularly focused on people who are made vulnerable by poverty, unemployment, disability, chronic illness or ageing. We aim to undertake research that:

- influences policy and practice and thereby helps to improve the lives of people who are vulnerable physically or materially;
- is methodologically rigorous and ethically sound;
- reports the views and experiences of service users, including those who have often been neglected in research, such as people with communication difficulties;
- recognises that people's lives cannot easily be divided up into neat segments that reflect professional or organisation boundaries.

These principles mean that our research is more relevant now than it has ever been, as there is an increasing acceptance among policy makers of the need for evidence-informed policy, of the case for involving service users, and of the importance of 'joined-up' policy and practice.

Research within the Unit is organised around three research teams, each of which is led by a senior member of staff:

1. Community Care for Adults

(led by Professor Caroline Glendinning)

2. Children and Families

(led by Professor Tricia Sloper)

3. Social Security and Living Standards

(led by Dr Roy Sainsbury)

The main highlights of the work of each of the research teams are set out in successive sections of the report.

The three research teams provide a flexible structure within which to organise and manage our research. However, they are not 'silos' and we also undertake projects that involve staff from more than one team. A prime example of the latter is our Department of Health-funded programme of research on the outcomes and quality of social care, which involves researchers from both the Adults and the Children and Families teams. Similarly, a recently awarded project, funded by the Department for Work and Pensions, involves members of both the Social Security and Adults teams researching into carers' aspirations and decision-making around work and retirement.

Our research income has increased in recent years and is now about £1.5 million per annum. During the period covered by this annual report we received funding from a wide range of organisations. These included the Department of Health, the Department for Work and Pensions, the Economic and Social Research Council, HM Treasury, the Inland Revenue, the Joseph Rowntree Foundation and the Community Fund. We are grateful to them for their support.



INTRODUCTION BY THE DIRECTOR

It is usual in annual reports to highlight major achievements and successes and this report is no exception. However, one very sad event during the year was the tragic death of Professor Sally Baldwin in an accident in Rome in October 2003. Sally worked in the Unit for 30 years and was its Director from 1987 to 2002. She was an excellent colleague and a wonderful friend, and will be greatly missed by those who knew her. We have plans to remember Sally in a variety of ways, including a memorial conference on the theme of 'cash and care' to be held at the University of York in April 2005, sponsored by the Department of Health. We are also hoping to find funds for a Sally Baldwin research studentship.

There were inevitably a number of staff changes during the period covered by this report. I would especially like to thank two long-standing members of staff who have recently left SPRU. Catherine Duncan, the Unit Administrator since 1988, moved to the Department of Music in August 2003. She was succeeded by Jeanette Whalley. Professor Hazel Qureshi, who led our Department of Health-funded programme of work on the outcomes of social care, took early retirement in December 2003. In her place, we welcomed back Professor Caroline Glendinning.

I would like to finish by thanking the Support Staff team in SPRU for their dedicated and highly professional contribution to the work of the Unit.

COMMUNITY CARE FOR ADULTS TEAM

Introduction by Professor Caroline Glendinning

The team has maintained its focus on service user and carer experiences and perspectives, as well as its commitment to ensuring that insights from research continue to inform policy and practice.

The period covered by this annual report has seen the completion of a stream of work, funded by the Department of Health, dedicated to ensuring that the findings of previous research on the outcomes of social care are translated into useable tools for organisational activity and individual practice.

Collaboration with a network of agencies interested in incorporating an outcome focus into their practices culminated in the production of a Resource Pack designed to support managers and trainers. This draws together the conceptual frameworks, principles for practice, and change management issues that had emerged from our previous research. The Pack was launched at a conference in London organised jointly with *The Guardian* newspaper, with a speech by Stephen Ladyman, the Parliamentary Under-Secretary of State for Community Care. The conference was chaired by Bill Kilgallon, the Chief Executive of the Social Care Institute for Excellence (SCIE).

Members of the Adults Team working on outcome-related projects also contributed plenary papers and workshops to a conference in Leeds to mark the completion of the Outcomes of Social Care for Adults (OSCA) research initiative funded by the Department of Health. We also helped organise an international conference on disability at the University of Lancaster, at which the UK Disability Studies Association was launched. Jennifer Harris presented one of the plenary papers. In addition, papers were presented at international conferences in Washington DC, Orlando, and Jyvaskyla.



*Professor
Caroline
Glendinning*

Meanwhile, Department of Health funded work on person-centred home care and on the introduction of an outcome focus in care management with disabled people of working age, has been progressing steadily throughout the period covered by this report.

A stream of work on carers has included several literature reviews funded by the NHS Service Delivery and Organisation R&D Programme, as well as longitudinal analysis of the British Household Panel Survey data funded by the Department of Health.

Team members have contributed to policy development in respect of the guidance on Fair Access to Care, the Single Assessment Process, General Principles of Assessment, the Performance Assessment Framework and the Social Care Research Governance Framework. Team members have also responded to proposals for changing social work education and through participation in Department of Health working groups.

The focus of Team activities during 2004 will be on consolidating knowledge derived from the various strands of research undertaken with SPRU's Department of Health funded programme (which includes research being conducted by the Children and Families Team). We will also be developing a new programme of research that builds on past achievements and current areas of expertise. In addition, we will continue to seek opportunities to secure additional, project-based research funding that draws on our range of expertise and skills, to complement the research funded by our Department of Health programme grant.

There were several changes in the team during this period. Elinor Nicholas' contract came to an end in



COMMUNITY CARE FOR ADULTS TEAM

December 2003. Hazel Qureshi took early retirement in order to pursue other interests and was replaced as Team Leader by Caroline Glendinning who returned to SPRU after a long period at the University of Manchester. Karen Jackson switched from being the Director's PA to research fellow.

Team members during the period covered by this annual report were Hilary Arksey, Jennifer Harris, Michael Hirst, Karen Jackson, Alison McNulty, Hannah Morgen, Charles Patmore and Hazel Qureshi. Administrative and secretarial support was provided by Sarah Starkey and Gill Gibbeson.



WORK FUNDED BY THE DEPARTMENT OF HEALTH

Outcomes into Practice Resource Pack and Network

Completed Project

*Department of Health Programme Grant
January 2001 to December 2003
Elinor Nicholas, Hazel Qureshi and Claire Bamford*

This stream of work developed from SPRU's earlier programme of work on the Outcomes of Social Care (1996-2000). The project had two, interrelated elements:

- the production of a practical Resource Pack that translates research evidence into guidance for outcome-focused practice and associated tools for training and development;
- the creation, co-ordination and support of an 'Outcomes into Practice' Network.

The Resource Pack was based on the findings of the 1996-2000 DH research programme, which had highlighted the conceptual and practical difficulties, as well as the value, of introducing outcome-focused practice into care management and associated evaluation activities (for example, surveys of users' and carers' views). As well as presenting these findings, the Pack was informed by the experience gained from SPRU's previous five researched development projects and by evidence from the broader literature on change management. The Pack aimed to promote an integrated approach to tackling the complexities of change, by encouraging would-be 'change agents' to engage with a range of stakeholders (managers, practitioners, users and carers); and to explore with them outcome ideas in ways that are meaningful and that connect with their perceived priorities and goals for service development. Our earlier research also suggested that the impact of the Resource Pack would be greatly enhanced if its content and design reflected current priorities and preferred styles of learning; and

also acknowledged the real constraints on the potential users of the Pack. The production of the Resource Pack was therefore a collaborative process, in which stakeholders (managers and trainers working in health and social care settings) played an active role in shaping ideas, commenting on drafts, testing materials, and contributing their own materials. This collaboration took place through the Outcomes into Practice Network organised by the Unit.

The Outcomes into Practice Network was established in 2001 with participants who had expressed interest following SPRU's first national conference on outcomes, held in November 2000. Although the main focus of the Network's activities was the production of the Resource Pack, the Network has also provided a forum for continued exchange and learning between researchers and practitioners interested in implementing outcome-focused practice. This exchange has been facilitated through occasional workshops, a website and e-mail. Participants have consistently confirmed the value of the Network in motivating and supporting their implementation of research findings. Although this funded stream of work concluded in December 2003, members plan to maintain the Network themselves, with a longer-term objective of securing an alternative source of funding.

Output

Nicholas, E., Qureshi, H. and Bamford, C. (2003) *Outcomes into Practice: Focusing practice and information on the outcomes people value. A Resource Pack for managers and trainers*, Social Policy Research Unit, University of York, York.

Nicholas, E. and Qureshi, H. Developing outcome-focused practice; examining the process, article submitted to *Research, Policy and Planning*.

Outcomes for Disabled Service Users

Ongoing Project

Department of Health Programme Grant

January 2002 to December 2004

*Jennifer Harris, Michele Foster, Hannah Morgan and
Karen Jackson*

The project aims to improve social services for disabled people of working age through the development and testing of tools that incorporate a focus on outcomes into assessment and review. Outcome-focused documents (OCFD) and practice guidance were developed in collaboration with local stakeholders and were piloted. Stakeholders included senior social service managers, care managers, occupational therapists, social workers, domiciliary services officers, community care workers, day care staff and service users.

The project has reached the end of its second year (of three). Following the development of the outcome-focused documents and practice guidance, staff were trained to use the documents and their use was implemented. The process of implementation was itself evaluated. This took the form of interviews with staff and service users and analysis of outcome-focused assessment documentation completed by staff. These data were analysed using computer-assisted qualitative data techniques. The documents and guidance are now in use in routine assessment and review practice activities, involving all front-line staff in the study area.

The project is now entering the comparative testing phase. All assessment documentation - community care assessments, care plans and care plan reviews - used by staff for six months prior to implementation of the new approach has been collected and is being analysed for content (levels and type of needs identified). Staff were also interviewed about their current practice, prior to the introduction of the new outcome-focused approach. At the end of the comparative testing phase, staff will be re-

interviewed and relevant documentation analysed. Analysis will aim to identify changes in practice following the introduction of OCFD.

Interim findings

- Overall, the researched trial implementation (RTI) was successful. Staff from all professions managed to use the OCFD and learn the outcomes approach (OCA).
- The RTI was detrimentally affected by a sudden and unforeseen reorganisation of the Social Services department in which it is taking place. Despite this disruption, the vast majority of staff who used the OCFD have found them to be useful, workable and an improvement on the existing documentation. Many occupational therapy staff who were initially very apprehensive and even hostile to the introduction of the OCA, had been 'converted' by the end of the RTI.
- Some staff complained that the OCA is repetitive; however they were found to be using it inappropriately, by duplicating information about requirements for services and failing to record how these needs would be met.
- Several staff had concerns about using the OCFD with terminally ill service users and the research team need to reconsider its appropriateness for this group.
- To date, over 100 staff have been trained across the local authority area and the plan is to roll out the outcome approach to the whole of the study authority's Disability Service. Management and the majority of the frontline staff have given unremitting, extensive support to the introduction of the OCA. Service users interviewed have been enthusiastic to date for the OCA.

Interim output

Morgan, H. and Harris, J. (2002) *Strategies for Involving Service Users in Outcome-Focused Research*.



Presentation to Consumers in NHS Research, Third National Conference, November, Harrogate, Yorkshire.

Morgan, H. and Harris, J. (2003) *Social Care Outcomes Seminar: Issues for Professionals and Service Users*, Woburn House, 8 May 2002, Research Report, Social Policy Research Unit, University of York, York.

Harris, J. (forthcoming May 2004) Incorporating the social model into outcome-focused social care practice with disabled people, in C. Barnes and G. Mercer (eds), *Implementing the Social Model of Disability: Theory and research in social care*, Disability Press, Leeds.

Morgan, H. and Harris, J. (forthcoming) Involving disabled 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.

Flexible, Person-Centered Home Care for Older People

Ongoing Project

*Department of Health Programme Grant
October 2001 to April 2004
Charles Patmore and Alison McNulty*

This study stemmed from concerns about the opportunities and constraints that can affect the capacity of home care staff to deliver individualised, flexible, person-centred care which, in turn, can have a significant impact on the morale of service users. The project aims to identify factors that enable home care services to help customers in a flexible, person-centred way; and to disseminate the findings in ways that can influence policy and practice.

Stage One of the project involved scoping activities and clarification of the key research questions. A review of recent research on the organisation of home care services and the delivery of individualised

care services was conducted. A series of in-depth telephone interviews was also conducted with independent sector and social services home care service providers in 12 contrasting local authorities.

Stage Two of the project examines six of these providers in depth. Interviews with samples of older customers have identified areas where person-centred practice is apparent, as well as areas where home care services apparently do not respond to individual needs and preferences. Subsequent interviews trace these issues through the different organisational and managerial levels of front-line home care staff, provider managers, care managers and senior social care commissioning managers. These interviews will enable the identification of factors at a number of different levels that cross the purchaser/provider boundary, that appear to inhibit or encourage responsive, person-centred home care services.

Interim findings

Key influences on flexible, person-centred home care include:

- the commissioning policies of social services purchasers;
- the degree of continuity among front-line home care staff;
- goodwill among provider staff;
- the attitudes of and practices of service provider managers;
- the capacity and autonomy of providers to respond to unanticipated changes in customers' needs;
- aspects of pay and conditions of home care staff employed by independent sector providers.

Interim output

Patmore, C. (2002) *Towards Flexible, Person-Centred Home Care Services: A guide to some useful literature for planning, managing or evaluating services for older people*, Social Policy Research Unit, University of York, York.

Patmore, C. (2003) *Understanding Home Care Providers*, Social Policy Research Unit, University of York, York.

Patmore, C. (2003) *Managing your home care – all the time*, *Home Carer*, May.

Patmore, C. (2003) *Independence day*, *Community Care*, 6-12 February.

Health Inequalities and Informal Care: Prospective, Population-based Study

Ongoing Project

*Department of Health Policy Research Programme:
Inequalities in Health Research Initiative
October 2001 to January 2004
Michael Hirst*

This study provides new evidence on the nature, extent, timing and persistence of health inequalities associated with the provision of unpaid care. The findings increase knowledge of the diverse impacts of caregiving and help to disentangle the effects of caring on health. They also begin to validate caregiving as an underlying social determinant in the creation of health inequalities, and to identify the circumstances in which caregiving might be an important variable in epidemiological analysis.

The research is based on secondary analysis of the first ten waves of the British Household Panel Survey. Health-related measures include the General Health Questionnaire for assessing psychological well-being, and a widely used health status questionnaire (SF36). The study is relevant to the Strategy for Carers, National Service Frameworks, Health Improvement Programmes, Health Inequalities Agenda, and partnerships between primary and social care.

Key findings

- Most carers do not present additional health problems because of their caring

responsibilities; however, risk of psychological distress increases with levels of involvement in and intensity of caring activities.

- Some groups of carers in more demanding roles – those looking after a spouse or partner, a parent or a child inside the same household – face increased risk of mental and psychological distress, women more so than men.
- In the high risk groups, raised levels of distress are observed around the start of care episodes and when caregiving ends.
- Heavily involved carers face an increased risk of recurrent or persistent distress throughout their caregiving episodes.
- Inequalities in psychological distress between heavily involved carers and non-carers did not diminish in the ten years to 2000.

Output

An end of project report will be available in January 2004 and subsequently papers will be prepared for a range of academic journals.

User Experience surveys: Extension Project

Ongoing Project

*Department of Health Policy Research Programme:
September 2002 to February 2004
Ann Netten and Jenny Francis (PSSRU, University of Kent) with Hazel Qureshi (SPRU)*

Local authorities with social services responsibilities have been required to undertake surveys of user satisfaction. This project followed from joint work by SPRU and the Office of National Statistics, on the design and testing of questionnaires for such surveys. Although only four survey questions were compulsory Best Value Indicators, the existence of a longer questionnaire provided an opportunity to test both the compulsory questions and a wider range of



questions, for their suitability as performance and quality indicators. Thirty-four authorities voluntarily agreed to collect responses to a core of common questions during their surveys of older home care service users. This generated a set of data containing responses from over 20,000 older people on aspects of the quality and outcomes of their home care service. This data is being analysed by PSSRU as part of their programme of Department of Health-funded work. The results will inform present and future developments in performance and quality assessment related to service user views.

Output

Qureshi, H. and Rowlands, O. (forthcoming) User satisfaction surveys and cognitive question testing in the public sector: The case of personal social services in England, accepted for publication in *International Journal of Social Research Methodology: Theory and Practice*.

**National Service Framework
for Long-Term Conditions**

**Brief Overview Study: User experiences
of health and social care services**

Completed Project

*Department of Health commissioned study
January to March 2003*

Jennifer Harris, Hannah Morgan, Hilary Arksey and Hazel Qureshi (SPRU), in collaboration with Stephen Piper, Alex McClimens (Sheffield), Carol Thomas (Lancaster), Sonali Shah, Geoff Mercer and Colin Barnes (Leeds)

This project was commissioned by the Department of Health to provide a brief overview of the literature relating to user experiences of health and social care services, to underpin the National Service Framework (NSF) for Long-Term Conditions (LTC). The NSF covers people of working age (18-65) and a potentially wide range of conditions. However, this study focused on

the experiences of people with epilepsy, multiple sclerosis (MS), motor neurone disease (MND), Parkinson's disease, brain injury, spinal cord injury, polio and cerebral palsy.

The study aimed to identify research evidence and other literature on the experiences of health and/or social care services by these groups of people; and to provide an overview of the types of evidence that exist, in order to underpin other review work being undertaken as part of the NSF LTC.

Selected key findings

- Users require access to a comprehensive range of support services in the community.
- Users confirm that the aim of therapeutic facilities should be to encourage independence and avoid institutionalisation.
- Users and carers should be involved in the design and planning of services.
- Users with the best health combine assistance by relatives with that given by unrelated persons.
- Users want more information on their condition and its management; on the side effects of medication; and on drug use in relation to pregnancy, fertility and parenthood.
- Users voice support for specialist nurse-run services. These services appear to improve communication deficits experienced elsewhere in the system.
- Users need emergency back-up services; access to aids and appliances; financial advice; and information on benefits and transport services.
- Patients with terminal conditions require fast tracking for aids and adaptations. Systems for ordering equipment can be slower than the progress of the disease.
- Prolonging home care and avoiding early institutionalisation is a high priority for service users with long-term conditions.

Output

Harris, J., Piper, S., Morgan, H., Thomas, C., McClimens, A., Shah, S., Barnes, C., Mercer, G., Arksey, H. and Qureshi, H. (2003) *Brief Review Study: National Service Framework for Long-Term Conditions. Users' experiences of health and social care services*, Social Policy Research Unit, University of York, York.

National Service Framework for

Long-Term Conditions

Brief Overview Study: Experiences of providing care to people with long-term conditions

Completed Project

Department of Health commissioned study March to May 2003

Jennifer Harris, Hannah Morgan, Hilary Arksey, Hazel Qureshi (SPRU), Sally Baldwin (Department of Social Policy and Social Work), Stephen Piper, Alex McClimens (Sheffield), Sonali Shah and Hannah Reynolds

This was a second commissioned study for the Department of Health, to underpin the National Service Framework (NSF) for people with long-term conditions (LTC). The study examined the evidence on carers' experiences of supporting people with epilepsy, multiple sclerosis (MS), motor neurone disease (MND), Parkinson's disease, brain injury, spinal cord injury, polio and cerebral palsy. The aim was to identify the types of evidence available on carers' experiences, including their relationships with health and social care services in their caregiving role.

Selected key findings

- In the UK, social services for carers are more aspirational than actual.
- Carers experience distress about behavioural and social problems experienced by the person with a long-term condition and adverse effects on families. Effective support

moderates the extent to which adverse effects cause depression.

- Carer support programmes are beneficial and carers report a need for more respite services.
- Caregiving spouses report high stress levels, burnout, anger, resentment and poor well-being. External help can ease the burden only if it is the work of caregiving and not the severity of the injury that causes problems for the carer.
- Carers frequently have negative experiences of service provision and often feel they are not listened to or valued. Bureaucracy and lack of funding may contribute to service users and their families not obtaining full or adequate information.
- The health status of patients has a negative effect on the health status of the carer.
- Carers feel they have to fight for services with the result that many individuals feel they receive too little too late.
- Carers experience distress about behavioural and social problems and about adverse effects of caregiving on the family. Effective support can moderate between these adverse effects and depression. Outside help can ease the burden only if it is the caregiving itself that is a cause of stress, rather than the severity of an injury.
- Professionals need to be aware of the stress factors for carers and plan services accordingly. Assessing stress and well-being of carers should be a priority for health care providers, in order to identify and provide services for people at risk.
- Helping patients and families to manage symptoms will enhance perceived control and is an important aspect of quality of care that may enhance both carer and patient well-being.



Output

Harris, J., Piper, S., Morgan, H., McClimmens, A., Shah, S., Reynolds, H., Baldwin, S., Arksey, H. and Qureshi, H. (2003) *Brief Review Study: National Service Framework for Long Term Conditions, Carers' experiences of providing care for people with long term conditions*, Social Policy Research Unit, University of York, York.

OTHER FUNDED PROJECTS

Access to Health Care for Carers: Barriers and Limitations

Completed Project

NHS Service Delivery and Organisation (SDO) R&D Programme

July 2002 to May 2003

Hilary Arksey and Karen Jackson (SPRU), Alison Wallace and Sally Baldwin (Department of Social Policy and Social Work), Su Golder (NHS Centre for Reviews and Dissemination), Elizabeth Newbronner and Philippa Hare (Acton.Shapiro)

Current government policy emphasises supporting carers in their caring role, and ensuring that the NHS and social services help them maintain their health. The intention that carers obtain quality health care services is not necessarily realised in practice, and many carers feel their health needs are overlooked. This study aimed to establish the barriers and obstacles that carers experience in accessing health care services, and to identify interventions that can improve accessibility.

The study involved a review of primary research published since 1987 on the factors that variously restrict, promote and improve carers' access to health care services. In addition, a consultation exercise was undertaken with national statutory and voluntary sector organisations, as well as local organisations that had introduced interventions specifically to improve access to health care for carers.

Key findings

- Carers face five main types of barriers to accessing health care: professional responses; the organisation of services; language or culturally-held beliefs or practices; carer or care recipient characteristics; lack of information and knowledge.
- Sub-groups of carers facing specific access barriers include: children and young people; older carers; carers of people with mental health problems; carers from ethnic minority groups; recent immigrant and refugee carers.
- Different types of intervention, for example primary care initiatives or home-based health care projects, have the potential to address variations in access to health care for different groups of carers. Some appear to work better for some groups than others.
- There is a lack of health economics analysis and little is known about the possible impact that barriers, or interventions to overcome them, have on costs.

Output

Arksey, H., Jackson, K., Wallace, A., Baldwin, S., Golder, S., Newbronner, E. and Hare, P. (2004) *Access to Health Care for Carers: Barriers and interventions*, NHS Service Delivery and Organisation, London [forthcoming].

Arksey, H. (2004) *Access to Health Care for Carers: Intervention evaluations*, NHS Service Delivery and Organisation, London [forthcoming].

Review of Respite Services and Short-Term Breaks for Carers for People with Dementia

Completed Project

NHS Service Delivery and Organisation (SDO) R&D Programme

February 2003 to August 2003

Hilary Arksey and Karen Jackson (SPRU), Karen Croucher (Centre for Housing Policy), Helen Weatherly (Centre for Health Economics), Su Golder (NHS Centre for Reviews and Dissemination), Elizabeth Newbronner and Philippa Hare (Acton.Shapiro), Sally Baldwin (Department of Social Policy and Social Work)

This study of respite services and short-term breaks for carers for people with dementia built on an earlier scoping study completed by SPRU in 2002 on services to support carers of people with mental health problems. It is estimated that dementia currently affects approximately 600,000 people in the UK, a figure that is increasing. The majority of older people with dementia are cared for at home by a relative or friend. Respite care is widely regarded as a key intervention to reduce the stress of caring, yet services are known to have low levels of utilisation. The identification of service models that benefit carers of people with dementia, and care recipients themselves, is essential. The review therefore aimed to establish the current state of knowledge about the effectiveness and cost-effectiveness of short-term breaks for this group.

The study involved a review of relevant literature published since 1985, together with a consultation exercise. The consultation involved telephone interviews with key individuals from statutory and voluntary organisations; and four focus groups with carers who are current or recent users of respite services.

Key findings

- The review found that, on the basis of the outcome measures used and on the services

that were offered, evidence of effectiveness and cost-effectiveness is limited. However, it would be wrong to assume that a lack of evidence means that respite is ineffective. This is a very complex area methodologically; undertaking studies of respite services is particularly challenging.

- Four studies assessed the cost-effectiveness of day care compared to standard care and one study assessed a multi-dimensional carer support package compared to standard community nursing. None of the results provided conclusive evidence on the cost-effectiveness of respite services. However, all day care services were associated with similar or higher benefits than standard care and in two of the studies cost-savings were reported, suggesting that these services were cost-effective.

Output

An end of project report will be available and papers will be prepared for academic journals in 2004.

Improving Community Care Assessment and Support for Black and Minority Ethnic Carers

Completed Project

Sir Halley Stewart Trust

July to September 2002

David Hepworth

This research followed both a previous study into carers' needs and the Carers Act, and consultative workshops in Bolton and Tameside on black and minority ethnic carers and their access to assessments. Contact was made with black and minority ethnic carers through community groups in Bolton and Tameside; and carer assessment instruments were tested, to gain an understanding of perceptions of the caring role. Local minority ethnic



workers were closely involved in planning the study, making contact with carers and acting as interpreters.

Key findings

- There were high stress levels among Asian carers, though it is not clear that these were caused by caring or by other social circumstances.
- The main sources of stress were physical demands; the relationship with the person receiving care; and social restrictions.
- On the other hand, carers had high levels of satisfaction derived from fulfilling their duty and demonstrating their faith.
- Carers welcomed the availability of documentation in their own language.

ESRC Research and Social Work and Social Care

Ongoing Project

*Social Care Institute for Excellence (SCIE)
September 2003 to February 2004*

Hilary Arksey, Ian Shaw (Department of Social Policy and Social Work), Audrey Mullender (University of Warwick, Department of Social Policy and Social Work)

The role of the Economic and Social Research Council has been significantly expanded in recent years, in order to promote the contribution of social science research to evidence-based policy and practice. The Social Care Institute for Excellence has therefore commissioned a review of the actual and potential coverage of social work and social care within ESRC programmes.

The review includes desk research; an open consultation exercise carried out via a number of different websites likely to be used by social work and social care academics and researchers; an e-mail questionnaire sent to all principal applicants of

projects funded under two ESRC research programmes: 'Growing Older: Extending Quality of Life' and 'Research Methods Phase 1'; a consultation workshop was held at SCIE; and face-to-face interviews were conducted with key ESRC officials.

Output

A report will be submitted to SCIE in early 2004.

Public Health: Making Community Nurses Count

Ongoing Project

*North and East Yorkshire and Northern Lincolnshire
Strategic Health Authority*

June 2003 to June 2004

Hilary Arksey (SPRU), Pauline Raynor, Nicky Cullum, Ian Watt and Trevor Sheldon (Department of Health Sciences)

The government's health strategy aims to improve the health of the general population and the health of the most disadvantaged in particular. Recently, the focus of public health activity has shifted to primary care. There is considerable scope for further involvement of nurses at all levels of public health activity, particularly within primary care settings. This study explores community nurses' emerging public health roles and the extent to which they are offering evidence-based public health interventions in practice.

Methods of data collection include in-depth interviews with different groups of community nurses and other key PCT stakeholders; and observation.

Output

Findings will be reported to the funding body and primary care trusts in the summer of 2004, prior to dissemination through conferences and publications.

Evaluation of People into Employment (PIE) Project

Ongoing Project

*People into Employment Project/Neighbourhood
Renewal Fund*

March 2003 to March 2004

Hilary Arksey

This evaluation led directly from a previous one completed by SPRU in 2002, which covered the first two years of the Project. PIE specialises in finding employment specifically for disabled people, carers and former carers. Now into its second tranche of funding, PIE continues to concentrate on 'hidden' individuals who are not known to statutory services. As before, the study aimed to assess PIE's effectiveness; and identify the Project's strengths, examples of good practice and areas where there is scope for further development. The evaluation was not only concerned with 'hard' outcomes (such as qualifications and jobs obtained), but also with 'soft' outcomes (for example, attitudinal skills and personal skills) and distance travelled towards employability.

The main fieldwork was undertaken in November and December 2003. This involved a questionnaire survey of PIE clients, three focus groups with PIE clients, one focus group with partner agencies and employers, and a joint interview with PIE's two development workers.

Output

A final report will be available in March 2004.

CHILDREN AND FAMILIES TEAM

Introduction by Professor Patricia Sloper

Children have been at the forefront of the policy agenda over the last year with the preparatory work for the Children's National Service Framework (NSF), publication of the NSF *Standard for Hospital Services* and *Emerging Findings*, the Laming Report and the subsequent Green Paper *Every Child Matters*, and the creation of the new post of Minister of State for Children within the new Children, Young People and Families Directorate in the Department for Education and Skills. Other policy imperatives are the continued emphasis on the need for joined up multi-agency working in children's services and on involving users of services, including children and young people and their parents/carers, in planning their own care and treatment and, more broadly, in decision-making around service development.

The Children and Families Team's research is highly relevant to this policy agenda. We completed a project on children and young people's participation in local health services development in January 2002. The following September we held a very successful conference on this topic, attended by over 200 people, at which we launched *'Having a Say in Health: Guidelines for involving young people in health services development'*. Professor Al Aynsley-Green, National Clinical Director for Children, highlighted the importance of children and young people's involvement for the NSF. Meanwhile, speakers in the plenary sessions and parallel workshops presented many examples of good practice in involvement. Some of the highlights of the conference were the presentations given by young people who had participated in developing services. The guidelines - which were produced with young people and based on the findings of the research project - were well received and have been widely distributed and used at a number of conferences organised by the Department of Health. Two new research projects will be adding to the sum of knowledge on children's involvement: one is looking



*Professor
Patricia Sloper*

at disabled children's participation within social services, and the other at how the new Patient Advice and Liaison Service (PALS) in health are promoting themselves to children and young people, and children's views of what makes a good PALS.

The team continues to carry out work on multi-agency care co-ordination for disabled children and their families and our link with Care Co-ordination Network UK helps us to ensure that this work is fed into practice. The issue of key workers for disabled children has risen up the policy agenda this year and we have been very busy trying to meet all the demands for conference presentations on this topic, as well as carrying out a new project looking at outcomes of different models of key worker services. Similarly, the neglected issue of the housing needs of families with disabled children has come to the fore after research carried out jointly by SPRU and the Centre for Housing Policy.

SPRU's expertise on the needs of disabled children and their families continued to play an important role in the development of the NSF, with Tricia Sloper and Bryony Beresford being members of both the External Working Group on Disabled Children and the NSF Research Group, which provides the evidence that underpins the NSF.

During the year we have seen a number of changes in the team. Jane Lightfoot left us to take up a post with the North Yorkshire Forum for Voluntary Organisations. Veronica Greco and Anita Franklin joined us to work on new research projects and Rachel Hazelwood joined CCNUK as Information Officer. Wendy Mitchell gave birth to a lovely daughter, Katherine. The story of how she went straight from SPRU to the hospital for Katherine's birth will go down in the annals of SPRU history! Claudine Crane joined us for a short time to cover Wendy's maternity leave.



CHILDREN AND FAMILIES TEAM

Introduction by Professor Patricia Sloper

Team members during the year have been Katy Barton, Bryony Beresford, Sue Clarke, Claudine Crane, Anita Franklin, Veronica Greco, Janet Heaton, Jane Lightfoot, Wendy Mitchell, Parvaneh Rabiee, Patricia Sloper and Rosemary Tozer. Administrative and secretarial support was provided by Teresa Frank and Rachel Hazelwood.



Priorities and Perceptions of Disabled Children and Young People and their Families Regarding Outcomes of Social Care

Ongoing Project

Department of Health

October 2001 to December 2004

Tricia Sloper, Bryony Beresford and Parvaneh Rabiee

There is a dearth of research on what outcomes disabled children and their parents desire from support services. Whilst the Looked After Children (LAC) system provides an initial framework within which to investigate such outcomes, problems of its applicability to disabled children, whose development may be compromised in one or more areas by their impairment, have long been recognised. Building on both the LAC framework and earlier SPRU work with adults, this project comprises a programme of work on outcomes that involves direct consultation with children, parents, managers and practitioners.

The aims are:

- to identify desired outcomes of social care from the perspectives of disabled children and their parents;
- to explore managers' and practitioners' perspectives on outcomes;
- working with local authority staff, children and parents, to develop ways of collecting outcome information that can be used in practice;
- to pilot and evaluate the use of outcome assessment in practice.

Working in three local authority areas, the research is using interviews and focus groups with disabled children and parents, and participatory workshops with key stakeholders amongst staff, to investigate views of outcomes. It will then work with steering groups of staff, children and parents to develop practical ways to collect outcome information, and to pilot and evaluate these. The project is focusing on

four groups of children: those with autistic spectrum disorders, communication impairments, complex health needs, or degenerative conditions.

Interviews with children and parents have just been completed and data are currently being analysed.

An Exploration of Different Models of Multi-Agency Partnerships in Key Worker Services for Disabled Children: Effectiveness and costs

Ongoing Project

Department of Education and Skills, Department of Health, HM Treasury, Welsh Assembly

October 2002 to December 2004

Tricia Sloper, Veronica Greco, Rosemary Webb (Department of Education of Educational Studies), Shelia Sudworth and Jennifer Beecham (University of Kent)

Previous research has shown that families with a key worker service are likely to have better outcomes than families without. This study aims 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 is divided into three stages. The *first stage* of the study analysed responses to a UK-wide survey, to determine which areas had key worker services, and details of the service models.

Key findings

- All three statutory agencies were involved in setting up and overseeing the majority of the schemes, but joint funding was still rare.
- The majority of the schemes had temporary funding, ranging from nine months to three years' duration.
- Training for key workers had not been set up in some schemes and training varied across schemes.

In the *second stage*, seven areas with differing models of key worker services were identified for further investigation in case studies and interviews were carried out with staff on each of the schemes.

The *third phase* of the study investigates the effectiveness of the services in providing co-ordinated care and in meeting families' needs, through questionnaires to all families receiving the services and through interviews with a sub-sample of these families.

Output

Greco, V. and Sloper, P. Care co-ordination and key worker schemes for disabled children: Results of a UK wide survey. Accepted for publication in *Child: Care, Health and Development*.

Participation of Disabled Children and Young People Under Quality Protects

New Project

Department of Health Quality Protects Research Initiative

April 2003 to May 2004

Anita Franklin and Tricia Sloper

Developing a culture of, and good practice in, children's participation is a key component of the Quality Protects programme. This attention to children's participation reflects the growing importance being attached to involving young service users in decisions about their own care and/or wider service planning. However, reports of evaluations of children's participation are as yet scarce. In addition, evidence from QP and elsewhere suggests that, while in general children are increasingly involved in decision-making, growth is slower for involving disabled children. While the emerging literature has general lessons for those wishing to involve children, less is known about additional, specific, factors which could promote disabled children's participation. There

is also little evidence about the outcomes of disabled children's participation in terms of its likely impact on service planning and/or individual care packages. It is these gaps that this research seeks to address.

The project focuses 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 are:

- to identify participation work which includes disabled children;
- to establish factors which can support and promote disabled children's effective participation.

The research has 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 current and planned participation. *Stage two* consisted of a survey of all Social Services Departments in England to identify and investigate current work concerning disabled children's participation in decisions on their own care and in service development. *Stage three* will undertake qualitative research with children (using verbal and non-verbal methods to facilitate communication), parents and staff in a sample of six local authorities to find out 'what works' in respect of the processes and outcomes of disabled children's participation. The data collected will inform the development of guidelines to support Social Services Departments in promoting disabled children's participation. Draft guidelines will be discussed at a workshop with project participants, in order to obtain their input into the final product.



Children's Young People's and Parents' Access to and Use of Patient Advice and Liason Services (PALS)

Ongoing Project

*Community Fund and Department of Health, in conjunction with Carnegie Young People Initiative
January 2003 to June 2005
Janet Heaton and Tricia Sloper*

Since 2002, all NHS Trusts and Primary Care Trusts in England have been required to establish a Patient Advice and Liaison Service (PALS). PALS have been set up to enable patients and the public to access information and raise issues of concern with their Trust. PALS are intended to serve all, including vulnerable and hard-to-reach sections of the community. This research will examine what PALS have done and can do to involve children, young people and parents.

The aims of the study are:

- to establish whether and, if so how, children's, young people's and parents' access to and use of PALS has been promoted by the service to date;
- to examine how PALS can facilitate children's, young people's and parents' access to and use of the service;
- to provide guidelines for NHS Trusts and Primary Care Trusts on how PALS can be developed in ways that are more inclusive of children, young people and their parents.

The research involves: a national survey of PALS to examine to what extent, and how, the service has been promoted to children, young people and their parents; discussion groups with young people and parents to examine their views on how PALS could be made more accessible to them; a survey of young people and parents who have used PALS to examine their experiences of using the service; and interviews with PALS staff.

Key findings from the national survey

- PALS have so far been developed as generic services, with some making efforts to promote the service to specific sections of the community.
- Where PALS have focused on potentially hard-to-reach groups, they have tended to concentrate most on older people and least on children.
- Training for PALS staff was more likely to include a focus on people with communication difficulties, ethnic minorities and older people, and least likely to focus on children, young people and parents.
- Respondents felt more positive about their ability to deal with the concerns of older people and parents than they did about children. They were generally confident of their ability to deal with the concerns of users in general.

Output

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. Available from the SPRU Information Office or the SPRU website.

Heaton, J. and Sloper, P. (2003) *National Survey of Patient Advice and Liaison Services (PALS) in England: Children, young people and parents' access to and use of PALS*, Social Policy Research Unit, University of York, York.

Care and Support Needs of Children with Cancer and Leukaemia and their Families

Ongoing Project

*CLIC (Cancer and Leukaemia in Childhood)
August 2002 to June 2004
Wendy Mitchell, Tricia Sloper and Susan Clarke*

The diagnosis and treatment of cancer or leukaemia in a child presents a considerable challenge to families. Major advances have been made in terms of treatment and it is recognised that psychosocial support is an important part of service provision. However, evaluation of psychosocial support is less developed. This project will investigate current patterns of provision, both statutory and voluntary, and how these meet children's and families' needs throughout the treatment period and beyond.

The key aims of the study are:

- to explore patterns of psychosocial support service provision throughout the UK for children with cancer and leukaemia and their families;
- to describe the needs of children, young people's and their parents' needs over the trajectory of the illness and post treatment;
- to compare patterns of support with parents' and children's views of their needs, and develop recommendations for the voluntary sector's provision of services.

The project has three stages: in *stage one*, information on service provision was collected via a postal survey of all 21 UK NHS paediatric oncology treatment centres and key voluntary agencies working with these centres. In *stage two*, children's and parents' experiences of psychosocial support were explored through focus groups and interviews. In *stage three*, the views of a larger sample of parents and young people from ten treatment centres will be

gathered through postal questionnaires based on themes identified in stage two.

Key findings from the survey of treatment centres

- The need for psychosocial support for parents and children is recognised in all centres.
- Provision of support varies widely between centres and procedures for assessment of needs and provision of support are rarely formalised.
- Many centres report insufficient input from psychologists.

Output

Clarke, S., Mitchell, W. and Sloper, P. (2003) *Current Patterns of Provision of Psychosocial Support and Practical Support Services at NHS Paediatric Oncology Treatment Centres in the UK: An overview*, Social Policy Research Unit, University of York, York.

Sharing Value: Developing a Website and Print Directory of User-Commended Support Services for Disabled Children and their Families

Completed Project

*Community Fund
January 2000 to June 2002
Wendy Mitchell, Tricia Sloper, Dot Lawton, Susan Clarke and Nicholas Pleace (Centre for Housing Policy) in collaboration with Barnados and the Family Fund Trust*

Past research has highlighted the absence of a national system for sharing information about valued services amongst families with disabled children and practitioners. Sharing Value sought to address this information gap by identifying and disseminating examples of specific services, which disabled children and their families have commended as valued. The project has created a directory of examples of these valued support services.



Key findings

In consultation with groups of parents, children and professionals, criteria were drawn up for deciding what are 'valued examples' of services. Some of these were regarded as 'core' criteria by parents and children, pivotal to any type of service.

Children's Core Criteria

- Staff understand about my illness or disability
- Staff know how to help and look after me
- Staff listen to me
- Staff ask me for my ideas and take notice of what I say
- I can ask the staff questions and they explain things to me
- Staff allow me to make choices.

Parents' Core Criteria

- Meeting the child and whole family's needs
- Listening to the child and family members
- Treating the child and all family members with respect
- Staff knowledge and training
- Welcoming and helpful staff
- Service respect family's culture.

Examples of valued services were collected via three postal questionnaires (for parents, disabled children and siblings) sent to a UK wide random sample of 14,538 families drawn from the Family Fund Trust database. Nominated services were contacted: around 1,300 services agreed to provide contact information and are listed in the directory; 200 of these services were visited and are described in greater depth. The directory is now available on the world wide web (www.sharingvalue.co.uk) and in a printed format.

Output

Mitchell, W. and Sloper, P. (2001) Quality in services for disabled children and their families: What can theory, policy and research on children's and parents' views tell us?', *Children and Society*, 15, 237-52.

Mitchell, W. and Sloper, P. (forthcoming) Quality indicators: Disabled children's and parents' prioritisations and experiences of quality criteria when using different types of support services, *British Journal of Social Work*.

Mitchell, W. and Sloper, P. (2002) Quality services for disabled children, *Research Works*, 2002-02, Social Policy Research Unit, University of York, York. Available from the SPRU Information Office or the SPRU website.

Technology and Time: Home Care Regimes and Technology- Dependent Children

Completed Project

*Economic and Social Research Council 'Innovative Health Technologies' Research Programme
January 2001 to December 2002*

Janet Heaton, Tricia Sloper, Jane Noyes (Department of Health Sciences) and Robina Shah (Independent researcher)

In the UK, advances in medical technology have enabled more children with complex health needs to survive and increasingly to be cared for at home. This study focused on the experiences of families with technology-dependent children who use one or more medical devices (such as dialysis, assisted ventilation, and intravenous feeding) on a daily basis. The aims of the study were:

- to describe the temporal organisation of care for technology-dependent children living at home;
- to examine the impact of the care regimes on the everyday lives of the children and their families;
- to identify the implications for policy and practice in health and social care, education, employment and any other relevant areas;

Interviews were carried out with children, their siblings and parents from 36 families and professionals were interviewed about good practice identified by the families, and about the wider organisation of services for this group.

Key findings

- Routines relating to the devices varied from family to family depending on what types of devices were used, the children's age and medical diagnoses, and fluctuations in their health status.
- Technical care was mainly provided by the children's parents, particularly mothers, with varying levels of involvement from other family members and service providers.
- In general, the children's use of medical devices was recognised to have benefited their health and quality of life, and made lives easier for their parents because the children's medical condition were more stable.
- However, families highlighted problems with: availability of appropriate respite care both away from the home and inside the home; difficulties combining caring and working; sleep disruption; social isolation; and children's and siblings' relatively limited or disrupted participation at school and in social activities.

Output

Heaton, J., Noyes, J., Sloper, P. and Shah, R. (2003) Technology-dependent children and family life, *Research Works*, 2003-02, Social Policy Research Unit, University of York, York. Available from the SPRU Information Office or the SPRU website.

Heaton, J., Noyes, J., Sloper, P. and Shah, R. (2003) *Technology and Time: Home care regimes and technology-dependent children*, Social Policy Research Unit, University of York, York.

Care Co-ordination Network UK (CCNUK)

Ongoing Development Project

Joseph Rowntree Foundation and Department of Health

April 2001 to March 2006

Katy Barton, Rachel Hazelwood and Tricia Sloper

Care Co-ordination Network UK (CCNUK) promotes care co-ordination or key working for disabled children and their families in England, Northern Ireland, Scotland and Wales. Currently based within SPRU, CCNUK developed out of a research project previously undertaken in the Unit. It was registered as a charity in July 2002.

Care Co-ordination Network UK 's aims are:

- to influence policy makers to recognise the benefits and implement the principles of care co-ordination for children and families;
- identifying, evaluating and promoting best practice in care co-ordination;
- establishing national standards;
- ensuring maximum participation of children, young people and families;
- collecting, distributing and disseminating information on care co-ordination;
- developing effective working relationships with other organisations and government bodies;
- providing a resource point about the principles of care co-ordination and its implementation.

Output

Sloper, P., Jones, L., Triggs, S., Howarth, J. and Barton, K. (2003) Multi-agency care co-ordination and key worker services for disabled children, *Journal of Integrated Care*, 11, 1, 9-15

Care Co-ordination News, issues 3, 4 and 5.

CCNUK Annual Report 2002-2003.

CCNUK Membership Pack, January 2003.

SOCIAL SECURITY AND LIVING STANDARDS TEAM

Introduction by Dr Roy Sainsbury

In the past six or seven years there has been considerable demand for social research that contributes to evidence-based policy and practice. For many years, SPRU has been developing expertise and knowledge and contributing to the evidence base in key policy areas: poverty and living standards, social security, and employment policies for disabled people. Since 1997 we have also developed expertise on welfare to work and tax credits.

During the period covered by this annual report, research continued on the evaluation of the New Deal for Disabled People National Extension, and commenced on new projects evaluating the government's Job Retention and Rehabilitation pilots, and Incapacity Benefit pilots. The Disability Services Research Partnership - comprising SPRU, the Strathclyde Centre for Disability Studies and the Welsh Centre for Learning Disabilities, led by Patricia Thornton - has completed projects on supported employment and policies on employing disabled people. Work is due to commence soon on a major evaluation of the WORKSTEP programme.

Projects were also completed on gender and poverty, the take-up of the Minimum Income Guarantee by older people, the drivers of social exclusion, and ladders out of poverty. Research began on the use of the Social Fund by families with children and on poverty among families interviewed in the Millennium birth cohort.

SPRU's contribution to wider debates in Europe and the rest of the world on poverty, family policy and disability continues to increase. Professor Peter Kemp has been appointed as General Secretary of the Foundation for International Studies of Social Security (FISS) and organised the annual research conference in Sigtuna, Sweden in June 2003. An edited volume of the principal papers is scheduled for publication in 2004. Jonathan Bradshaw, Naomi Finch and Emese



*Dr Roy
Sainsbury*

Mayhew have been working on comparative projects on child well-being, and on welfare policy and employment in the context of family change. Meanwhile, Patricia Thornton and Anne Corden have worked with colleagues in the Netherlands and the USA on projects concerning employment policies for disabled people. Between them, members of the team have visited and given papers in the USA, Australia, South Africa, Norway, Sweden, Finland, Spain, the Czech Republic, Cyprus, the Netherlands and Belgium. With sponsorship from the Department for Work and Pensions, Peter Kemp and Patricia Thornton have contributed to a comparative project, organised by the International Social Security Association, on trends in incapacity benefit in six countries.

Closer to home SPRU's expertise continues to be sought by a range of individuals and organisations. Jonathan Bradshaw has been advising the House of Commons Select Committee on poverty, Peter Kemp's expertise on housing benefit has been sought by the Department of Work and Pensions, and Roy Sainsbury has acted as consultant to the National Audit Office in its work on decision-making and appeals. SPRU researchers also contribute to the wider academic development of social policy through memberships of the editorial boards of the *Journal of Social Policy*, *Benefits*, the *Journal of Social Security Law*, and *Research Matters*.

Anne Corden and Roy Sainsbury were awarded a grant in the ESRC's Research Methods Programme, to investigate the theory, practice and impact of using verbatim quotations in qualitative research reporting.

As a result of all this activity we are pleased to have made two new appointments in 2003. Dr Angela Meah has joined us from the University of Sheffield to work with Patricia Thornton on the programme of work of the Disability Services Research Partnership. Katharine Nice, who recently completed an MA in



SOCIAL SECURITY AND LIVING STANDARDS TEAM

Social Policy at the University of Birmingham, has been appointed to work on the evaluations of the job retention and the Incapacity Benefit pilots.

Team members during the year were Jonathan Bradshaw, Anne Corden, Naomi Finch, Michael Hirst, Peter Kemp, Emese Mayhew, Angela Meah, Katharine Nice, Roy Sainsbury, Patricia Thornton and Julie Williams. Administrative and secretarial support was provided by Sally Pulleyn.



Evaluation of the Incapacity Benefits Pilots

New Project

Department for Work and Pensions

September 2003 to March 2007

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

The Incapacity Benefit pilots commenced in October 2003 in three locations in Great Britain and will be extended to a further four locations in April 2004. The aim of the pilots is to extend new forms of help to 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, work focused interviews, access to health condition management programmes for mental health, musculo-skeletal, and cardiovascular conditions, and financial help in the form of a wage supplement of £40 a week for up to 12 months (known as the 'return to work credit').

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 will commence and continue for a period of nine months. Three further cohorts are planned for later in 2004 and 2005. There will also be separate studies of different aspects of the pilots including the work of Incapacity Benefit personal advisers and other Jobcentre Plus staff, the role of GPs, the impact of the return to work credit, the workings of the health management programmes, and the impact on Incapacity Benefit appeals.

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

Evaluation of the Job Retention and Rehabilitation Pilots

New Project

Department for Work and Pensions

April 2003 to December 2005

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

The Job Retention and Rehabilitation Pilots (JRRP) commenced in April 2003 and will continue for two years. The aim of the pilots is 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 are using random assignment techniques to measure the impact of different 'interventions'. Voluntary participants are 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 are delivering the JRRP in six locations in Great Britain. SPRU is contributing 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. These will be reported to DWP in 2004. Further work will include two more cohorts in the client longitudinal study, and studies of the roles of GPs and employers in the pilots, and studies to identify how the pilots contribute to the return to work from the perspectives of the provider organisations, clients, and employers.

A final report will be presented to DWP in September 2005.

Incapacity Benefit Appeals - Medical Evidence Pilot Evaluation

Completed Project

Department for Work and Pensions

March 2003 to November 2003

Roy Sainsbury, Anne Corden

This project followed on from an evaluation (described in last year's annual report) of the medical evidence pilot scheme in which GP records are used to help determine entitlement to Incapacity Benefit. This new project was designed to explore whether the pilot arrangements for collecting medical information directly from GP records had an impact on the processing and experience of appeals against disallowances of incapacity benefit. Interviews were held with claimants who lodged appeals, claimants who had *not* lodged appeals, Chairs of Appeal Tribunals and medical members of tribunals.

Key findings

- The evaluation showed that information from GPs contributes little to people's decisions about whether to appeal against disallowance decisions. The hope that new arrangements for collecting information directly from GPs' records might lead to a reduction in the number of appeals is therefore unlikely to be realised.
- Although tribunal members were not able to recall details about individual pilot cases, they were attracted by the pilot arrangements since current arrangements produce limited and partial medical evidence from GPs. Under the pilot arrangements they were guaranteed at least some medical evidence.
- Claimants who recalled details of the pilot arrangements were generally in favour of using GP records as this was perceived as providing better information on their health conditions and seen to reduce the burden on GPs.

The report from the project will be published in 2004 as Sainsbury, R. and Corden, A. (2004) *Medical Evidence and Incapacity Benefit Appeals: Evaluation of a pilot study*, in the DWP Research Report series.

Evaluating Disabled Person's Tax Credit: Views and Experiences of Recipients

Completed Project

Inland Revenue

May 2001 to March 2003

Anne Corden and Roy Sainsbury

Disabled Person's Tax Credit (DPTC) was introduced in October 1999 and was aimed at working people at a disadvantage in getting or keeping paid work as a result of illness or disability. DPTC was designed to help make work pay and to provide a minimum income guarantee. The Inland Revenue commissioned two evaluative studies of DPTC: a national survey of recipients, conducted by the Institute for Employment Studies, and qualitative work, conducted by SPRU.

The aims of the qualitative study were:

- to consider the views and experiences of a range of DPTC recipients;
- to consider the impact of DPTC on work incentives and as a means of supporting people to remain in work;
- to throw further light on issues arising from the findings of the national survey.

The work was conducted in two stages. The *first stage* was a series of qualitative interviews with 54 DPTC recipients in four local areas, completed during June/July 2001. The *second stage* comprised five group discussions with recipients in four areas in September 2002, and focused on information and communication issues for people using tax credits.



Key findings

- For some people, DPTC did fulfil the policy aims of increasing personal and financial security; helping to meet costs of child care and increasing the income flow towards children. People who felt financially better off than before were pleased with the amounts received.
- Constraints on achieving policy objectives included problems for people in conceptualising a tax credit and generally low levels of understanding of the main structural features. This was likely to be lowering take-up, for example by reducing the incentives perceived.
- Structural and administrative elements of DPTC perceived negatively by some people included employer involvement; the overall effect of tapers and interactions with housing benefit; the way in which people were asked to demonstrate disadvantage at work; and dislike of categorisation as 'disabled'.

Findings from this study informed the development of the 'second generation' of tax credits. DPTC itself was short-lived, and was replaced in April 2003 by Working Tax Credit and Child Tax Credit. Findings from the two evaluative studies will be published by the Inland Revenue in 2003. To date, the report has been posted on the Inland Revenue website as Corden, A. and Sainsbury, R. (2003) *Evaluation of the Disabled Person's Tax Credit: Views and experiences of recipients*, Inland Revenue Research Report 5 (see www.inlandrevenue.gov.uk/research/index.htm).

UK Policies and Practices Facilitating Employment of Disabled People

Completed Project

Department for Work and Pensions

January to April 2003

Patricia Thornton

The Department for Work and Pensions commissioned this review to bring together findings from the published research literature on 'what works' in raising the employment level of disabled people in the UK. The review also served as a briefing document for a UK-US Ministerial seminar held in Washington DC in May 2003.

Key findings

- There are indications that some interventions work, or might be made to work, but more research is needed to assess their impact.
- Differences in programme eligibility criteria and inconsistent research definitions make it hard to gauge the relative success of interventions.
- Some interventions designed for disabled people are very small scale. Even if their impact could be improved, they would make only marginal differences to employment rates.
- Many disabled people face multiple barriers, which suggests combining service elements rather than a multiplicity of isolated programmes.
- Gaps in research include understanding why disabled people do not take up work incentives, bring cases under the Disability Discrimination Act or use voluntary employment programmes. There is a need for greater understanding of how employers behave.

Employability and Problem Drug Users

Ongoing

Unfunded

Peter Kemp and Joanne Neale (Department of Social Policy and Social Work)

Since 1997, a central tenet of social security policy has been 'work for those who can, security for those who cannot'. However, the Social Security Advisory Committee has argued that 'hard to help' groups do not fit easily into this concept. This project aims to examine this question in relation to problem drug users. The research is based on a sample of 559 individuals beginning a new episode of drug treatment. (The survey was conducted by the Centre for Drug Misuse Research at Glasgow University as part of the Drug Outcome Research in Scotland study funded by the Robertson Trust with the support of the Scottish Executive.)

Analyses conducted to date have shown that people approaching drug treatment services experience a very wide range of serious personal, health, housing, life style and other problems. These tend to make them unsuitable for current welfare-to-work programmes, such as the New Deal, Progress2work and the New Futures Fund. It is concluded that drug users' treatment needs and other chronic problems need to be addressed before they will be in a position either to take up and retain paid employment or successfully complete an employability programme.

Output

Kemp, P.A. and Neale, J. Employability and problem drug users, submitted to *Critical Social Policy*.

Trends in Disability Benefits

Reciprocity Rates

Ongoing Project

Department for Work and Pensions

January 2003 to December 2004

Peter Kemp and Patricia Thornton (in association with the International Social Security Association)

The International Social Security Association (ISSA) has launched a six-country study to understand reasons for growth in rates of receipt of disability benefits. In the *first stage* of this project, the Department for Work and Pensions and Peter Kemp and Patricia Thornton at SPRU are collaborating to produce a chapter on Great Britain for a book to be published for ISSA in 2005. Denmark, Israel, the Netherlands, Sweden and the USA are also participating in the study. The *second stage* involves writing a comparative chapter, contributing to a second comparative chapter, and contributing to the editing of the book.

Learning from Others:

Partial Disability Benefits

Ongoing Project

US government funded research, commissioned from Rutgers University, New Jersey

November 2003 to August 2004

Anne Corden and Patricia Thornton

The United States pays disability benefits only to people totally and permanently disabled. Some other countries pay benefits for 'short-term disabilities' or on a partial basis, and there may be useful lessons for the US from other countries' systems of temporary, short-term and partial benefits. Of key importance is any relationship between such benefit programmes and reintegration of workers into the work force.

The US government has therefore commissioned research from the Program for Disability Research



(PDR) at Rutgers University, New Jersey. Anne Corden and Patricia Thornton are contributing to this study by providing information about the main benefits and tax credits available to disabled people in Great Britain, and services that support disabled people who want to work.

The overall study examines the experiences of selected countries with experience of partial and temporary disability benefits, in collaboration with Rehabilitation International. Representatives from each of eight countries will provide data about their own disability programmes, using a standard questionnaire, and then work with PDR staff to draft outline chapters for a report.

Anne and Patricia are technical consultants for the UK contribution. Other participating countries are: Australia, Germany, Japan, the Netherlands, Norway, South Africa and Sweden.

Work began in November 2003, and the GB questionnaire has been completed and sent to PDR. Findings from the study will be presented at the Rehabilitation World Congress in Oslo in June 2004 and a final report submitted from PDR in August.

Evaluation of the WORKSTEP Programme

Under a five-year Framework Agreement with the Department for Work and Pensions, the Disability Services Research Partnership, headed by SPRU, has developed a programme for the evaluation of WORKSTEP. Previously known as the Supported Employment Programme, WORKSTEP aims to provide support in jobs for disabled people who face more complex barriers to finding and keeping jobs. Two projects were undertaken in 2002 and 2003.

1. Review of results-based funding in supported employment systems

Completed Project

Department for Work and Pensions

April to May 2002

Anne Corden and Patricia Thornton

The modernised supported employment programme known as WORKSTEP took effect from April 2001 with a new emphasis on increasing the proportion of people who move from supported to mainstream employment. New funding arrangements replaced an occupancy-based mechanism that tended to discourage progression. They aimed both to provide incentives for providers to work with supported employees towards mainstream employment and to provide safeguards for those who need long-term support. One concern of policy makers was that the new funding model could discourage providers from working with supported employees with the greatest support needs.

The review commissioned from SPRU included reports and articles and unpublished material from practitioner contacts.

Key findings

- Results-based funding seems not to be used in employment services for disabled people in European or English-speaking countries other than Australia, the USA and the UK.
- Models of results-based funding are widespread in supported employment in the USA, where 'Milestones' developed in Oklahoma in 1992 and was adopted state-wide in 1997. Variants were being used in five other states and an enhanced model to meet specific needs of services for people with mental health problems began in New York in 2000.
- In Australia, the Case Based Funding Trial of services providing assistance in open and supported employment took place from 1999 to 2002.

- Adverse selection of clients (called 'cream skimming' or 'creaming') is considered a potentially serious problem in the models studied and is addressed structurally in the design of the payment systems. Different approaches all aim to maintain providers' confidence that they can manage the perceived economic risk of providing services to clients who may need more support. There is little direct evidence of the effectiveness of these approaches in preventing or reducing adverse selection.

Output

Corden, A. and Thornton, P. (2003) *Results-based Funded Supported Employment: Avoiding disincentives to serving people with greatest need*, Research Report W160, Department for Work and Pensions, Sheffield.

2. New providers of WORKSTOP

Completed Project

*Department for Work and Pensions
March to December 2003*

Patricia Thornton (SPRU), Sheila Riddell and Pauline Banks (Strathclyde Centre for Disability Studies) and Stephen Beyer (Welsh Centre for Learning Disabilities)

In 2001-2002, voluntary, public and private organisations were invited to tender to provide supported placements in certain areas where there was believed to be a shortage of places. Contracts were agreed with 25 organisations of which 13 were new to delivering WORKSTEP. We were commissioned to carry out in-depth interviews with these new providers to explore what they brought to WORKSTEP and issues they were confronting in its delivery. We also carried out a postal survey of Disability Employment Advisers working in the areas covered by the new providers, with some follow-up

telephone interviews, to investigate their views of the providers and of WORKSTEP more widely.

The findings were fed back to the Department for Work and Pensions as a series of briefing papers and an integrated report is likely to be published in 2004.

Comparative Reviews on Disability and Employment: National Informant

Completed Projects

In 2002 and 2003, Patricia Thornton was commissioned to serve as national informant on three cross-national studies on aspects of policy to promote employment of disabled people.

1. The first study was led jointly by CTNERHI in Paris (the Research Centre on Disability Policy) and the Division of Research and Statistics at the French Ministry of Social Affairs. The main objective was to study, within a comparative perspective, how the conceptualisation and definition of 'disability' influences national legal frameworks and hence access to employment services and benefits. A further purpose was to gather information on how policies work in practice. In addition to compiling a UK report and attending working group meetings, Patricia Thornton facilitated a study trip by the French researchers to policy makers in the Department for Work and Pensions in London and Sheffield. The other countries studied were Germany, the Netherlands, Spain and Sweden. The findings were used to inform thinking about reforms in France.

2. The Netherlands Council for Work and Income commissioned TNO Work and Employment to carry out a comparative study of sheltered and supported employment. As well as Great Britain, the study countries were Australia, Austria, Denmark and Sweden. The Council for Work and Income is the official and independent consultative body for



representatives of employers, employees and local authorities for the Dutch Minister of Social Affairs and Employment with reference to policy on work and income. The purpose of this study was to learn from practices abroad and to acquire useful ideas to improve the functioning of sheltered and supported employment in the Netherlands.

3. Another TNO-commissioned study for which Patricia Thornton served as informant for Great Britain examined arrangements for contracting-out employment services for unemployed and disabled people. The Netherlands Council for Work and Income also commissioned this review. The other countries studied were Australia, the Netherlands, Sweden and the United States of America. The purpose was to improve the existing models of contracting out of reintegration services in the Netherlands or, if necessary, replace these by alternative models. With the help of the results the Council was due to advise the Minister early in 2004.

Welfare Policy and Employment in the Context of Family Change

Ongoing Project

Nordic Research Council

May 2002 to April 2005

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

This is a comparative study of the interactions between changing family forms, the labour market and related social policies in the Nordic countries - Norway, Sweden, Denmark, Finland and Iceland - and Germany, the Netherlands and the UK. It will 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 have been prepared on the three topics and then

syntheses will be written. Each member of the collaborating team is taking responsibility for a specific comparative sub study.

The project will result in one book, a variety of papers and a conference. The national working papers can be viewed on SPRU's website (see www.york.ac.uk/inst/spru/research/summs/welempfc.htm).

COST Action 19: Child Welfare

Ongoing Project

Department for Work and Pensions

September 2001 to June 2005

Jonathan Bradshaw, Bryony Beresford and Emese Mayhew in collaboration with Emma Uprichard and Tess Ridge (Bath University)

COST Action 19 is looking at children's welfare in aging societies. It will seek to understand the interplay of material, social and institutional forces through emphasising theoretical and methodological approaches to children's welfare. COST is an inter-governmental framework for European Co-operation in the field of Scientific and Technical Research.

Three areas of welfare are being highlighted in the research:

- Children's economic and social welfare
- Children's access to space and use of time
- Children's rights and discourses.

Jonathan Bradshaw is UK representative on this project, which involves a number of countries in collaborative research on child welfare. Bryony Beresford serves on the Time/Space working group and Jonathan Bradshaw serves on the Economic Well-Being working group. A book on the UK covering these topics will be published in 2004.

Literature Review on the Drivers of Social Exclusion

Completed Project

Social Exclusion Unit

November 2002 to March 2003

Jonathan Bradshaw, Peter Kemp, Emese Mayhew and Abigail Roe

Social Exclusion is what can happen when people or areas suffer from a combination of linked and mutually reinforcing problems, for example: poverty, ill-health, crime and housing. The Social Exclusion Unit has commissioned SPRU to review existing evidence about current and possible future drivers of social exclusion in England. The review has three objectives:

- to identify the current drivers;
- to identify emerging drivers that might have an impact on social exclusion in the future;
- to assess the relative strength of the drivers.

Output

Bradshaw, J., Kemp, P.A., Baldwin, S. and Rowe, A. (forthcoming) *The Drivers of Social Exclusion: A Review of the Literature*, London: Social Exclusion Unit.

Ladders out of Poverty: A Review Paper

Completed Project

Joseph Rowntree Foundation

May 2003 to September 2003

Peter Kemp, Jonathan Bradshaw, Paul Dornan (Department of Social Policy and Social Work), Naomi Finch and Emese Mayhew

The aim of this project was to undertake a review of ladders out of poverty (LOOP).

Detailed objectives:

- to provide a comprehensive overview of what are, or could be, ladders out of poverty for individuals, families and communities;

- to review critically the existing evidence of what works and what does not and why this is the case;
- to highlight the gaps in knowledge and potential for exploiting existing data sources, and recommend any areas for future studies including if necessary the need for primary research;
- to provide some guidance on where the priorities lie and what shape future JRF research in this area should take.

For the purpose of the review, poverty has been defined to mean income and asset poverty as well as other forms of social exclusion that result from inequality in income, wealth and opportunity. The review is focusing on key client groups:

- young people;
- families with children including lone parents;
- unemployed people of working age;
- the working poor;
- older people.

Output

Kemp, P.A., Bradshaw, J., Dornan, P., Finch, N. and Mayhew, E. (2004) *Ladders out of Poverty*, Social Policy Research Unit, University of York, York. Available from the Joseph Rowntree Foundation.

Gender and Poverty

Completed Project

Equal Opportunities Commission

July to October 2002

Jonathan Bradshaw, Peter Kemp, Naomi Finch, Emese Mayhew and Julie Williams

This project aimed to examine how and why poverty varies by gender. It involved a review of the literature on poverty and gender, secondary analysis of data from the Family Resources Survey and Scottish Household Survey, and a review of government social security policies bearing upon gender and poverty. The project also involved running a seminar for the EOC.



Key findings

- In 1999/2000, after housing costs, 25 per cent of the female population compared with 22 per cent of the male population were living in households with equivalent incomes below 60 per cent of the median.
- Women are more likely to be lacking two or more socially perceived necessities than men, they are more likely to feel poor, are more likely to be dependent on Income Support and are more likely to be poor on several dimensions of poverty at the same time.
- Even if socio-economic factors are controlled for, women are still poorer than men with the same characteristics.
- Some reasons for higher poverty rates among women are: occupational segregation; child-birth and caring responsibilities; interrupted labour market activity; higher rates of part-time work associated with lower pay; lower basic pension entitlement (resulting from interrupted/part-time work histories); unequal distribution of resources within the household; societal preconception of women primarily as carers rather than earners.
- Women most at risk of poverty are single mothers and pensioners.
- Reducing gender inequality in poverty is not one of the explicit aims of the Government's anti-poverty strategy; yet many of the numerous measures introduced by the Government to tackle poverty benefit women considerably, and in some cases, more than men.
- There is a need to devise appropriate poverty measures to identify and count the poor. Present measures of poverty are not 'gender sensitive' enough.

Output

Bradshaw, J., Finch, N., Kemp, P.A., Mayhew, E. and Williams, J. (2003) *Gender and Poverty in Britain*,

Working Paper Series No.6, Equal Opportunities Commission, Manchester.

Take-up of the Minimum Income Guarantee

Completed Project

*National Audit Office
February 2002 to April 2002*

*Gary Craig (University of Hull), Paul Dornan
(Department of Social Policy and Social Work) and
Jonathan Bradshaw*

The objective of this study was to explore the impact of additional benefit income on the living standards of older people. The work included a literature review, qualitative interviews with 25 hard to reach older people and secondary analysis of the Family resources and Family Expenditure Surveys.

The main findings were that older people experience a wide range of actual and potentially beneficial impacts as a result of the receipt of additional benefit income to which they have been entitled but which they had previously been unaware.

The research was used in the report of the National Audit Office (2002) *Tackling Pensioner Poverty: Encouraging take-up of entitlements*, HC37, TSO, London.

Output

Craig, G., Dornan, P. and Bradshaw, J. (2003) *Underwriting Citizenship for Older People: The impact of additional benefit income for older people*, Working Papers in Social Sciences and Policy No 9, University of Hull, Hull.

Use of the Social Fund among Families with Children

Ongoing Project

Department of Work and Pensions

May 2003 to February 2004

Peter Kemp, Naomi Finch, and Julie Williams

People in receipt of Income Support or income-based Jobseeker's allowance can apply to the Social Fund for a loan to help them pay for one-off or expensive items that are difficult to budget for out of their weekly benefit payment. The loans are interest-free and repaid by direct deduction from the recipient's benefit. This project is investigating the use of Social Fund budgeting loans by families with children. It aims to compare the characteristics and circumstances of families that apply to the Social Fund for a loan with those that do not apply. It is also looking at the impact of loans over time on well-being, financial hardship and debts. The method of investigation is secondary analysis of the Families and Children Survey data for 1999 to 2002 including the panel sample of lone parents and low-to-moderate income families within this survey.

Output

Finch, N. and Kemp, P.A. (2004) *The Use of the Social Fund by Families with Children*, In-house Report, Department for Work and Pensions, London [forthcoming].

The Role and Function of the Social Security Commissioners

Ongoing Project

Nuffield Foundation

May 2001 to March 2004

Roy Sainsbury with Trevor Buck, David Bonner and Sarah Scott (Leicester University)

This project, funded by the Nuffield Foundation, aims to chart the development of the role of the Social Security Commissioners since 1975 and to evaluate the effectiveness of their work for claimants and their advisers, and in the development of social security law. The research team, from the Universities of York and Leicester, is exploring (a) developments in the last 25 years, for example, changes in workloads, what might account for these, and how these have affected the capacity of claimants to obtain satisfactory resolutions of their appeals, and (b) the experiences of Commissioners and appellants concerning the appeal process.

Data have been collected using a variety of methods, including qualitative interviews with the Social Security Commissioners, legal officers and administrative staff, a telephone survey of appellants and their representatives, and analysis of administrative records.

Recommendations will be made for reforming and improving the operations of the Commissioners that will increase access to justice for social security claimants and child support clients.

Output

Bonner, D., Buck, T. and Sainsbury, R. (2001) Researching the role and work of the Social Security and Child Support Commissioners, *Journal of Social Security Law*, 8, 1, 9-34.



Poverty and Childbirth

Ongoing Project

Unfunded

December 2003 to July 2004

Emese Mayhew and Jonathan Bradshaw

Britain has relatively high rates of low birth-weight; social class differentials in birth weights are wide and appear to be growing; children born to teenage mothers have worse birth outcomes in terms of both mortality and morbidity and futures generally. The first sweep of the Millennium Cohort Study offers the opportunity for a new and more up-to-date investigation of the relationship between poverty and childbirth. The objectives of this study are to:

- derive measures of poverty and social exclusion from the variety of questions asked in the survey;
- estimate the proportion of babies born to women who were poor during their pregnancy and/or childbirth – including an estimate of those who were born to women receiving the childless single or couple rate of Income Support;
- describe the socio-economic characteristics of babies born poor;
- explore the relationship between poverty in pregnancy and birth outcomes including prematurity, birth-weight, birth complications, maternal mental well-being and mother child interactions.

The work will be published as a chapter in a book to be entitled *Children of the New Century*.

The Well-being of Children and Young People in the UK

Ongoing Project

Save the Children

October 2002 to March 2005

Jonathan Bradshaw and staff in SPRU, Centre for Housing Policy, Social Work Research and Development Unit, Department of Social Policy and Social Work

The project involves the production of a second volume on the state of children and young people in the UK. The book involves 23 chapters covering different aspects of the physical, cognitive, behavioural and emotional well-being of children. 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.

Key findings of first report

- Children's well-being varies by country and region as well as by age of child, gender, family type, ethnicity and socio-economic level.
- Children's well-being is improving overall but is also becoming more segregated. For example there is a growing gap between poor children and better-off children.
- Main positive trends: falling child poverty; declining infant mortality; increased rates of breastfeeding; better survival rates of cancer and cystic fibrosis; fewer children entering care; improved childcare provision; (high yet) falling teenage conception rates; improving housing conditions; improving educational attainment; drop in youth suicide rate.
- Main negative trends: increase in child obesity; falling immunisation rates; higher rates of self-reported morbidity; increase in diabetes and asthma, HIV and sexually transmitted infections; longer stays in care; reduced safe spaces for play; a fall in free play.

Output

Bradshaw, J. (ed.) (2002) *The Well-being of Children in the UK*, Save the Children, London.

data and professionals, policy makers, advocates, communities, children and youth.

The York team was responsible for deriving the indicators for the economic well-being domain.

**Multi-National Project:
Measuring and Monitoring Children's
Well-being**

Ongoing Project

Unfunded

Jonathan Bradshaw and Beverley Searle

The Multi-National Project for Monitoring and Measuring Children's Well-Being is an ongoing, multi-phase effort to improve our ability to measure and monitor the status of children around the globe. During phase One, over 80 experts from a variety of disciplines and organizations in 28 countries worked collaboratively to redefine the concept of children's well-being, and to identify new and more appropriate indicators for measuring and monitoring the status of children beyond survival. During this phase the project was known as 'Measuring and Monitoring Children's Well-being: Beyond Survival'. Five domains of children's well-being and approximately 60 indicators were identified. The project's second phase was launched in 2001 and will continue until 2005. Renamed as the 'Multi-National Project for Monitoring and Measuring Children's Well-Being', the objectives are fourfold:

- to identify indicator measures and build a reliable and valid scientific protocol for collecting new data on children's well-being;
- to build a collaborative multi-national network of partners and local researchers who use this protocol to study children's well-being;
- to develop an archive of the data collected in the national and local studies;
- to build a strategic plan for disseminating the knowledge gained from the studies, and to build partnerships with potential users of the

**UK Expert on National Action Plans for
Social Inclusion Panel**

Ongoing Project

European Union

January 2003+

Jonathan Bradshaw and Fran Bennett (University of Oxford)

At the Lisbon summit in 2000, the European Council agreed to adopt an 'open method of co-ordination' in order to make a decisive impact on the eradication of poverty and social exclusion by 2010. Member states adopted common objectives at the Nice European Council and all member states drew up National Action Plans against poverty and social exclusion (NAPs/inclusion).

Early in 2003, the European Commission established a group of non-government experts responsible for providing an independent critical review of member states' NAPs/inclusion. At the first meeting of the Group in Brussels on 26 February 2003, it was agreed that each country expert would produce three reports in the next period:

- A *First Report* by 15 April 2003, reviewing developments since the 2001-2003 NAP/inclusion. The report on the UK was submitted in April 2003. A *Second Report*, which updated the first report, and also reviewed the involvement of actors in the NAP/inclusion for 2003; the report for the UK was submitted on 21 August 2003.
- This *Third Report* is a review of the 2003-2005



NAP/inclusion for the UK, which was published on 31 July 2003 together with eight annexes. This review is designed to help inform the Second Joint Report on Social Inclusion being prepared by the Commission, especially the UK chapter in Part II.

Only the first of these reports is in the public domain. The work continues in 2004/5 and future reports will be published on the NAP website.

Output

Bradshaw, J. and Bennett, F. (2003) *First Report on the United Kingdom National Action Plan on Social Inclusion: Group of non-government experts in the fight against poverty and social exclusion*, Social Policy Research Unit, University of York, York.

Bradshaw, J. and Bennett, F. (2003) *Second Report on the United Kingdom Action Plan on Social Inclusion: Group of non-government experts in the fight against poverty and social exclusion*, Social Policy Research Unit, University of York, York.

A Comparative Study of Child Benefit Packages in 22 countries

Ongoing Dissemination

*HM Treasury and Department for Work and Pensions
March 2001 to February 2002*

Jonathan Bradshaw and Naomi Finch

This study replicates and extends a comparative study on the same topic undertaken by SPRU and published in 1993. It sought to collect details of the tax benefit package available to families with children. National informants were commissioned to complete a model families matrix providing details of how taxes, benefits and services impact on a range of families with a range of earnings levels. This data was used to compare the level and structure of the child benefit

package and how it varies by earnings, family type, number and ages of children. The national informants also completed a questionnaire which enabled us to place the results in the context of the demographic and labour market context in each country.

Output

Bradshaw, J. and Finch, N. (2002) *A Comparison of Child Benefit Packages in 22 Countries*, Department for Work and Pensions Research Report No.174, Corporate Document Services, Leeds.

Verbatim Quotations in Applied Social Research: Theory, Practice and Impact

Ongoing Project

*Economic and Social Research Council
November 2002 to September 2004
Anne Corden and Roy Sainsbury*

Less attention has been paid to the way qualitative researchers write than to data collection and analysis. In presenting findings from applied social research one technique is to include respondents' verbatim quotations within the author's written text.

The aims of the study are:

- to review conceptual and theoretical arguments for using verbatim quotations;
- to explore current beliefs and practice among social researchers;
- to investigate the views of those who speak the words presented;
- to test accessibility, acceptability and impact of different ways of including quotations in written outputs.

There are four stages to the research:

- a review of what the theoretical and



methodological textbooks say about using quotations;

- a review of recent social research texts, to identify different types of use of quotations;
- selection of 12 illustrative texts, and exploration of preferences about using quotations with the authors, and research users (policy makers, funders, other researchers);
- testing the impact of different approaches, with three versions of a report from a small study of low-income households.

In 2003 progress was made with the first three stages of the project. After completion of the research, findings will be published in a book and academic papers. This study is funded as part of the ESRC Research Methods Programme.

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UNIT STAFF AND PROFILES

DIRECTOR	Professor Peter Kemp BSc MPhil DPhil
PA TO THE DIRECTOR	Lisa Goode BA
UNIT ADMINISTRATOR	Jeanette Whalley BA
ASSOCIATE DIRECTOR	Professor Jonathan Bradshaw BSS MA DPhil
CHILDREN AND FAMILIES TEAM	Bryony Beresford BSc PhD Sue Clarke BA Anita Franklin BA MSc Veronica Greco BSc DPhil Janet Heaton BA Wendy Mitchell BA MA DPhil Parvaneh Rabiee BA PgDiploma MA PhD Professor Patricia Sloper BA MA PhD (Team Leader)
<i>Team Secretary</i>	<i>Teresa Frank</i>
COMMUNITY CARE FOR ADULTS TEAM	Hilary Arksey BA PhD Professor Caroline Glendinning BA DipComWk MPhil (Team Leader) Jennifer Harris BA PhD CQSW Michael Hirst BA PhD DipSocAdmin Michele Foster BsocWk PhD Karen Jackson BA MA Charles Patmore BA
<i>Team Secretary</i>	<i>Sarah Starkey BA</i>
SOCIAL SECURITY TEAM	Jonathan Bradshaw BSS MA DPhil Anne Corden BA DipSocAdmin Naomi Finch BA MSc Emese Mayhew MA Katherine Nice LLB MA Roy Sainsbury BA PhD (Team Leader) Patricia Thornton MA DipSocAdmin
<i>Team Secretary (SENIOR SECRETARY)</i>	<i>Sally Pulleyn</i>
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INFORMATION OFFICER	Rachel Pitman BA MA
INFORMATION ASSISTANT	Ruth Dowling BSocSc
CLERICAL ASSISTANT	Maureen Brownbridge
CARE CO-ORDINATION NETWORK UK NETWORK MANAGER INFORMATION AND MEMBERS' OFFICER	Katy Barton BA DipSocAdmin CQSW Rachel Hazelwood BA

UNIT STAFF AND PROFILES

Research Staff



Hilary Arksey joined SPRU in 1995 as a research fellow in the Community Care for Adults Team. Her research interests are in the areas of informal care; carers, disability and employment; and qualitative research methods.

Her research projects include an evaluation of the process and outcomes of assessment under the Carers (Recognition and Services) Act 1995 and an examination of employers' provisions for carers. She has recently completed studies focusing on the effectiveness and cost-effectiveness of services for carers for people with mental health problems, barriers to carers' access to healthcare, and the effectiveness and cost-effectiveness of respite services and short-term breaks for carers for people with dementia. Hilary's current work includes a project looking at community nurses' involvement in public health and a new study of carers' aspirations and decisions around work and retirement.



Bryony Beresford joined the Unit in 1991, and during that time has carried out research on a number of issues concerned with disabled or chronically ill children and adolescents and their families. Her work has included research

on children and parents' needs (for example, housing, community equipment, information) as well as studies concerned with issues of service provision and multi-agency working. She is currently working on a project looking at the outcomes disabled children and their families desire from support services, and how information about outcomes can be collected and used by services. Bryony's on-going interests include developing methodologies for research with children, children's experiences of illness and disability, and the issues and processes surrounding the implementation of research findings into practice. Bryony acts as research advisor to the Family Fund and was a member of the Housing and Equipment Task Group of the Disabled Children's External Working Group (EWG) for the forthcoming Children's National Service Framework. She was also involved in reviewing evidence to inform the work of the Disabled Children's EWG.



Jonathan Bradshaw has been Associate Director of SPRU since 1994 and is a member of the Social Security Team. He is Head of Department of Social Policy and Social Work. His research interests include social security policy; family policy; poverty and living standards; comparative social policy; demography and social policy; well-being of children. His current research includes: welfare policy and employment in the context of family change (Nordic Research Council); COST Action 19 Child Well-being (EU); UK expert on National Action Plans for Social Inclusion panel (EU); and Analysis of the Millennium Cohort poverty data. He teaches quantitative methods, demography and social policy and comparative social policy in the Department.



Sue Clarke is a research assistant in the Children and Families Team. Sue is currently working on a study of the care and support needs of children and young people with cancer and leukaemia and their families, funded by the charity CLIC. She joined SPRU in January 2000 to administer the Sharing Value project, funded by the Community Fund. This involved a large-scale UK-wide survey of disabled children and their families to identify the support services they valued. The Sharing Value Directory of examples of valued support services is available on the internet.



Anne Corden joined the Unit in 1980, having previously worked as a social worker. She has conducted long programmes of work on take-up and delivery of in-work benefits, low-income self-employment, financial and regulatory systems for people at lower income levels, transitions to and from paid work, and disability and employment. Anne specialises in qualitative research methods; she has carried out comparative and evaluative research, and also has experience of research in local areas and communities.

UNIT STAFF AND PROFILES

Research Staff



Naomi Finch is a research fellow in SPRU and has undertaken research focusing on issues of poverty, living standards, employment and family policy. These have been for both governmental and other funders. Mainly a quantitative researcher, she has skills and experience of both quantitative and qualitative data collection and analysis. Current work includes a comparative project on welfare policy and employment in the context of family change (funded by the Nordic Council of Ministers), which explores the relationship between the three themes. Also, she is undertaking a qualitative study on lone parents, childcare and work (Department for Work and Pensions), which explores lone parents' perceptions and experiences of different kinds of childcare and how these are balanced with decisions about employment. Naomi has also recently completed a comparative study of Child Benefit Packages in 22 countries (completed for DWP), which involved analysis of all aspects of the child benefit package, including a comparison of the costs and benefits for different family types.



Michele Foster joined SPRU in January 2004 from the Research Centre for Clinical Practice Innovation at Griffith University, Queensland, Australia. She has recently managed a two-year evaluation of a chronic disease self-management programme for older adults. Her PhD examined referral practices and factors influencing referral to rehabilitation following traumatic brain injury. Her research interests include: equity and access to services for people with long-term disabilities and factors influencing professional decision-making, and the implications for social and health policy.



Anita Franklin joined the Unit in April 2003, after working for four years within the research department at The National Children's Bureau. Anita is particularly interested in the research of children and young people's participation, and she is currently working on a project entitled 'The participation of disabled children and young people under Quality Protects'.



Caroline Glendinning joined SPRU in January 2004 to lead the Unit's programme of research on adult community care. Before this she was Professor of Social Policy in the National Primary Care Research and Development Centre at the University of Manchester, where she led a programme of research on partnerships between primary care and other services and sectors. During 2003 she was seconded to the Audit Commission to work on a series of studies on older people in partnership with Better Government for Older People. Since 1998 she has served on research commissioning groups for the Department of Health, ESRC, Joseph Rowntree Foundation and the Mental Health Foundation. She is also a member of a number of Editorial Boards, including those of the journals *Social Policy and Society* and *Social Policy and Administration*, and the Policy Press. Caroline was Honorary Secretary of the Social Policy Association from 1997-2000 and had responsibility for the overall strategic development and co-ordination of the Association's work. From 2000 to 2003, she was Vice Chair of the Social Policy Association, with responsibility for its external relations, including liaison with the Academy of Learned Societies in the Social Sciences, the British Academy and other 'learned societies'. She is herself an Academician of the Academy for the Learned Societies in the Social Sciences.



Veronica Greco joined SPRU in October 2002 after working for two years as a post-doctoral research fellow in the Department of Psychology at the University of Sheffield, in a project on Quality of Life of children with cancer, funded by Cancer Research UK. Previously, she had completed a DPhil in psychology at the University of York. Veronica's research is within the Children and Families Team at SPRU whose work centres around research on the needs and experiences of disabled or chronically ill children and their families. She is currently working on a project entitled 'An exploration of different models of multi-agency partnerships in key worker services for disabled children: effectiveness and costs'.

UNIT STAFF AND PROFILES

Research Staff



Jennifer Harris joined SPRU in January 2000 as a Senior Research Fellow. She leads SPRU research for the Department of Health on disabled adults of working age. Her research interests are in the fields of cultural deafness, disability studies and qualitative research methods. Jennifer has an international reputation for her work in the field of qualitative methodology and in site co-ordinator for the International Institute for Qualitative Methodology in Alberta, Canada.



Janet Heaton graduated in Sociology from the University of York in 1986. She joined SPRU in 1996 from the Nuffield Institute for Health at the University of Leeds, having previously worked as a researcher in the NHS. She has worked on a number of research projects at SPRU, including studies on: carers' perspectives on hospital; discharge arrangements for young adults with physical and complex disabilities; the effectiveness of rehabilitation therapies following total hip replacement; the measurement of outcomes of equipment and adaptations; and the organisation and effects of home care regimes on technology-dependent children and their families. She is currently working on a study looking at children's, young people's and parents' access to and use of Patient Advice and Liaison Services (PALS). She is also interested in qualitative research methods and has recently published a book on the re-use of qualitative data called 'reworking qualitative data' (published by Sage).



Michael Hirst joined SPRU in 1981 to develop a programme of research on disabled young people, including the delivery of benefits and services and informal care. He left SPRU in 1992 but returned in 1994 since when he has worked part time on a number of projects, including the evaluation of the disability living allowance, take-up of Family Fund grants, the development of a knowledge-based system for the adjudication of disability benefits, and variations in practice nurse provision. Michael has also worked for the Disability Services Research Partnership, carrying out research for

the Employment Service. His current research interests include the dynamics of informal care and health outcomes for unpaid carers.

Karen Jackson joined SPRU in 1998 as the Director's PA and became a research fellow in the Community Care for Adults Team in January 2003. She has worked with Dr Hilary Arksey on two literature reviews for the NHS Service Delivery & Organisation (SDO) Research and Development Programme - Barriers to Access to Health Care for Carers and Interventions to Remedy Variations; and Respite Services for Carers for People with Dementia. Karen is currently working with Jennifer Harris on a project looking at outcomes for disabled service users.



Peter Kemp has been Director of the Social Policy Research Unit, and Professor of Social Policy, since 2002. Before returning to York he was Professor of Housing and Social Policy at the University of Glasgow. Between 1990 and 1995 he was the first holder of the Joseph Rowntree Chair of Housing Policy, and founding Director of the Centre for Housing Policy, at the University of York. He has a long-standing interest in the implementation of policy and the outcomes that result from it. Having spent many years studying housing policy, Peter's research is now focused on social security, welfare reform, welfare to work and housing benefit. Recent projects include a review of ladders out of poverty, research on use of the Social Fund by families with children, and a study of employability and problem drug users. His current projects include a comparative study of trends in incapacity benefits and a study of carers' aspirations and decision-making about employment and retirement. Peter is General Secretary of the Foundation for International Studies of Social Security, a member of the research advisory board of the International Social Security Association, and a member of the Department for Work and Pensions' Housing Benefit Reform Steering Group. He is on the Editorial Board of the *Journal of Social Policy*.



UNIT STAFF AND PROFILES

Research Staff



Emese Mayhew joined SPRU in 2002 after completing an MA in Social Policy at the University of York. She has worked on a variety of projects at SPRU, including studies of: child demography and child poverty; gender inequality; youth poverty; comparative research of family benefit packages; and health care access for carers. Her current project concerns poverty during pregnancy and related health outcomes for children using secondary analysis of the Millennium Cohort Study. Emese's interests are in the fields of poverty and social exclusion; comparative social policy; family policy and demography.



Angela Meah joined SPRU in December 2003 as part of the team of researchers working on projects related to social security, employment and living standards. Her work involves carrying out case studies of service providers and an additional project focusing on outcomes for users. Her methodological interests include user participation, focus groups and oral life histories. Her background before coming to SPRU was in exploring issues concerning gender, sexual knowledge and sexual risk.



Wendy Mitchell joined SPRU in January 2000 from the University of Teesside, where she worked on a community-based project exploring young people's perceptions of risk and everyday risk management strategies. Before that, she completed doctoral research into the post-school leaving experiences of disabled young people at the University of York. Since joining SPRU, Wendy has combined her research interests in the fields of youth, disability studies and qualitative research methods involving young people within three projects: Sharing Value - developing a website and print directory of user commended support services for disabled children and their families; The Care and Support Needs of Children and Young People with Cancer or Leukaemia and their Families; and Implementing and Evaluating the Integrated Children's System.



Katharine Nice joined SPRU in November 2003 after completing her Masters degree in Social Policy at Birmingham University. Her work was on education policy, specifically investigating Headteachers' experiences and views of OFSTED inspections and the impact of inspection on their sense of professionalism. She is part of the Social Security Team whose work centres on research into employment, living standards and social security. She is currently working as part of the team commissioned by the Department for Work and Pensions to evaluate the Job Retention and Rehabilitation Pilot, and Incapacity Benefit Pathways to Work Pilot.



Charles Patmore joined SPRU in 1997 to work on community care for older people. Prior to joining SPRU, he was a research officer in Social Services. His current 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. Currently he is concluding a research project on factors which enable home care for older people to be flexible and person-centred.



Parvaneh Rabiee joined SPRU in October 2001. She is currently working within the Children and Families Team research programme, on a project identifying priorities and perceptions of disabled children and young people and their families regarding the outcomes of social care. She was previously a research fellow in the Centre for Disability Studies at Leeds University where she completed work on a project involving young disabled people leaving care, an evaluation project concerning 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. Parvaneh has contributed to the MA and Diploma courses in Disability Studies at Leeds University. Parvaneh's other research interest is developing methodologies for research with children.

UNIT STAFF AND PROFILES

Research & Support Staff



Roy Sainsbury joined SPRU in 1988. He leads the social security and living standards team of researchers in SPRU with particular responsibility for projects commissioned by the Department for Work and Pensions. His research interests include social security and the labour market, sickness and disability benefits, housing benefit, and the administration and delivery of benefits, including social security fraud. Current projects include evaluations of three government welfare to work programmes: the New Deal for Disabled People, the Job retention and Rehabilitation pilots, and the incapacity benefit reform pilots. Roy has been a member of government advisory bodies on disability benefits and social security fraud, and is currently a member of the *Journal of Social Security Law* editorial board and the editorial board for the journal *Benefits*.



Patricia Sloper joined SPRU in October 1995 and leads the Children and Families Team research programme. Her research interests include the needs of children and young people with chronic illness or disability and their families; psychosocial issues in health, particularly in relation to stress and coping; research on the views of users of services; multi-agency working in children's services and the implementation of research findings in policy and practice. She has published extensively on topics concerning childhood disability and chronic illness. Patricia is a member of the Children's National Service Framework External Working Group on Disabled Children and the Children's National Service Framework Research Group; York Health Services NHS Trust Research Ethics Committee and the City of York Children's Trust Board. She was awarded a personal chair in 2001.



Patricia Thornton who joined SPRU in 1987 is a Senior Research Fellow. Her main research interests lie in policies and services to support the labour market participation of disabled people and people with health problems both in the UK and comparatively. She has worked on a number of evaluations of Government programmes to

support moves into work amongst recipients of incapacity related benefits, including the current New Deal for Disabled People national extension, and is involved in the evaluation of the Job Retention and Rehabilitation pilots. Since 2002 she has directed an evaluation of the WORKSTEP programme for the Department for Work and Pensions, through the Disability Services Research Partnership, which she manages.

Support Staff

Maureen Brownbridge provides clerical support to the Information Office, the Unit Administrator and the Secretarial Team.



Laura Clark graduated from the University of Manchester with an MA in Social Anthropology. Before joining SPRU, Laura worked in the insurance industry as an underwriter and account handler. She became the Unit Finance Assistant in August 2003. Laura is responsible for the administration of the Unit's general finances and research grants. Her role involves reporting on and monitoring project budgets, processing invoices and expense claims, dealing with income received and administering petty cash.



Ruth Dowling works as Information Assistant in the Publications and Information Office. Before joining SPRU in 1992, she worked as the Administrator for a housing association in Bradford.



Teresa Frank joined SPRU in 1993. She is personal assistant to Patricia Sloper and she provides secretarial and administrative support to the Children and Families Team.



UNIT STAFF AND PROFILES

Support Staff



Lisa Goode joined SPRU in November 2003. She is personal assistant to the Director and is responsible for administration of the Senior Management Group.



Rachel Pitman joined SPRU in June 2003 and is responsible for the Unit's Information Service. This includes maintenance and improvements to the website, publicising the Unit's work, responding to external enquiries, and working closely with the research and support staff to ensure their information needs are met. Rachel is involved with the creation and running of the new Alcuin Research Resource Centre Library and Archive service. The ARRC initiative is a new multidisciplinary collaborative support infrastructure for researchers, created on the Alcuin site of the University. Prior to joining SPRU she worked for The British Library as a team manager in their cataloguing department.



Sally Pulleyn joined SPRU in 1989. She is personal assistant to Roy Sainsbury and provides secretarial and administrative support to the Social Security Team. Sally is Senior Secretary and is responsible for the overall management of the secretarial staff.



Sarah Starkey joined SPRU in 2000. She is personal assistant to Caroline Glendinning and provides secretarial and administrative support to the Community Care for Adults Team. As Systems Secretary to the Unit, Sarah is responsible for software support, with particular interest in systems development.



Jeanette Whalley graduated in Leisure and Tourism Management from the University of North London in 1995. She has since worked for the Royal College of Physicians of London as Research Unit Administrator, before moving to Yorkshire. Jeanette joins SPRU from her previous position of Research Administrator at the Institute for Transport Studies at the University of Leeds, where she spent four years. She was appointed to the post of Unit

Administrator in October 2003 and takes responsibility for Unit finances and personnel issues.

Julie Williams graduated from the University of Bradford with an honours degree in Mathematics. Before joining the Unit she was an applications programmer in the Computing Service at the University of York. Julie provides statistical assistance with general survey and data analysis, including secondary analysis of the Family Resources Survey. She is also involved in the design and development of databases used within SPRU and in supporting computer users.



Care Co-ordination Network UK

Katy Barton joined SPRU in 2001 as Development Co-ordinator for a new organisation - Care Co-ordination Network UK. In April 2003 she was appointed as Network Manager. Her professional experience includes over 20 years in the social work field as a manager and practitioner in both the statutory and voluntary sector. Her interests are in disabled children and their families. Prior to joining SPRU she worked for the Family Fund and she has recently updated and revised one of their publications, *Taking Care*. She was also involved with helping the Trust to look at the practical implications of using the social model of disability.



Rachel Hazelwood joined the Care Co-ordination Network UK in July 2003 as the Information and Members' Officer. Rachel assists the Network Manager in managing and developing the work of CCNUK by providing information and support to members. She also provides administrative support to the charity. Prior to joining the Network, Rachel worked as a production co-ordinator for Yorkshire Television. She was also secretary of the York Coalition of Disabled People, a group, which promoted awareness of the Disability Discrimination Act around York by implementing projects such as the Yellow Card Scheme. Yellow cards were given as a warning to venues, which were inaccessible to disabled people.



