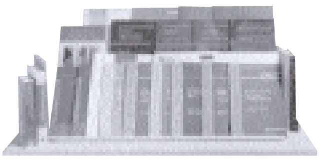
contents

ANNUAL REPORT 2001 – 2002



introduction

BY THE DIRECTOR

Professor Peter Kemp

It gives me great pleasure to write my first Director's introduction to the annual report of the Social Policy Research Unit (SPRU). The report describes our research and publications during the year from April 2001 to March 2002.

SPRU is a research centre based within the Department of Social Policy and Social Work at the University of York. We undertake and disseminate research on health and social care, poverty, social security, and employment. Research within the Unit is organised around three teams: Children and Families, Community Care for Adults, and Social Security and Living Standards. Our work is informed by a number of guiding principles.

Firstly, we undertake work that is relevant to public policy and practice. Our aim is to contribute to the evidence base underpinning policy and practice and thereby to help enhance the lives of people made vulnerable by poverty, ageing, chronic illness or disability. As part of this, we are committed to the effective dissemination of the findings of our projects. In addition to publishing in peer-reviewed academic journals, we produce publications such as research reports, summaries, and good practice guides that are accessible to a range of different audiences. Equally, we contribute to the development of policy and practice by organising and participating in various networks, meetings and other forums. Not all of these activities are undertaken as part of research projects. Indeed, many are funded out of SPRU's own resources. However, they are often as important as our publications in influencing policy and practice. Current examples include our contribution to the development of the Children's National Service Framework, advice to the Scottish Parliament's crosscutting expenditure review of children in poverty, and membership of the steering group overseeing the implementation of Housing Benefit reform. We also engage with practitioners through activities such as our Outcomes into Practice Network.

A second guiding principle for SPRU is to undertake research that is methodologically rigorous, stands up to external scrutiny (including peer review), and conforms to ethical principles. Of course, research is often constrained by very tight project timetables and limited budgets. Nonetheless, within these constraints we aim to undertake research that is robust and of international excellence. Much of our funding is won through competitive tendering processes and our Department of Health funded programme of research on the outcomes of social care is subject to scientific review. In addition, our work contributes to the Research Assessment Exercise (RAE) returns of our parent department (which was awarded a rating of 5 for Social Policy and 5 for Social Work in the latest RAE).

A third commitment underpinning our work is to report the views and experiences of service users. This includes people who are often neglected in research, such as people who suffer from dementia, are dependent on medical technology, or have communication difficulties. We also consult service users in order to ensure that they are involved in shaping our projects and are not just the passive 'subjects' of research. A good example of this is our Department of Health funded programme of work on the outcomes of social care. An important aspect of our work within the programme has been research on the views of service users about what they consider to be the desirable outcomes from social care. Both the Community Care for Adults Team and the Children and Families Team have been involved in the outcomes programme of research.

A fourth guiding principle is to recognise that people's lives are complex and not readily divisible into separate compartments that reflect and suit professional and agency boundaries. We aim, therefore, to undertake studies that cross professional divisions and take into account the holistic nature of people's lives. For example, co-ordinated care or key working for disabled children and their families is the central concern of the Care Co-ordination Network UK, which is based within SPRU and developed with sponsorship from the Joseph Rowntree Foundation (JRF). Similar concerns have led the Government to emphasise what is often now referred to as 'joined up' policy and practice.

Although not a guiding principle, an important component of SPRU's research portfolio is comparative work, particularly in the areas of poverty, employment and social security. One example of our comparative work in this year's annual report is the completion of a major study, funded by HM Treasury and the Department for Work and Pensions, of child support in 22 countries. This project built upon a stream of comparative social security research projects that have been carried out in SPRU, including a previous study of child support. Another recently completed comparative project involved a review of research evaluations of interventions designed to enable disabled people to enter, sustain or retain paid employment.

Much of our comparative work has involved collaboration with researchers and research institutes in other countries. Working in collaboration with others is also becoming an increasingly important aspect of our UK focused research as well. Although working with researchers based elsewhere can add to the complexity of project management, it can also generate considerable added value, especially by bringing together different skills and expertise. Moreover, the scale of some projects is such that working in research consortia is the most effective or sometimes the only way in which they can be carried out.

SPRU has also benefited considerably from collaboration with colleagues in the University of York. This includes projects undertaken with the Centre for Housing Policy (CHP) and the Social Work Research and Development Unit, which are also based within our parent department. One example here is our research on the housing needs of disabled children and their families, the third of a series of projects on this theme funded by JRF and undertaken in collaboration with CHP.

One exciting new development within the University is the 'Alcuin Collaboration'. This involves the health and social policy departments and research units in the University moving together to the newly redeveloped Alcuin College. It will provide many new opportunities for joint working and strengthening the links between researchers in health and social policy. I shall report in more detail on this venture in the next annual report. Within SPRU, other future developments will include building up our research on carers, undertaking more projects that reaches across our three research teams, and expanding our work on social security, tax credits and employment.

I would like to finish by recording some acknowledgements. We were delighted that our nomination of Philippa Russell CBE (Director of the Council for Disabled Children) for an Honorary Degree of the University of York was successful. Philippa has been a tireless campaigner for improvements in social, health and educational services for disabled children and their families. Over the years, she has also provided advice on numerous research projects conducted in SPRU and we are, as ever, indebted to her for her time, energy and wisdom.

introduction BY THE DIRECTOR

I would also like to thank Professor Toyo Okamura, from Kyusyu Sangyo University in Japan, who was a Visiting Fellow in SPRU during the year. As well as carrying out his own work on the role of the voluntary sector in the UK, Toyo added considerably to our knowledge of social policy in Japan.

For eleven of the twelve months covered by this annual report, the Director of SPRU was Professor Sally Baldwin. She took over as Director in October 1987 and remained in post until February 2002. I would like to thank Sally for her great skill, hard work and dedication in developing the Unit and building so successfully on the foundations laid by the first Director, Professor Jonathan Bradshaw.

Since taking over as Director, I have been greatly impressed by the professionalism and commitment of the research staff in the Unit and the secretarial and administrative staff that support them in their work. The pages that follow are a credit to them all.

HEALTH AND SOCIAL CARE RESEARCH PROGRAMME

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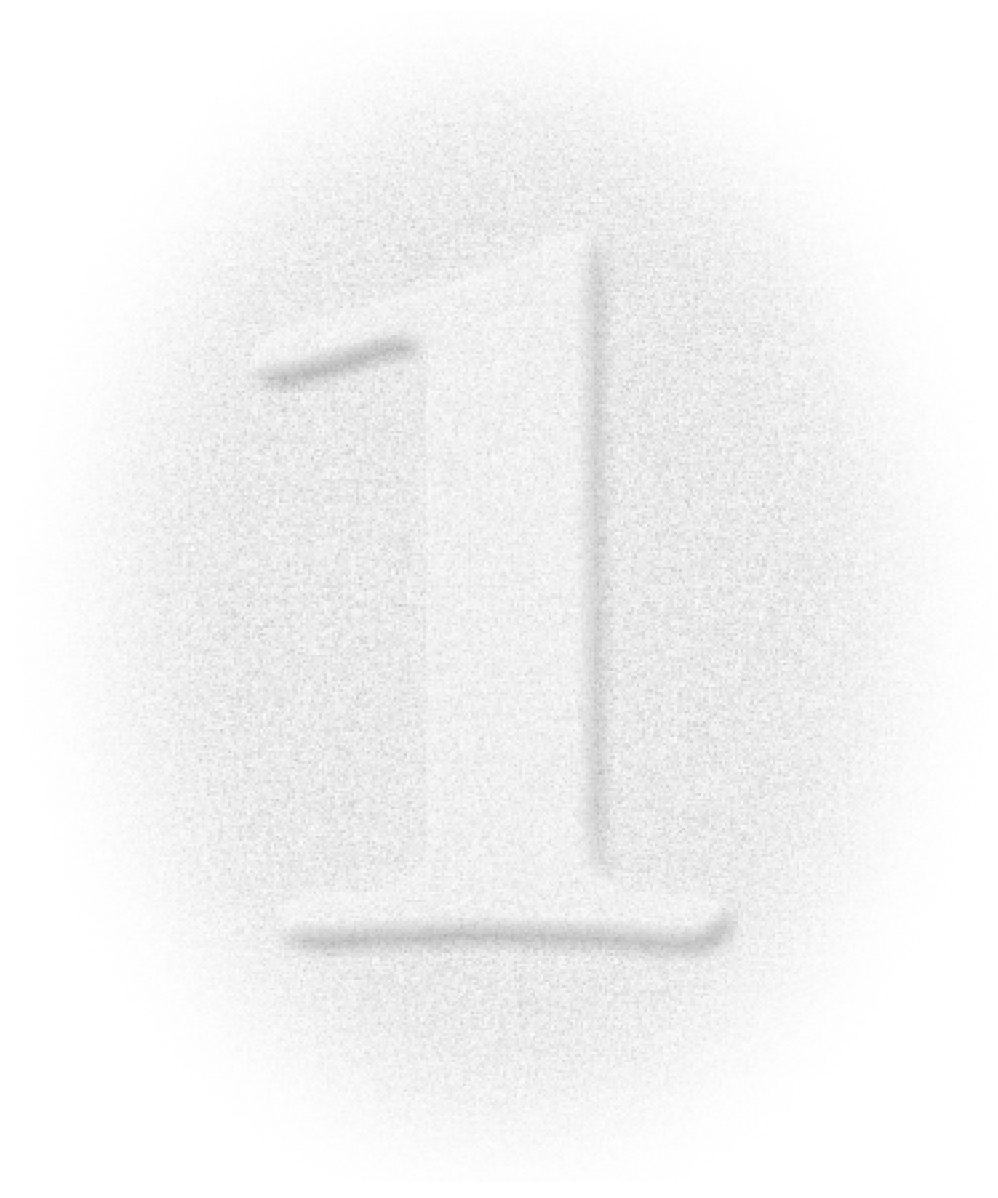

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HEALTH AND SOCIAL CARE RESEARCH PROGRAMME

introduction

Community Care for Adults Team


Professor Hazel Qureshi

Ensuring service quality and taking account of user views remain high on the agenda of policy makers. The establishment of the Social Care Institute for Excellence, and the implementation of Best Value and performance assessment in Local Authorities, and the National Service Frameworks, are all evidence of this continuing emphasis. The focus of the team's work has continued to be on research that aims to ensure the improvement of policy and practice through taking account of the views and experiences of people with chronic illness, disability or impairment, and their families. Pursuit of this aim has encompassed a range of studies including reviews of literature and secondary analysis of large-scale data sets, as well as primary studies. We have valued being able to obtain funding for work with groups often marginalised or excluded such as disabled refugees and asylum seekers, and family carers from minority ethnic groups. As well as producing research reports and published papers, team members have presented their work at a range of national conferences, and have contributed to international conferences in Ambleside, Banff, Helsinki, Montreal, and Vancouver. We have undertaken collaborative work with user and carer organisations, councils with social services responsibilities, the NHS Centre for Reviews and Dissemination (based in the University of York), the Refugee Council, independent consultants and the Office of National Statistics.

During 2001 a new set of projects on outcomes of social care for adults were negotiated and agreed with the Department of Health, as part of a programme of work on outcomes and service quality. As will be reported, these projects have now commenced, and include work on home care, and care management services for a range of service user groups. At the same time, we have continued to promote and monitor use of the tools and guidance developed in the Unit's previous programme. We have also continued to work collaboratively with a range of councils with social services responsibilities, to develop and test training and other resources to support outcome-related developments in agency organisation and practice. The final report of the programme was published in November 2001, and a steady flow of publications and presentations has continued dissemination of the findings.

Funding for the team's work has been received from a range of Government and voluntary sector sources including the Department of Health (Policy Research Programme and Inequalities in Health Research Initiative), the NHS Service Delivery and Organisation R&D programme, National Lottery Charities Board, Joseph Rowntree Foundation and the Sir Halley Stewart Trust.

Team members during the year:
Hilary Arksey, Jennifer Harris, David Hepworth, Michael Hirst, Hannah Morgan, Elinor Nicholas, Charles Patmore, Hazel Qureshi, Keri Roberts. Administrative and secretarial support was provided by Sarah Starkey and Sally Pulleyn.

Services to Support Carers for People with Mental Health Problems

Completed Project

NHS Service Delivery & Organisation (SDO) Research and Development Programme

October 2001 to March 2002

Hilary Arksey, Lisa O'Malley, Sally Baldwin and Jennifer Harris (SPRU); Anne Mason (Centre for Health Economics); Elizabeth Newbronner and Philippa Hare (Acton.Shapiro).

Up to 1.5 million people may be involved in caring for a relative or friend with a mental illness or some form of dementia. Recent government policy, including the national strategy for carers and the National Service Frameworks (NSFs) for Mental Health and Older People, puts a high priority on meeting the practical, health and emotional needs of carers for people with mental health problems. Given the current emphasis on research-based evidence, it is important to find out just what is known about the effectiveness and cost-effectiveness of services to support this group of carers. We were commissioned by SDO to undertake a scoping review of evaluation studies. The overall aim was to advise the SDO Programme what further research should be commissioned in this area.

There were two elements to the study. First, a review was conducted of research reports evaluating interventions for carers of people with mental health problems published between 1985 and 2001. Secondly, a consultation exercise was undertaken with three groups of stakeholders, including national, local organisations and key informant carers.

Key findings:

- Evaluations are required of individual interventions directly or indirectly relevant to the implementation of recent legislation and major policy initiatives. These include: carers assessments; breaks from caring; family support; educational and training programmes; support groups for carers; telephone and computer-based technology; provision of information, advice and independent advocacy
- Research focusing on interventions for specific groups of carers, particularly young and young adult carers, and Black and ethnic minority carers, is needed
- Further economic research on all interventions is needed, with the possible exception of assertive outreach for patients with severe mental illness
- Studies of services and interventions in their natural or everyday health and social care context would be valuable
- Alternatives to standard outcome measures should be explored

Reports

Arksey, H., O'Malley, L., Baldwin, S., Harris, J., Newbronner, E., Hare, P. and Mason, A. (2002) *Services to Support Carers of People with Mental Health Problems: Overview Report*, York: Social Policy Research Unit, University of York.

Arksey, H., O'Malley, L., Baldwin, S., Harris, J. and Mason, A. (2002) *Services to Support Carers of People with Mental Health Problems: Literature Review Report*, York: Social Policy Research Unit, University of York.

Newbronner, E. and Hare, P. (2002) *Services to Support Carers of People with Mental Health Problems: Consultation Report*, York: Social Policy Research Unit, University of York.

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HEALTH AND SOCIAL CARE RESEARCH PROGRAMME

Community Care for Adults Team

Evaluation of People into Employment Pilot Project

Completed Project

People Into Employment (PIE) Project
April 2001 to March 2002
Hilary Arksey

The government is keen to support disadvantaged groups into employment. Partnership is also a central plank of UK government policy. This was an evaluation study of project-based partnership working. The partnership arrangements supported People into Employment (PIE), a pilot project based in Sunderland in the north east of England. PIE aimed to help disabled people, carers and former carers obtain jobs, or improve their employability. In the evaluation of the effectiveness of the services offered by PIE, the study also aimed to identify the project's strengths and examples of good practice, as well as areas where there was scope for further development.

The research design involved collecting both quantitative and qualitative data at two points in time. We administered two postal questionnaire surveys of PIE clients, and conducted qualitative interviews with clients, the Project Development Officer and professionals from partner agencies and employers. An interim evaluation report, based on the Time 1 findings, was produced in September 2001. This report contained a list of key messages; those that could be taken forward were addressed immediately. The final report, drawing on both Time 1 and Time 2 findings, was completed in May 2002.

Key findings

- PIE was achieving its aims of helping disabled people and carers overcome the barriers they faced in obtaining employment.
- PIE's strengths included: the Partnership arrangements; excellent networking with other agencies; informality and flexibility; neutrality and independence; providing a first stop shop service; tailoring support to individual clients; the Project Development Officers dedication and commitment.
- For Partnerships to work well, roles and responsibilities must be clarified; it is better to work at the level of the organisation/system rather than the individual; on-going commitment is important.

Report

Arksey, H. (2002) *People into Employment Project: Final Report*, York: Social Policy Research Unit, University of York

Disabled Refugees in Britain

Completed Project

National Lotteries Charities Board and Joseph Rowntree Foundation
September 1999 to April 2002
Keri Roberts and Jennifer Harris

The aims of the project were to: investigate the numbers and social characteristics of disabled refugees and asylum seekers in Britain; identify the needs and experiences of disabled refugees in accessing social and welfare services; review changes to the social and welfare entitlements of disabled refugees; investigate service providers experiences of supporting disabled refugees and disseminate research findings to refugees, asylum seekers, their advisors and service providers. Qualitative interviews were undertaken with 38 disabled refugees across Britain to explore requirements for social and welfare services. Interviews were conducted by trained first language interviewers who recruited individuals from Somali, Vietnamese, Sorani (Kurdish) and Tamil communities. Qualitative interviews were also conducted with service providers to elicit their experiences of supporting disabled refugees and asylum seekers. These were eleven representatives from Refugee Reception Assistant Organisations and seven from local authorities.

Key findings

- Unmet personal care needs, unsuitable housing and lack of aids and equipment were common among the disabled refugees and asylum seekers interviewed. Other themes were: not knowing entitlements or how to get a community care assessment, communication difficulties and extreme isolation.
- Most workers in reception assistant organisations lacked knowledge about the disability-related entitlements and needs of refugees and asylum seekers.
- Service providers were critical of the government's dispersal policy and its lack of consideration for the needs of disabled people who are seeking asylum.
- There was a need for improved joint working between reception assistant organisations, local authority social services departments and NASS (National Asylum Support Service).
- With few exceptions, relations between key agencies seemed strained, arising from unclear policies and procedures, and lack of named contacts equipped to handle enquiries about disabled asylum seekers, especially in NASS.
- There was considerable confusion in and across agencies about responsibilities for financing community care packages and suitable housing.
- Social services resources were overstretched. Sometimes the needs of disabled refugees and asylum seekers were seen as less pressing than those of other disabled people in the locality.

Publications

Roberts, K. and Harris, J. (2002) *Disabled people in refugee and asylum seeking communities*, Joseph Rowntree Foundation / Policy Press Bristol.

Roberts K. & Harris J. (2002) *Disabled Refugees in Britain*, Final report for the Refugee Council and National Lotteries Charities Board, York, SPRU, University of York.

Roberts, K. & Harris J. (2002) 'Disabled people in refugee and asylum seeking Communities in Britain', *Findings*, York, Joseph Rowntree Foundation

Surveys of PSS User Satisfaction and Experience: designing new collection

Completed Project

Department of Health Social Care Division

October 2000 to September 2001

Hazel Qureshi and Olwen Rowlands (Office of National Statistics)

In partnership with ONS, SPRU won a contract to assist the Department of Health in preparing questions and guidance for surveys of user satisfaction and experience, required under the Modernising Social Services agenda. Members of SPRU and colleagues from the Social Work section of the department of Social Policy and Social Work prepared expert research-based briefings on aspects of service quality and service delivery that are important in achieving good social care outcomes for service users and carers. These briefings were used by ONS to develop and cognitively test questions for use in the surveys. SPRU also contributed expertise and networks of contacts to enable ONS to explore experiences of conducting user surveys, to inform the preparation of realistic guidance for authorities. Questions and guidance for the first wave of surveys will be issued later in 2002.

Publication

Qureshi H. and Rowlands O. (forthcoming 2003) 'User satisfaction surveys and cognitive question testing in the public sector: the case of personal social services in England', accepted by the *International Journal of Social Research Methodology: theory and practice*.

Outcomes into practice - Resource Pack and Network

Ongoing Project

Department of Health Policy Research Programme
January 2001 to September 2002
Elinor Nicholas and Hazel Qureshi

Building on earlier work within the Outcomes Programme (1996-2001), there has been continued collaboration between SPRU and staff from social and health care agencies who are actively engaged in implementing outcome-focused practice or information systems within their local contexts. This collaboration, which is facilitated mainly through the Outcome into Practice Network has been productive in:

- enabling the exchange of ideas and experience related to outcomes in practice,
- extending mutual learning about the opportunities for, and challenges of implementation,
- shaping materials for a Resource Pack to support implementation strategies, drawing on the findings of the Outcomes Programme, and the expertise of managers, trainers and development staff, some of whom have used, or adapted, the materials for use within their local contexts.

This year some network members have participated in a series of workshops exploring a variety of topics, including: the relevance of outcome-focused approaches to achieving key policy objectives, such as the National Service Framework for Older People, intermediate care and the single assessment process. Members have given lively presentations about their own development and training initiatives, which have included imaginative use of draft materials for the resource pack, and stimulated additional ideas and contributions for the latter.

A recent review of the network with members has indicated that it has made a valuable contribution to supporting and equipping those who are responsible for taking forward outcome-related innovations within their localities. Members appreciated the opportunity to meet with and learn from others who are engaged with similar developments, and were keen for the network to continue and possibly to broaden its remit and membership. The Resource Pack is being developed for publication.

Flexible, person-centred home care for older people

Ongoing Project

Department of Health Policy Research Programme
October 2001 to April 2004
Charles Patmore and Hazel Qureshi

This project aims to identify factors which enable Home Care to respond flexibly and effectively - yet within affordable resources - to heartfelt values and priorities among individual older service users. The first phase has been completed. This comprised gathering background information through a review of relevant literature and through a survey of how a sample of home care providers address issues pertinent to the project.

Community Care for Adults Team

From the literature review a report is to be published: *Towards flexible, person-centred home care services: guide to some useful literature for planning, managing or evaluating services for older people*. This includes summaries of some pioneering projects in person-centred services for older people in Britain and in the United States. The survey of home care providers comprised telephone interviews with managers at 23 home care provider services. These were a mix of Independent Sector and Local Authority providers in a set of Local Authorities selected for contrasting local circumstances. This data is being analysed.

Later stages of the project will include research and development in a range of local authorities, selected to reflect contrasting organisational models for the delivery of home care. Methods for review which include elicitation of user values and preferences, will be developed and tested, and the responses of these contrasting organisations to information derived from these reviews will be examined.

Publication
Patmore, C. (2001) ‘Improving home care quality: an individual-centred approach’, *Quality in Ageing* 2 (3), 15 - 24.

Outcomes For Disabled Service Users

Ongoing Project

Department of Health Policy Research Programme
January 2002 to December 2004
Jennifer Harris and Hannah Morgan

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. We are currently piloting the outcome-focused tools that we have developed in collaboration with local stakeholders. These stakeholders are senior social service managers, care managers, occupational therapists, social workers, domiciliary services officers, community care workers, day care staff and service users.

The initial stages of the project have involved a wide consultation exercise involving 84 social services staff and seven training sessions. A Service User Panel has been established and begun its work. In the next stage the tools will be subjected to trial implementation. A seminar is being planned in consultation with the leading service users organisation, *Shaping Our Lives*. Service users and representatives from social services across Britain will come together to discuss service outcomes for disabled people.

Later stages of the project will involve comparative testing to investigate the relative effectiveness of the new tools compared with conventional approaches.

Improving community care assessment and support for black and minority ethnic carers

Ongoing Project

Sir Halley Stewart Trust
July 2002 to September 2002
David Hepworth

This research followed on from a previous study into Carers Needs and the Carers Act and consultative workshops in Bolton and Tameside on Black and Minority Ethnic Carers and Access to Carers Assessment. Contact was made with black and minority ethnic carers through community groups and agencies in Bolton and

Tameside to use the carer assessment measures developed by Nolan et al. to gain an understanding of their perceptions of the caring role and test out the use of the measures. Local minority ethnic workers helped with planning the study, making contact with carers and acting as interpreters and support to interviews and group workshops. Most of the final sample of 28 Asian heavily involved carers took advantage of the assessment forms translated in first languages as well as English (Gujarati and Urdu) and accepted the support of minority ethnic workers in the interviews and discussions.

The analysis is not complete. The findings relate to the particular Asian carers and households who agreed to participate. Yet feedback meetings with minority ethnic staff and representatives have suggested that some preliminary findings do have credibility and relevance for the assessment and support of Asian carers more generally. These findings related to:

- High stress levels among the Asian carers
- Some suggestion that this was a reflection of what was happening in life generally and not just to do with the caring role.
- As with other carer study samples, the main sources of stress were the physical demands and carers reaction to caring, the carer/dependent relationship and restrictions on social life, with physical demands and restrictions on social life being the major sources of stress with the Asian carers.
- High levels of satisfaction generally, with certain sources of satisfaction rating very high, mainly linked with fulfilling their sense of duty, showing their faith and their personal development.
- Carers valued the availability of forms in their first language, many choosing to also use the English version for reference.
- Whilst, on the whole, the Asian carers found the forms to make sense and be relevant, and the process of completing and discussing them helpful, in many cases there was the proviso about the availability of translations and first language support being important.

Health Inequalities and Informal Care: A Prospective, Population-Based Study

Ongoing Project

Department of Health Inequalities in Health Policy Research Initiative

October 2001 to January 2004

Michael Hirst

This project is investigating the extent to which providing care for a relative, partner, or friend is associated with health inequalities. Health differences between carers and non-carers, and between different groups of carers, will be related to the incidence, timing, duration and intensity of caring episodes. By measuring the impact of care giving on health inequalities over time, the research aims to:

- Estimate the health risks for carers, focusing on their psychological well-being.
- Identify those carers who are most at risk of poor health and develop population estimates for a typical health authority and primary care trust.
- Discover when stress-related symptoms, anxiety and depression, are most likely to arise during a caring episode and beyond.
- Estimate the impact of caring-related health inequalities on the use of primary care and provide benchmark estimates to base service development.
- Describe and interpret trends in carers' health inequalities during the 1990s.
- Establish national baseline data that could be used to monitor recent initiatives on maintaining carers' health and reducing health inequalities.

The study is relevant to the National Strategy for Carers, the National Service Frameworks for Mental Health and for Older People, Health Improvement Programmes and partnerships between primary and social care. As well as increasing knowledge about caring-related health inequalities, the findings will inform policy, service developments and good practice in three arenas:

- Supporting carers in their caring role.
- Improving carers' mental and emotional health.
- Developing primary care-based recognition of carers' health needs.

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 ill health, and the Short-Form 36, a widely used health status questionnaire.

Partnership Initiatives in Communities

Ongoing Project

Joseph Rowntree Foundation
December 2000 to August 2002
Tim Newburn (London School of Economics), Alan Dearling (Enabler Publishing and Training Services) with Hilary Arksey

This is an evaluation study over a three-year period of socially isolated communities living in deprived council estates in receipt of Single Regeneration Budget funding in three different local authorities. SPRU is undertaking the fieldwork in one of the three areas. The aim is to see whether the spending has had any impact on residents' personal lives; what use they make of education and social welfare services and overall whether they feel that life on the estate is improving, staying the same or getting worse.

The research involved conducting interviews with two residents from different generations in twenty households on the estate. The study was longitudinal; each person being interviewed three times, nine months apart. The first round of interviews examined life on the estate in relation to: employment, education and training opportunities; leisure and recreational facilities; crime and community safety issues; shopping; transport and health care. Visual stimuli such as photographs and maps were used to arouse interest and generate in-depth responses.

The second round of interviews focused on how people passed their time in the neighbourhood, including taking part in local groups or clubs, voluntary work, and the impact of living in the area on their physical and mental health. Participants were given disposable cameras and asked to photograph places and people they felt were good or bad, safe or unsafe, or needed to be changed or improved in some way.

The final series of interviews took place in August 2002. Street maps of the area were used to explore boundary and territorial issues.

The analysis is being undertaken by Alan Dearling; the final report is expected to be available in spring of 2003.

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HEALTH AND SOCIAL CARE RESEARCH PROGRAMME

introduction

Children and Families Team

Professor Patricia Sloper

This has been stimulating and productive year for the Children and Families Team. Our work centres around research on the needs and experiences of disabled or chronically ill children and their families, with a particular focus on obtaining the views of children and young people, as well as those of their parents and the professionals involved in their care. During the last year, policy developments have underlined the importance of this approach. For example, the policy emphasis on patient and public involvement in healthcare has brought increased attention to the importance of finding out children's and their families' views of their care and treatment. The development of the Children's National Service Framework (NSF) now provides an outstanding opportunity to improve services for children and young people. The views of children and young people, parents and carers are central to the development of the NSF. In addition, there is a strong emphasis on producing standards which are based on research evidence. Members of the team are playing an important part in the NSF, as part of the External Working Group on Disabled Children, and in reviewing the evidence for the standards to be set by this group.

Part of the work of the NSF External Working Groups is to find examples of good practice from which other services can learn. The Children and Families Team's research to identify services commended by disabled children and their families has just been completed. We hope that the resulting 'Sharing Value Directory' of over 1,300 services will be valuable to policy makers and practitioners who want to find out about services seen by families as providing really good support, and to families who are looking for services. The directory will shortly be available on the world wide web (www.sharingvalue.co.uk).

The completion of another project has also coincided with an increase in policy interest in the topic addressed by the research. The project investigated the involvement of disabled or chronically ill children and young people in local health service development. A survey of health authorities and NHS Trusts in England identified a number of local initiatives and six of these were selected as case studies. Interviews with the young people and staff involved provided information on factors which can support and promote young patients' involvement in service development. We then worked with a group of staff and young people to draw up guidelines for involving young people in health services development. These will be published shortly and we are organising a national conference on this topic to be held in September 2002.

In the autumn of 2001, we commenced a new project investigating the perspectives of disabled children and their families on the outcomes they seek from services. This research will inform further work with partner agencies to develop and test ways of collecting outcome information in practice. The project is part of the Department of Health programme of work in SPRU and builds on both the Community Care for Adults Team's work on social care outcomes for adults and our own work on the experiences of disabled children and their families. We have welcomed the opportunity for cross team collaboration and a series of meetings of staff working on outcomes are proving extremely helpful. Parvaneh Rabiee joined us in October as one of the researchers on this project.

The Care Coordination Network, which was set up in 2001, continues to develop and grow. Membership is now over 150. In April 2002, the Network held a highly successful conference, attended by 160 people, and it is now producing a regular newsletter, providing information on care coordination and key working projects throughout the UK.

Further details of these and other projects and publications from the team are provided in the following pages. Team members have continued to publish in national and international journals and to present their work at a variety of conferences. With more new projects starting in late 2002 and early 2003, we expect the next year to be as energetic as this one.

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

HEALTH AND SOCIAL CARE RESEARCH PROGRAMME

Children and Families Team

Involving Children and Young People with a Chronic Illness or Physical Disability in local decisions about Health Services Development

Completed Project

Department of Health: Health in Partnership Initiative
July 1999 to January 2002
Jane Lightfoot and Patricia Sloper.

Emphasis in existing policy and practice in user involvement in the NHS has focused on adults, with children a potentially marginalised group. Knowledge is patchy as to the extent of their current involvement, the appropriateness of the methods used - particularly from the perspective of children themselves - and the impact of children's involvement on service development decisions. The focus of this project was children with a chronic illness or physical disability, who are likely to be long-term and heavy users of a range of health services.

A survey of health authorities and NHS Trusts in England was conducted to 'map' existing activity in children's involvement in local NHS service development. The experiences of children and staff in six initiatives, drawn from the survey, with differing approaches to involvement were investigated in interviews and focus groups.

Key findings

- Consultation activities with chronically ill or disabled young patients are few in number, but encompass a range of ages and service settings and use a variety of methods. Young patients are rarely involved in subsequent decision-making to develop services.
- Work with young patients appears to be developing independently from general NHS Trust strategies for patient and public involvement.
- Involvement can bring a range of benefits for young people and staff.
- Young people want a say over consultation topics and to be kept informed about the progress of their ideas for service change.
- There is no single 'right' method for consultation. In addition to more formal consultation, young people would like a 'listening culture' that encourages them to approach staff at any time.

Draft guidelines on involving young people were developed from the research findings and finalised at a workshop with staff and young people.

Publications

Lightfoot, J. and Sloper, P. (2002) *Having a Say in Health: guidelines for involving young patients in health services development*, Social Policy Research Unit, University of York.

Lightfoot, J. and Sloper, P. (forthcoming) Having a say in health: involving young people with a chronic illness or physical disability in local health services development, *Children and Society*.

Sloper, P. and Lightfoot, J. (forthcoming) Involving disabled and chronically ill children and young people in health service development. *Child: Care, Health and Development*.

Housing, disabled children and their families: obtaining national evidence

Completed Project

Joseph Rowntree Foundation
May 2000 to November 2001
Bryony Beresford, Christine Oldman
(Centre for Housing Policy)

This is the third in a series of projects funded by Joseph Rowntree Foundation, which has sought to develop an evidence base on the housing needs of disabled children and their families. The aim of this project was to collect national, quantitative data on housing need and current provision. This was achieved through a postal survey of a nationally representative sample of over 2500 families with a severely disabled child, and the collection of information about local policy and practice through contact with more than 100 managers of housing and social services and occupational therapists in over forty local authorities.

The survey was used to identify the range and extent of housing needs experienced by families, and to explore the associations between factors such as age and nature of impairment on the types of housing difficulties experienced. Information about current provision and other supply issues proved extremely difficult to access as disabled children are typically not classified as a separate client group within local authority records.

Key findings

- Families with a disabled child experience far greater problems with their housing than families with non-disabled children. Nine out of ten families reported at least one difficulty with their housing with many reporting multiple problems.
- Difficulties with housing can be experienced by any family with a disabled child: not just where there is physical impairment. In dealing with their housing problems, many families would prefer to move rather than adapt their current home.
- Inside the home, the most frequently reported problem was the lack of space: space for play, for privacy or ‘time out’, for equipment use and storage, and for carrying out therapies. Other common problems related to house condition and access.
- Over a third of families also found the location of their home to be a problem, either because it was an unsafe place for the child or because of difficulties with neighbours.
- Only a minority of families had received assistance from statutory agencies in order to address their housing needs. Typically, at a local level no single agency or department assumes lead responsibility for meeting the housing needs of disabled children. In addition, the lack of strategic information collection hampers improvements in service provision and delivery.

Publication: Beresford, B. and Oldman, C. (2002) *Housing Matters: national evidence relating to disabled children and their housing*, Bristol: Policy Press.

Community Equipment: use and needs of disabled children

Completed Project

Department of Health
April 2001 to September 2001
Bryony Beresford

This short piece of work sought to ascertain current levels of use of community equipment being used by severely disabled children and their families in England, and to identify levels of unmet need. Just under 3000 parents completed a postal survey about the equipment they used and needed. In addition, key practitioners and relevant organisations were consulted about issues pertaining to Community Equipment Services including: perceived areas of unmet need, groups of disabled children neglected by Community Equipment Services, recycling of equipment, and duplication of equipment in different settings.

Key findings:

- Over of half of the respondents were using at least five different pieces of equipment in their homes.

- Almost all families reported unmet equipment needs. Families from minority ethnic groups, and families with children aged 2 - 4 years reported most unmet equipment needs.
- The way in which the child's equipment needs were managed in other care settings varied according to the type of setting. Children spending time in other people's homes (for example, relatives, short term care schemes) and their carers were far more likely to have to manage without appropriate equipment compared to children using residential short term care facilities.
- Practitioners involved in the study believed that community equipment services for disabled children needed to change in a number of areas. These included:
  - The assessment of equipment needs of children should be different from that used to assess an adult or older person.
  - The equipment needs of children with learning difficulties and those with behavioural problems need to be acknowledged.
  - The untapped potential for recycling equipment needs to be addressed.
  - Funding from central government should increase.

Community Equipment: use and needs of disabled children and their families by Bryony Beresford, Julie Williams and Dot Lawton is available from the SPRU information office.

Technology and time: home care regimes and technology dependent children

Ongoing Project

Economic and Social Research Council 'Innovative Health Technologies' research programme

January 2001 to December 2002

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

In the UK, children who are dependent on medical devices (such as dialysis, assisted ventilation, and intravenous feeding) are increasingly cared for at home rather than in hospital. Previous research in the USA and elsewhere has shown that while technological advances have enabled children to be discharged home, the associated care regimes can be complex and demanding. Families have experienced particular problems with the availability, scheduling and coordination of services, limiting their ability to live ordinary lives.

This study examines families' experiences of these care regimes in the UK. It has three main aims:

- 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.

Qualitative methods are being used to examine the experiences of the children, their siblings and parents from 36 families recruited from three areas of the North of England. This fieldwork is now complete. In the next stage professionals will also be interviewed about good practice identified by the families, and about the wider organisation of services for this group. The results of the work will be available early in 2003.

HEALTH AND SOCIAL CARE
RESEARCH PROGRAMME

Children and Families Team

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
Patricia Sloper, Bryony Beresford, 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 will use 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 will focus on four groups of children: those with autistic spectrum disorders, communication impairments, complex health needs, or degenerative conditions.

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

Ongoing Project

Community Fund
January 2000 to June 2002
Wendy Mitchell, Patricia Sloper, Dot Lawton, Susan Clarke, Nicholas Pleace (Centre for Housing Policy) in collaboration with Barnardos 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 and 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
- Knowledgeable, well-trained, 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 will be available from September 2002 on the world wide web at www.sharingvalue.co.uk and in a printed format.

Publications

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 parent's views tell us?', *Children and Society*, 15, 4, pp.237-252.

Mitchell, W and Sloper, P. (2003, 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*.

Lister, S., Mitchell, W., Sloper, P. and Roberts, R. (forthcoming) 'Participation and partnerships in research: listening to the ideas and experiences of a parent-carer', *International Journal of Social Research Methodology: Theory and Practice*, 6.

Care Co-ordination Network UK (CCNUK)

Ongoing Development Project

Joseph Rowntree Foundation
April 2001 to March 2003
Katy Barton, Patricia Sloper

Following on from the project *Getting into Practice: implementing a key worker service*, SPRU has been part of a steering group to set up an organisation to promote and develop care co-ordination or key working for disabled children and their families.

In April 2001, Katy Barton was appointed as development co-ordinator to set up and develop Care Co-ordination Network UK. The organisation covers England, Northern Ireland, Scotland and Wales and intends to secure long term and ongoing funding for its work. It is currently applying for charitable status.

During its first year CCNUK has established a membership scheme, produced a membership pack and regular newsletter and held its first AGM and launch of the organisation in April 2002. It has started to map who is providing care co-ordination or key working throughout the UK. This will provide valuable information for parents, policy makers and professionals working with disabled children and their families.

The network's aims are:

championing

- to influence national, regional and local policy makers to recognise the benefits and implement the principles of care co-ordination for disabled children and their families.

sharing information

- collecting, distributing and disseminating information on topics relevant to care co-ordination

- developing effective working with other organisations and government departments
- providing a resource point about the principles of care co-ordination and its implementation.

promoting best practice
- identifying, evaluating and promoting best practice in care co-ordination
- establishing national standards
- including participation of disabled children, young people and their families.

SPRU involvement and support of CCNUK illustrates the Unit's ongoing commitment to putting its research messages into practice and the important role it can play in improving the services disabled children and their families receive.

Publications
Care Co-ordination News, Issue 1, Autumn 2001; Issue 2 Spring 2002
CCNUK membership pack December 2001.

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

New Project

Funded by CLIC (Challenging Childhood Cancer and Leukaemia
August 2002 to March 2004

Wendy Mitchell, Patricia Sloper, Susan Clarke, Claudine Crane

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 and young people with cancer and leukaemia and their parents 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 will be collected in 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 will be explored through focus groups and interviews. In stage three, the views of a larger sample of families will be gathered through postal questionnaires based on themes identified in stage two, and sent to 300 families (one for parents and one for children) within 10 treatment centres.

HEALTH AND SOCIAL CARE RESEARCH PROGRAMME

Children and Families Team

2

SOCIAL SECURITY RESEARCH PROGRAMME

introduction


Dr Roy Sainsbury

In the pages that follow 21 project summaries (of completed, ongoing and new work) are an indication of the continuing enterprise and productivity of the team of researchers in SPRU specialising in work on the important policy areas of poverty and living standards, families and children, social security, tax credits and the labour market, employment policies for disabled people, housing benefits, the administration and delivery of benefits and international comparative studies.

Throughout 2001-02 the government has continued to develop policies and programmes aimed at increasing the number of people in work through active employment, social security and tax programmes. Our portfolio of research reflects this policy emphasis. Work has continued on the evaluation of the New Deal for Disabled People National Extension. The Disability Services Research Partnership comprising SPRU, the Strathclyde Centre for Disability Studies and the Welsh Centre for Learning Disabilities, and led by Patricia Thornton continues to thrive. We are particularly pleased that the Partnership's original three-year contract due to end in April 2003 has already been extended by a further two years, an indication of its growing success and reputation. New work will include a major long-term evaluation of the WORKSTEP programme, which provides among other things supported employment services to disabled people.

SPRU continues to be active in the field of comparative research into employment and disabled people, and into poverty and child welfare. Patricia Thornton has served as UK reporter for a Dutch study of supported employment, is currently acting as UK reporter for a French comparative study, and will contribute expertise on vocational re-integration to a German-run study of the interface between medical, social and vocational rehabilitation. Anne Corden and Patricia Thornton have given presentations to conferences in Brussels and Helsinki. Jonathan Bradshaw and Naomi Finch have worked on projects concerning poverty measurement and child benefits, and attended seminars and meetings in Sweden, Norway, Luxemburg, and the USA.

SPRU's expertise continues to be sought by a range of individuals and organisations. In 2001-02 we have hosted visits from Malcolm Wicks, Minister of State at the Department for Work and Pensions; Sir Richard Tilt, the Social Fund Commissioner; members of the House of Commons Select Committee on Work and Pensions; members of the Disability Rights Commission; and representatives of the Treasury. Anne Corden has acted as a consultant to the National Audit Office on benefit take up, and has become a member of the Bereavement Research Forum.

Emese Mayhew joined the social security research team in 2001. She has been working with Jonathan Bradshaw on a number of projects on poverty and family policy. And a welcome addition to SPRU's social security research capacity has been the appointment of Professor Peter Kemp as Director of SPRU in March 2002.

Among all this activity, not everything gets done, however. In last year's report I set up a hostage to fortune by suggesting that it was possibly time to reconsider whether calling ourselves the 'social security group' within SPRU was appropriate when our diverse work covered not only benefits policy but also tax, employment, child and family policy. That we have not renamed ourselves is more a reflection of how busy we have been during the year than anything else. Hopefully, by the time of next year's report we will have found a more accurate title for the group. Or not.

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

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SOCIAL SECURITY RESEARCH PROGRAMME

Evaluating the Transitional Housing Benefit Scheme in Wales

Completed Project

National Assembly for Wales
June to December 2001
Roy Sainsbury, Christine Oldman
(Centre for Housing Policy)

This project was commissioned by the National Assembly for Wales as a follow-up to an earlier study funded by DSS and DETR into the implementation of the Transitional Housing Benefit Scheme (THBS). Funding for supported accommodation in Wales after 2003 will be slightly different from the arrangements in England and Scotland, with the National Assembly temporarily retaining responsibility for the provision of funds to Registered Social Landlords through the Supported Housing Revenue Grant. This has implications for the way in which local authorities fund the rest of the supported accommodation sector under the Supporting People policy initiative.

Case studies were carried out in four local authority areas in Wales in the autumn of 2001 in which key stakeholders were interviewed. These included Housing Benefit staff, officers from housing and social services departments, and providers of supported accommodation. Two workshops were later held which brought together supported accommodation providers and officers from all 22 local authorities in Wales to discuss emerging findings and to identify ways of implementing THBS successfully in the future.

Key findings

- THBS had not received the levels of commitment and resources that are needed.
- There were few examples of effective joint working between Supporting People staff, Housing Benefit officers and providers of supported accommodation.
- A barrier to joint working in some areas was the lack of trust between registered social landlords and local authorities.
- One of the biggest barriers to implementation of THBS in Wales has been a climate of uncertainty about the strategic direction of Supporting People and the funding arrangements that will be put in place for April 2003 and beyond.
- For providers, costing supported housing not just a technical exercise; it is also a strategic issue. This has slowed the process of restructuring rents down and caused providers to load costs onto rent.

Publication

Sainsbury, R. and Oldman, C. (2002) *Implementing the Transitional Housing Benefit Scheme in Wales*, Cardiff: National Assembly for Wales.

Evaluating Access to Work and WORKSTEP: A Feasibility Study

Completed Project

Employment Service
May to September 2001
Michael Hirst

The Access to Work and WORKSTEP programmes are designed for people with long-term health problems or impairments who require additional support to take up, retain or progress in paid employment. An important question for policy is what would have happened to clients had they not been supported by these distinct programmes. Population groups that are equivalent in every way to clients, except that they have not participated in either programme, are required to address this question. The aim of this desk study was to investigate the feasibility of forming such comparison groups, comparing their labour market experiences with those of clients, and measuring the impact of Access to Work and WORKSTEP on employment and other outcomes.

The study considered the feasibility of:

- defining client groups and identifying differences between clients for sub-group analysis of programme effects,
- designating comparison groups and controlling for known differences between them and the client groups at both the sampling and the analysis stage,
- measuring outcomes that relate to the objectives of each programme,
- implementing a prospective study design to compare outcomes between client and comparison groups over time,
- calculating sample sizes capable of yielding precise estimates of the impact of each programme.

The usefulness of administrative and management data as sources of information about outcomes for disabled people, and sampling frames for identifying comparison groups, was also assessed.

It was concluded that a comparison group design offers a feasible methodology for evaluating Access to Work and WORKSTEP. However, there was uncertainty about whether the size and timescale of an evaluation would be realistic and affordable. Recommendations for developing an evaluation strategy further - refining the sample design and testing survey instruments, including outcome measures - have been adopted by the Department for Work and Pensions.

The unpublished report, *Evaluating Access to Work and WORKSTEP: A Feasibility Study*, by Michael Hirst, was submitted to the Employment Service in September 2001.

Employment Programmes for Disabled People: Lessons from Research Evaluations

Completed Project

Department for Education and Employment
January 2001 to July 2001
Anne Corden, Patricia Thornton

The New Deal for Disabled People Personal Adviser Service pilot programme ran from 1998 to mid 2001 and was followed by a near nation-wide network of Job Broker services for incapacity benefits recipients and separate job retention and rehabilitation pilot projects. To inform the development of these initiatives, the Department for Education and Employment commissioned SPRU to conduct an international review of research evaluations of interventions designed to enable disabled people to move into, sustain or retain employment.

The review was carried out systematically, with policy-related and research-related criteria for inclusion of evaluation studies. We used multiple search methods to locate research published from 1990. Six programmes were identified for review, from UK, USA, Canada, Australia (two programmes) and Austria.

Key findings

- Lessons for future evaluations include designing evaluation strategies alongside programme design, and including longitudinal elements and use of administrative data.
- Most of the programmes reviewed concentrated on the pre-employment period. There are arguments for extending the scope of programmes to include maintaining participants in work and equipping them with skills for advancement.
- In terms of design of intervention, there are

arguments both for extending an open invitation and for targeting people most likely to benefit from the programme. Increasing incentives for people to take part and reducing fears of negative consequences are important.

- There were few strong indicators of ‘the kind of person’ for whom services work best, and little strong evidence about which factors contributed to positive outcomes for clients. Evidence from the wider literature suggests that the more successful programmes tend to take an individualised approach and that job search was effective in increasing placement rates.
- Services reviewed were funded by block grants based on inputs and processes, or outcome funding based on results for clients. Outcome funding for programmes does not always work in the way designed.

The report *Employment Programmes for Disabled People: lessons from research evaluations* by Anne Corden and Patricia Thornton was published in January 2002 by the Social Research Branch of the Department for Work and Pensions as In-house report 90.

The Added Value of Supported Employment

Completed Project

Employment Service
September 2000 to December 2001
Michael Hirst

Supported Employment is a long-standing government programme for disabled people at a disadvantage in getting or keeping a job. Organisations contracted to Jobcentre Plus (previously the Employment Service) arrange jobs in mainstream employment or in businesses set up to employ disabled people, and provide support to employers and supported employees. The old Supported Employment Programme was replaced in April 2001 by WORKSTEP, with a new focus on supporting progression within and beyond the programme.

The Employment Service commissioned the Disability Services Research Partnership to estimate the net cost of the Supported Employment Programme and to assess the individual benefits to its disabled workers. The study also set out to explore the net cost and effectiveness of the different delivery models. The findings provide a baseline to assess the impact of the modernised WORKSTEP. The Welsh Centre for Learning Disabilities was our partner in this project, and carried out the net cost analysis study as well as taking day-to-day responsibility for much of the design and conduct of the research.

A multi-method approach involved focus groups with users, contractor staff and some employers; a postal survey of random sample of Supported Employment Programme contractors; a primarily postal survey of a random sample of users; and a postal survey of Disability Employment Advisers.

The report is expected to be published by the Department for Work and Pensions as Beyer, S., Thomas, J. and Thornton, P. *The Net Costs and Social Benefits of the Supported Employment Programme*.

Mapping Employment Focused Services for Disabled People

Completed Project

Department for Education and Employment
February to October 2001
Patricia Thornton, Hilary Arksey, Julie Williams

In the last decade in Great Britain a huge growth in services to help disabled people to obtain or retain employment was encouraged by government policy to contract services to the independent sector, by European funding programmes and by initiatives of charitable funders and disabled people's organisations. However, there was a lack of comprehensive information on the types of service provided, the target groups, funding sources and regional distribution.

In this context, we were commissioned to produce a directory of employment-focused services for disabled people in Great Britain and an analysis of current provision. Methods included accessing existing directories, approaching funding bodies, searching on the internet and contacting providing organisations directly. In England, Welfare to Work Joint Investment Plans for Disabled People were a major source.

Key findings

- Data were obtained on 2,520 projects. Fewer than one in ten projects provided services aimed at both disabled and non-disabled people. Just 17 per cent of projects for which information was available were open to disabled people irrespective of their impairment. The groups most commonly targeted were people with learning difficulties and people with mental health problems.
- Over two-thirds of projects provided more than one type of service, with four in ten of those offering as many as four or more types. Vocational training was recorded for around four in ten projects, and work placement and supported employment each recorded for around one in four.
- At least three in ten projects required referral by a professional. Jobcentre and social services staff were the main referral sources. Self-referral was an option in only 11 per cent of services.
- Mutliple funding sources suggested that a significant number of projects were investing time and effort in chasing funding as well as reporting to different funders.

A CD directory of projects and services and a report entitled *Mapping Employment Focussed Services for Disabled People* by Hilary Arksey, Patricia Thornton and Julie Williams were published by the Department for Work and Pensions Social Research Branch in January 2002 as In-house report 93.

Evaluating the Impact of Access to Work

Completed Project

Employment Service
May 2001 to February to 2002
Patricia Thornton, Anne Corden

The Access to Work programme provides help with the costs of environmental adaptations and human support in the workplace, as well as with the costs of travel to work. The study aimed to examine the difference the programme makes in enabling its users to take up and stay in work and also to estimate whether the same outcomes could be achieved without the programme.

Using an innovative case study approach which combined qualitative interview techniques with agreement scales, the researchers asked users and their employers to judge likely outcomes if Access to Work were not available at the time they applied and at the time of interview. Eighty-seven full case studies were achieved, comprising interviews with users and their respective employers and extracts from case records. There were interviews with a further 30 users who were self-employed or for whom no employer interview could be achieved.

Because users often receive more than one type of support, question modules were developed for each support element. In-depth questioning provided detailed insights into how the programme works to achieve employment outcomes for its users.

Key findings

- There is strong evidence that help with taxis to work and with support workers are essential to taking up a job and very important in sustaining employment.
- Help with travel to work can affect employment outcomes by increasing work standards and reliability and reducing sick leave.
- Support workers can enable disabled people to work on an equal footing with non-disabled people.
- The main contribution of alterations to work premises was to increase equality of access, not necessarily affecting employment outcomes.
- Use of aids and equipment was thought to be associated with less sick leave and improved work performance.

At the end of the interview users in paid work were asked to rate on a 100 point scale the likelihood of being in their job if Access to Work was not available. Over one third (35 per cent) thought it highly unlikely while just under one in five (28 per cent) though it highly likely. The impact was the highest in the case of people who used travel to work and lowest for users of aids and equipment.

The study was carried out by SPRU under the Disability Services Research Partnership Agreement. The report from the project will be published in September 2002 as Thornton, P. and Corden, A. (2002) *Evaluating the Impact of Access to Work: A case study approach*, WAE Report 138, Sheffield: Department for Work and Pensions.

Poverty Measurement Using Consumption Data

Completed Project

Not externally funded
January 1999 to May 2001
Jonathan Bradshaw, Michael Hirst, Peter Saunders (SPRC, University of New South Wales)

This project was a comparative analysis of Australian and UK expenditure data to establish whether it is possible to develop a measure of poverty based on the point in the income distribution where households spend little or nothing on luxuries. Papers based on the results have been presented at conferences (FISS and IARIW) and an article appeared in the *Journal of Social Policy and Administration* in June 2002.

Child Poverty in Social Inclusion Partnerships

Completed Project

Scottish Executive
May 2001 to May 2002
Peter Kemp, Jo Dean and Daniel Mackay (University of Glasgow)

Together with the UK Government, the Scottish Executive has pledged to eradicate child poverty within the next generation. It has introduced a range of measures to achieve this goal, many of which are located in multi-agency Social Inclusion Partnerships (SIPs).

The aims of this project were to establish the characteristics of households with children in Scotland that were experiencing poverty or at risk of poverty; to establish the geographical distribution of these households across Scotland; and to examine how SIPs were addressing child poverty. The research involved secondary analysis of the Scottish Household Survey for 1999 and 2000 and the Households Below Average Income data for 1999/00; and qualitative interviews with people working in area-based SIPs. The Scottish Executive subsequently commissioned follow-up work on child poverty in rural Scotland.

Key findings

- In 1999/2000, 29% of children in Scotland were in poverty, defined as living in households with disposable income after housing costs of less than 60 per cent of the median.
- The child poverty rate was particularly high among workless households, adults with no educational qualifications, lone parents, families with three or more children, and tenants. The rate of child poverty was significantly higher in urban than in rural Scotland.
- Half of all children in SIP areas were experiencing poverty, compared with a quarter elsewhere in Scotland.
- People working in SIPs had a much wider perspective on child poverty than just low income, but tackling child poverty was not one of their explicit objectives. While SIPs were not tackling child poverty in a strategic manner, numerous initiatives in these areas were helping to reduce the problem.

The report of the study, *Child Poverty in Social Inclusion Partnerships*, by Peter Kemp, Jo Dean and Daniel Mackay was published on the Scottish Executive website: www.scotland.gov.uk.

The impact of additional benefit income for older people

Completed Project

National Audit Office
March to June 2002
Jonathan Bradshaw, Paul Dornan, Gary Craig (University of Hull)

This short project was designed to explore the consequences for living standards of well-being of older people claiming their entitlement to benefits (mainly Minimum Income Guarantee and Attendance Allowance). It consisted of a literature review, qualitative interviews with a sample of 24 older people and secondary analysis of a variety of data sets. NAO will publish a summary of the results and a working paper is available on http://www-users.york.ac.uk/~jrb1/.
Child Poverty in Social Inclusion Partnerships

2

SOCIAL SECURITY RESEARCH PROGRAMME

The costs of poverty and social exclusion among 16-18 year olds

Completed Project

Department for Education and Science

February to May 2001

Sandra Hutton, Jonathan Bradshaw, Bob Coles (Department of Social Policy and Social Work), Christine Godfrey (Department of Health Sciences), Gary Craig (University of Hull)

This project was commissioned by the Department for Education and Science to support its bid in the spending round to develop ways of reducing the numbers of young people not in education, training or employment. The Social Exclusion Unit, the No 10 Policy Unit and the 14-19 Strategy Group also had interests. The project was in two parts. The first part of the project consisted of a literature review of the ways in which young people may be socially excluded and estimates of the numbers involved. The second part of the project took these estimates and produced individual, family, resource and public finance costs. Estimates of the total and per capita present value costs were obtained. Also as an alternative hypothetical life courses have been created and the associated costs indicate how certain young people incur costs under many heads.

The final report will be published by DFES - see the SPRU website for details.

Views and experiences of recipients of Disabled Person's Tax Credit

Ongoing Project

Inland Revenue

May 2001 to November 2002

Anne Corden, Roy Sainsbury

Disabled Person's Tax Credit (DPTC) is aimed at working people who are at a disadvantage in getting or keeping paid work as a result of illness or disability, and is designed to help make work pay and to provide a minimum income guarantee.

The Inland Revenue has commissioned two major evaluative studies of DPTC: a national survey of recipients, conducted by the Institute for Employment Studies at the University of Sussex, 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 has been conducted in two stages. The first stage was a series of qualitative interviews with 54 DPTC recipients in four local areas, which were completed during June/July 2001. Findings were reported to the Inland Revenue and have informed development of the next generation of tax credits.

The second stage is a series of group discussions with recipients, with a focus on information needs and provision, in relation to Disabled Person's Tax Credit.

Small groups of lone parents; parents in two-parent families; younger people; people aged over 50 years and self-employed people will meet to discuss these issues, in different locations during September 2002.

Findings from the two evaluative studies will be published by the Inland Revenue in 2003.

Good Practice in Work Preparation

Ongoing Project

Employment Service
August 2001 to June 2002
Patricia Thornton (with the Strathclyde Centre for Disability Research)

About 270 providers nationwide deliver the Work Preparation programme under contract to Jobcentre Plus. They can help disabled people to set goals and identify the most suitable type of work, arrange short work placements and generally help to build confidence and develop strategies for coping with work. People at risk of losing their job for disability-related reasons can also be supported through the programme.

As part of a review the Employment Service (now Jobcentre Plus) commissioned work from the Disability Services Research Partnership to inform good practice in the structure and delivery of the programme. The Strathclyde Centre for Disability Research at the University of Glasgow was our partner in this project.

The work comprised:

- an international review of the literature on work preparation and vocational rehabilitation
- a ‘baseline’ study of the relationship between recorded inputs, outputs and user characteristics in three regions
- consultations with providers, Disability Services staff and some clients and employers.

Key findings from the research presented at a seminar in May 2002 to stimulate ideas for the development of the programme.

Two reports from the research will be published in August 2002:
P. Banks, S. Riddell and P. Thornton (2002) *Good Practice in Work Preparation: Lessons from Research*, WAE Report 135, Sheffield: Department for Work and Pensions.
S. Riddell (2002) *Work Preparation and Vocational Rehabilitation: A literature review*, WAE Report 136, Sheffield: Department for Work and Pensions.

A Comparison of child benefit packages in 22 countries

Ongoing Project

HM Treasury and Department for Work and Pensions
March 2001 to September 2002
Jonathan Bradshaw and Naomi Finch

This project replicates and extends a comparative study on the same topic undertaken by SPRU and published in 1993. This study seeks 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 is 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 complete a questionnaire which enables us to place the results in the context of the demographic and labour marker context in each country.

The results of the project were published by DWP in September 2002: Bradshaw, J. and Finch, N. (2002) *A Comparison of Child Benefit Packages in 22 Countries*, Department for Work and Pensions Research Report No.174, Leeds: Corporate Document Services.

The state of the children in the UK

Ongoing Project

Save the Children UK
March 2001 to March 2006
Jonathan Bradshaw with contributions from the Department of Social Policy and Social Work

Save the Children have commissioned the Department of Social policy and Social Work to write a biennial report on the State of Children in the UK. The first report is due to be published in 2002 and thereafter in 2004 and 2006. This project draws on the expertise that exists in the wider Department on children. Twenty-three 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.

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

Welfare policy and employment in the context of family change

Ongoing Project

Nordic Research Council
May 2002 to April 2004
Jonathan Bradshaw Naomi Finch, Anne Skevik (Nova, Norway) and national rapporteurs

SPRU and NOVA, in Oslo jointly bid for this project to the Norwegian Research Council. It 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 are being 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 findings from the project will be published in a book and academic papers.

COST Action 19: Child Welfare

Ongoing Project

European Union
September 2001 to August 2003
Jonathan Bradshaw and Bryony Beresford

Jonathan Bradshaw is UK representative on this project, which involves a number of countries in collaborative research on child welfare. The project has two working parties: Time/Space which Bryony Beresford serves on and Economic Well-Being which Jonathan Bradshaw serves on. The research team will produce a report for the UK covering these topics.

Evaluation of the New Deal for Disabled People National Extension

OngoingProject

Department for Work and Pensions

August 2001 to May 2004

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

Following the completion of the New Deal for Disabled People (NDDP) personal adviser pilots in 2001, the government introduced what it described as a ‘national extension’ of the pilots to run for three years from 2001 to 2004. Under the national extension contracts for the provision of job broking services have been let across Great Britain to approximately 75 organisations from the public, private and voluntary sectors. Job brokers have the freedom to decide how they deliver services to help people move towards and into work and are funded according to the results they achieve.

The evaluation of the national extension is being carried out by a consortium of research organisations of which SPRU is a core member. The research design incorporates a range of quantitative and qualitative techniques, including surveys of participants, non-participants and employers, the analysis of administrative data to measure the cost-effectiveness of the programme, and a suite of qualitative work with participants, job broker staff and employers. An interim report will be published in 2003 and the project will continue for the lifetime of the national extension until the Spring of 2004.

The role and function of the Social Security commissioners

Ongoing Project

Nuffield Foundation

May 2001 to October 2003

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 will explore (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.

It is expected that 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. A research monograph is planned for 2003.

Publication:
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, Vol.8, Issue 1, pp.9-34.

Incapacity benefit medical evidence pilot evaluation

Ongoing Project

Department for Work and Pensions
March 2002 to February 2003
Roy Sainsbury, Anne Corden, Naomi Finch, Peter Kemp

Decision making on claims for incapacity benefit rely on information provided by claimants' GPs. The arrangements for collecting information have been in place since 1994 and are known to present problems. For many years it has been known that the quality of information has been variable, and has been thought to contribute to the high level of appeals made by incapacity benefit claimants. It is also government policy to reduce where possible the amount of paperwork GPs are asked to complete. A pilot scheme was therefore set up designed to tackle both these issues.

The aim of the pilot is to test alternative arrangements designed to provide Jobcentre Decision Makers and Medical Services doctors with better evidence on which to base decisions about eligibility for incapacity benefit. People applying for incapacity benefit who agree to take part, and whose GPs have also agreed to take part, are assessed for eligibility on the basis of evidence taken directly from GP medical case notes rather than forms completed by GPs.

The research will contribute to the overall evaluation of the pilot by DWP. Qualitative interviews are being carried out with samples of all the principal parties affected by the pilot, including incapacity benefit claimants, GPs and their administrative staff, Medical Services doctors, and Jobcentre processing and decision making staff.

A report is expected to be published in early 2003.

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

New Project

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

Less attention has been paid to the way qualitative researchers write and present data than to data collection and analysis. One technique, in presenting findings, is to include verbatim quotations from respondents within or alongside the author's written text.

The aims of this 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 around 12 illustrative texts, and exploration of assumptions and preferences about using quotations with the authors and users of the research (policy makers, funders, other researchers, research subjects),
- testing the impact of different approaches, with three versions of a report from a small empirical study of low income households.

This study is funded for two years as part of the ESRC Research Methods Programme. The findings from the project will be published in a book and academic papers.

Poverty and Gender

New Project

Equal Opportunities Commission
July to October 2002
Jonathan Bradshaw, Peter Kemp, Emese Mayhew, Naomi Finch, Julie Williams

This project involves running a seminar for the EOC and writing a report to be published by them. It seeks to answer the questions how and why poverty varies by gender. It is designed to inform new EOC activity on gender and poverty. It will consist of a review of the literature and the secondary analysis of large data sets.

SOCIAL SECURITY RESEARCH PROGRAMME

3

PUBLICATIONS APRIL 2001 TO MARCH 2002

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PUBLICATIONS

APRIL 2001 TO MARCH 2002

Journal articles

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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

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UNIT STAFF AND PROFILES

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UNIT STAFF AND PROFILES

Director	Professor Peter Kemp BSc MPhil DPhil *(from March 2002)* Professor Sally Baldwin MA DipSocAdmin DPhil *(to February 2002)*
Secretary to the Director	Karen Jackson BA MA
Unit Administrator	Catherine Duncan BA
Assistant Director	Professor Hazel Qureshi BA DipSoc MA PhD
Associate Director	Professor Jonathan Bradshaw BSS MA DPhil
Children and Families Team	Bryony Beresford BSc PhD Janet Heaton BA Jane Lightfoot BA Wendy Mitchell BA MA DPhil Keri Roberts BA PhD Professor Patricia Sloper BA MA PhD (Team Leader)
Project Administrator	Sue Clarke BA
Team Secretary	*Teresa Frank*
Community Care For Adults Team	Hilary Arksey BA PhD Jennifer Harris BA PhD CQSW David Hepworth BA PhD DipASS CertPSW DPA Michael Hirst BA PhD DipSocAdmin Hannah Morgan BA MA *(joined January 2002)* Elinor Nicholas MA CQSW Charles Patmore BA Hazel Qureshi BA DipSoc MA PhD (Team Leader)
Team Secretary	*Sarah Starkey* BA
Social Security Team	Jonathan Bradshaw BSS MA DPhil Anne Corden BA DipSocAdmin Naomi Finch BA MSc Sandra Hutton MA MPhil DPM Roy Sainsbury BA PhD (Team Leader) Patricia Thornton MA DipSocAdmin
Team Secretary **(Senior Secretary)**	*Sally Pulleyn*
Development Co-ordinator *(Care Co-ordination Network UK)*	Katy Barton BA DipSocAdmin CQSW
Statistical and Computer Officer	Julie Williams BTech
Information Officer	Lindsey Myers BSc DipILS ALA
Information Assistant	Ruth Dowling BSocSc
Clerical Assistant	Maureen Brownbridge

UNIT STAFF AND PROFILES

Research Staff

Hilary Arksey BA (Open); BA (Hons) (Lancaster); PhD (Lancaster)
Hilary Arksey joined SPRU as a research fellow in October 1995. 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. Hilary has contributed to the Disability Services Research Partnership study of users' views of the Access to Work programme and is currently working on a DfEE funded project to map employment-focussed services to support disabled people into work. Hilary's research interests are in the areas of informal care, employment and disability, and qualitative research methods.

Sally Baldwin MA (Hons) (Glasgow); DipSocAdmin (York); DPhil (York)
Sally Baldwin has been the Director of the Social Policy Research Unit since October 1987. She is also Head of the Institute for Research in the Social Sciences (IRISS). She graduated from Glasgow University with an honours degree in English Literature and Language and subsequently moved to the University of York where she obtained the Diploma in Social Administration (with distinction). In 1973 she was appointed research fellow on the Family Fund Research Project (later SPRU). Her DPhil was awarded on the basis of a study of the financial consequences of severe childhood disability. She became Deputy Director in 1986 and was appointed to a Personal Chair in Social Policy in 1990. Her research interests include policy and the delivery of services and benefits to disabled people and their family carers; resource allocation, outcomes and the cash and care mix in social care; gender issues in social and health care; and the utilisation of research findings by policy makers and professionals.

Sally Baldwin is a member of the NHS R&D Commissioning Panel for Research Awards in Primary Care. She is chair of the Association of the Directors of Research centres in the Social Sciences (ARCISS), is a Trustee of the Family Fund Trust, and a Non-Executive Director of York NHS Trust. In 1999 she was elected as a founding Academician of the Academy of Learned Societies of the Social Sciences.

Katy Barton BA (Hons) (Exeter); DipSocAdmin (Bristol); CQSW (Leeds)
Katy Barton joined SPRU in April 2001 as Development Co-ordinator for a new organisation Care Co-ordination Network UK. 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. She has experience of project management and was responsible for setting up a family-based short-term care service for disabled children and their families. Prior to joining SPRU she worked for The Family Fund Trust 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.

Bryony Beresford BSc (Hons) (Surrey); PhD (Exeter)
Bryony Beresford joined the Unit in 1991, and has worked on several studies of families with a severely disabled child, including a literature review of methods used to access the views and experiences of disabled children themselves. Bryony's other interests include developing methodologies for research with children, children's experiences of illness and disability, the issues and processes surrounding the implementation of research findings into practice, and the housing needs of disabled children and their families.

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UNIT STAFF AND PROFILES

Research Staff

Jonathan Bradshaw BSS; MA(Dublin); DPhil (York)

Jonathan Bradshaw has been Associate Director of SPRU since 1994. His personal research interests include social security policy, family policy, poverty and living standards and comparative social policy. He was Founding Director of SPRU from 1972-1986, Head of the Department of Social Policy and Social Work 1986-1996, and Director of the Institute for Research in the Social Sciences 1994-1998. Currently his research includes a study for HM Treasury/Department for Work and Pensions of child benefit packages in 22 countries and a study for Save the Children (UK) of the well-being of children. He has recently completed a study for Eurostat of the measurement of absolute poverty, a study of the outcomes of child poverty funded by the ESRC, a national survey of poverty and social exclusion funded by the Joseph Rowntree Foundation. Research completed in the last few years includes a national study of non resident fathers, comparative studies of lone parent's labour supply, social assistance and child benefits, budget standards research and a national survey of lone parents. He teaches quantitative methods, demography and social policy and comparative social policy in the Department. He is Chair of the York Welfare Benefits Unit and President of the Foundation for International Studies in Social Security. More details can be found at http://www-users.york.ac.uk/~jrb1

Anne Corden BA (Oxon); DipSoc Admin (Bristol)

Anne Corden joined the Unit in 1980, having previously worked as social worker. Her interests have focussed on social security issues, family policy, employment and disability. She has conducted long programmes of work on take-up and delivery of in-work benefits, low-income self-employment, regulation of people at lower income levels, and transitions to and from paid work. 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. Anne also works for the Disability Services Research Partnership carrying out research for the Employment Service.

Naomi Finch BA (Hons) (York); MSc (Oxon)

Naomi Finch joined SPRU in November 2000 after completing an MSc in Comparative Social Policy at the University of Oxford. Since joining SPRU, Naomi has worked on a variety of projects ranging from research on young people, sport and disability to a comparative study of child benefit packages in 22 countries. Other projects have included analysis of the National Poverty and Social Exclusion Survey and a study for Eurostat on the measurement of absolute poverty. Naomi's interests are in the fields of child and family policy, poverty and social exclusion.

Jennifer Harris BA (Hons) (Lancaster); PhD (Lancaster); CQSW

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 in the Outcomes of Social Care team. 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 is site co-ordinator for the International Institute for Qualitative Methodology in Alberta, Canada.

Janet Heaton BA(Hons) (York)

Janet Heaton graduated in Sociology from the University of York in 1986. She joined SPRU in 1995 from the Nuffield Institute for Health at the University of Leeds, having previously worked as a researcher in the health service. She has worked on a number of

Research Staff

research projects at SPRU, including studies of: the discharge arrangements for younger disabled adults and their carers; the effectiveness of rehabilitation therapies following total hip replacement; and the measurement of outcomes of equipment and adaptations. Janet is currently working on a study of the home-care regimes of technology-dependent children and their families, and continuing to pursue her interest in the use of secondary analysis as a qualitative methodology.

David Hepworth DipASS, CertPSW (Soton); BA (Open); DPA (London); PhD (Nottingham)
David Hepworth has a background in mental health social work, qualifying in psychiatric social work and probation work at the University of Southampton. He joined SPRU as a part-time Research Fellow in January 1998 on the evaluation of the process and outcomes of assessment under carers legislation. He started an eight-month part-time study in July 2001, funded by Sir Halley Stewart Trust, into further improving community care assessment and support for black and minority ethnic carers. Other interests include part-time prison chaplaincy work with young offenders, Doncaster Methodist Social Responsibility Secretary and membership of the Racial Equality Council.

Michael Hirst BA (Liverpool); PhD (Liverpool); DipSocAdmin (York)
Michael Hirst graduated in Geography from the University of Liverpool in 1966 and subsequently lectured at Makerere University, Kampala, Uganda and the University of Western Australia, Perth, Australia. He joined SPRU in 1981 to develop a programme of research on young people with disabilities, 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. His current research interests include the dynamics of informal care and outcomes for carers. Michael also works for the Disability Services Research Partnership carrying out research for the Employment Service.

Sandra Hutton MA (Edinburgh); Diploma PM (Strathclyde); MPhil (York)
Sandra Hutton joined SPRU in 1980 and is now working part time. Sandra's research interests are mainly in the field of living standards and financial outcomes. Her current project concerns young people involving secondary analysis of national data sets. In addition, she maintains an interest in poverty analysis and, in particular, fuel poverty.

Peter Kemp BSc (Southampton) M.Phil (Glasgow); D.Phil (Sussex)
Peter Kemp has been Director of the Social Policy Research Unit, and Professor of Social Policy, since March 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. Peter has published extensively on a wide range of topics in the field of housing studies and has a long-standing interest in the implementation of policy and the outcomes that result from it. His current research interests include housing benefit (which he has been researching since 1983), social security, tax credits and welfare reform. Peter's recent work includes research on child poverty in Scotland, reform of housing benefit and tax credits, and public attitudes to social security benefit fraud. He is also a member of the Editorial Board of the Journal of Social Policy.

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UNIT STAFF AND PROFILES

Research Staff

Jane Lightfoot BA (Newcastle upon Tyne)

Since joining the Unit in 1991, Jane lightfoot's work has allowed her to develop interests around community nursing, the health needs of school age children and the work of professionals at inter-agency boundaries, in particular health and education. Her current research interests concern children and young people's participation in service development, in particular the NHS. Jane is a member of the Scarborough and North East Yorkshire Community Health Council, and a member of the Editorial Board for the journal Primary Health Care Research and Development.

Wendy Mitchell BA(Hons) (Warwick); MA (York); DPhil (York)

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. Wendy will combine her research interests in the fields of Youth and Disability within a project entitled Sharing Value: developing a website and print directory of user commended support services for disabled children and their families, working in collaboration with Barnardos and The Family Fund Trust.

Hannah Morgan BA MA (Leeds)

Hannah Morgan joined SPRU in January 2002. She was previously a research officer at the Centre for Disability Studies at the University of Leeds where she was involved with the Creating Independent Futures project, an evaluation of user-led service provision. Hannah has also contributed to the under-graduate, M.A. and Diploma courses in Disability Studies at Leeds University. Hannah's research interests are in the areas of disability studies, social care, EU citizenship and qualitative research methods.

Elinor Nicholas CQSW (Plymouth); MA (Essex)

Elinor Nicholas joined SPRU in 1997. Her professional experience includes 20 years as a Social Worker, Trainer, and Project Development Manager. Elinor is part of the team working on the Department of Health funded programme on the outcomes of community care. Elinor's research interests include outcomes/service support for carers of adults, the management of change and innovation, care management/social work and the development of research-practice relationships. She is currently involved in assisting the implementation of outcomes-focused approaches within social care, through the development of a resource pack, an interactive network and web site, with participating managers and trainers from social and health care agencies.

Charles Patmore BA (Oxon)

Charles Patmore joined SPRU in 1997 to work on community care for older people within the Department of Health programme on outcomes of community care. Recently he began a research project on flexible, person-centred home care for older people, which is funded by the Department of Health. Prior to joining SPRU, he was a research officer in Social Services. One of his current interests is ways of adjusting social care for older people to reflect individuals' values and aspirations. Another interest is ways of supporting morale and quality of life for older people who suffer disability or long-term illness.

Research Staff

Hazel Qureshi BA (Warwick); Dip Sociol. (Reading); MA (Kent); PhD (Manchester)
Hazel Qureshi joined SPRU in October 1993 as Assistant Director responsible for the social care research programme. She is the leader of the Community Care for Adults Team, and heads the Unit's Department of Health funded programme of work on social care outcomes. Her established research interests in social care and service evaluation began during several years in practice in social work and social care. Published work includes studies of people with learning difficulties who show challenging behaviour, family care of older people, and the role of paid and unpaid helpers in case-managed community care. Publications include Outcomes of Community Care for Users and Carers (with Andrew Nocon), The Caring Relationship (with Alan Walker) and Helpers in Case-managed Community Care (with David Challis and Bleddyn Davies). She was awarded a Personal Chair in Social Care in 1998.

Parvaneh Rabiee BA (Tehran University); MA (Leeds); PhD (Leeds)
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 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 M.A. and Diploma courses in Disability Studies at Leeds University.

Keri Roberts BA(Hons) (Wales); PhD (Sheffield)
Keri Roberts joined SPRU in 1997 following doctoral research into refugee labour force experiences at the University of Sheffield. She initially joined SPRU to work on the needs and circumstances of families with disabled children for the Family Fund Trust. She now combines her interests in the fields of disability and refugee resettlement in a project entitled Disabled Refugees in Britain for the Refugee Council.

Roy Sainsbury BA (Hons) (Leeds); PhD (Edinburgh)
Roy Sainsbury joined SPRU in 1988 from Edinburgh. He leads the team of social security researchers in SPRU with particular responsibility for projects commissioned by the Department of Social Security. His research interests include social security and the labour market, sickness and disability benefits, housing benefit, and the administration and delivery of benefits, in particular the appeals system and social security fraud. He 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. In 2000 he edited (with Jonathan Bradshaw) a series of three monographs on aspects of poverty: Getting the Measure of Poverty: The early legacy of Seebohm Rowntree, Experiencing Poverty, and Researching Poverty.

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UNIT STAFF AND PROFILES

Research Staff

Patricia Sloper BA MA (Nottingham); PhD (Manchester) C.Psychol.

Tricia Sloper joined SPRU in October 1995 and is responsible for the Children and Families Team research programme. After graduating she worked as a social worker, before going into research and obtaining a PhD from the University of Manchester. 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; and the implementation of research findings in practice. Tricia is a member of the Children's National Service Framework External Working Group on Disabled Children; the National Association for Colitis and Crohn's Disease Social and Psychological Research Committee; The Family Fund Trust Research Committee; and York Health Services NHS Trust Research Ethics Committee.

Patricia Thornton BA(Hons) (Edinburgh); DipSocAdmin (Liverpool)

Patricia Thornton is Senior Research Fellow working on SPRU's programme of research on the labour market participation of disabled people, and is manager of the Disability Services Research Partnership, which carries out research on employment services for disabled people under an agreement with the Employment Service. Patricia has an international reputation for her comparative research on policies and practices to promote employment opportunities for disabled people. She has a long-standing interest in enabling users' voices to be heard in the evaluation and development of services.

UNIT STAFF AND PROFILES

Support and secretarial staff

Karen Jackson graduated in Sociology and Education from the University of York and also has a Masters in Criminology from the University of Hull. Before joining SPRU in 1998 she worked in a variety of jobs including departmental secretary with the University of Oxford's Theoretical Physics Department and secretary with Oxfordshire Mental Healthcare NHS Trust. Karen is mainly responsible for secretarial and administrative support to the Director and administration of the Senior Management Group.

Maureen Brownbridge provides clerical help both to the Information Office, the Unit Administrator and to the Team Secretaries.

Sue Clarke graduated from Bedford College, University of London, in Sociology. She joined SPRU in January 2000 to provide secretarial and administrative support to the Sharing Value Project, which runs until June 2002.

Ruth Dowling graduated in Social Administration from the University of Birmingham in 1988. She joined SPRU in 1992 to work in the Publications and Information Office. Before coming to SPRU, she worked as the Administrator for a small housing association in Bradford.

Catherine Duncan graduated from Queen Mary College, University of London, in modern languages. She joined SPRU in 1988 as the Unit secretary after a varied career ranging from editing a publication on warships through running a perfume manufacturing and export business and providing training for accountants. She was appointed to the post of the Unit Administrator in 1990 and takes responsibility for Unit finances and personnel issues.

Teresa Frank joined SPRU in 1993. She is secretary to the Children and Families Team and provides secretarial and administrative support to Dr Patricia Sloper, the team leader.

Lindsey Myers joined SPRU in 1998 as the Unit's Information Officer. She graduated in Sociology from University of Plymouth and also has a Diploma in Information and Library Studies from Liverpool John Moores University. Previous professional experience includes working as a Subject Librarian for the University of Plymouth with responsibility for Sociology, Politics and the Institute of Health Studies. She is responsible for the flow of information within the Unit, the provision of information to the external world and the development of SPRU's website.

Sally Pulleyn joined SPRU in 1989. She is senior secretary and provides secretarial and administrative support to the Social Security Team. She is responsible for the overall management of the secretarial office.

Sarah Starkey graduated in History of Art and Design from De Montfort University, Leicester in 1996. Before joining SPRU in 2000 she worked as a committee administrator for City of York Council. She is secretary to Professor Hazel Qureshi and her team. As Systems Secretary for the Unit, Sarah is responsible for software support, with particular interest in database and spreadsheet design and development.

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.