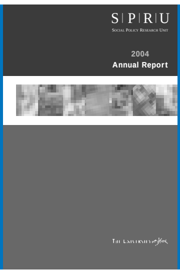
S | P | R | U

SOCIAL POLICY RESEARCH UNIT

2004
Annual Report

THE UNIVERSITY *of York*



Contents

Children and Families Team

Community Care for Adults Team

Social Security and Living Standards Team

Publications

Unit Staff

Director

Professor Peter Kemp BSc MPhil DPhil

Children and Families Team

Professor Patricia Sloper BA MA PhD
(Assistant Director)
Bryony Beresford BSc PhD
Sue Clarke BA
Anita Franklin BA MSc
Veronica Greco BSc DPhil
Janet Heaton BA
Wendy Mitchell BA MA DPhil
Parvaneh Rabiee BA PgDiploma MA DPhil

Community Care for Adults Team

Professor Caroline Glendinning BA DipComWk MPhil
(Assistant Director)
Hilary Arksey BA PhD
Jennifer Harris BA PhD CQSW
Michael Hirst BA PhD DipSocAdmin
Michele Foster BSocWk PhD
Karen Jackson BA MA
Charles Patmore BA

Social Security and Living Standards Team

Roy Sainsbury BA PhD (Assistant Director)
Professor Jonathan Bradshaw BSS MA DPhil
(Associate Director)
Anne Corden BA DipSocAdmin
Naomi Finch BA MSc
Emese Mayhew MA MA
Angela Meah BA MA MA Econ PhD
Katharine Nice LLB MA
Patricia Thornton MA DipSocAdmin

Support Staff Team

Unit Administrator
Jeanette Whalley BA

Finance Assistant
Simon Johnson BS

PA to the Director
Lisa Goode BA

Senior Secretary
Sally Pulleyn

Secretary
Christine Carpenter

Secretary
Teresa Frank

Information Officer
Rachel Pitman BA MA

Information Assistant
Ruth Dowling BSocSc

Clerical Assistant
Maureen Brownbridge

Statistical and Computing Officer
Julie Williams BTech

Care Co-ordination Network UK

Network Manager
Katy Barton BA DipSocAdmin CQSW

Project Administrator
Caz Byrne BSc

Introduction by the Director

Professor Peter Kemp

The Social Policy Research Unit (SPRU) is a research centre based within the Department of Social Policy and Social Work at the University of York. Since it was established in 1973, it has become recognised as one of the leading centres for research in social policy in the UK.

Our research is particularly focused around people who are vulnerable because of poverty, unemployment, ageing, disability or chronic sickness. We are particularly committed to the effective dissemination of our findings to the users of research. As well as articles in academic, peer-reviewed journals, we also produce reports written for policymakers and practitioners, research summaries and good practice guides.

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

Children and Families Team (led by Professor Tricia Sloper)

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

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

The year 2004 was a very active one for SPRU staff. One major event was the scientific review of our programme of research funded by the Department of Health. The current five-year research programme, which runs to the end of 2005, is focused on the outcomes of social care. This work is described in more detail in subsequent pages of this annual report.

The scientific merit, policy and practice relevance, and value for money of the research programme, were assessed in 2004 by external referees and by an independent review panel appointed by the Department of Health. The panel comprised academic experts, service users and policy customers. We are naturally delighted to report that the review panel recommended that SPRU be funded for a new programme of research from January 2006. The new research programme will be focused on ‘choice and independence over the life course’.

During 2004, the Government published the National Service Framework (NSF) for Children, Young People and Maternity Services, a ten-year programme intended to achieve a long-term improvement in children’s health and social services in England. Staff in the Children and Families Team within SPRU played a role in the development of the section of the NSF devoted to disabled children. This involvement in the NSF is one example of a variety of ‘behind the scenes’ contributions that we make to policy development; others include policy briefings, membership of advisory committees and participation in ‘Chatham House rules’ seminars.

In the spring we moved to new offices within the University campus. Although the move was inevitably disruptive, it has provided us with larger and better accommodation than we had before. We are now based in refurbished offices in the Alcuin College site, alongside the other health and social policy research centres, and the lecturing staff in the Departments of Social

Policy and Social Work, Economics and Related Subjects, Health Sciences, and the new Hull-York Medical School.

This relocation brings together in one site within the campus the large number of research and lecturing staff working in health, social policy and social work at the University. This proximity will provide enhanced interaction and new opportunities for collaborative research between staff in the different research units and departments.

One outcome of the collaboration has been the completion in 2004 of the Alcuin Research Resource Centre (ARRC). ARRC is a new resource for social science research at the University and includes facilities for data collection, analysis and archiving, as well as an information service. It was funded by a £4 million grant from the ESRC/Welcome Joint Infrastructure Fund, for which SPRU was a joint applicant.

The building from which we moved was subsequently renamed after the late Professor Sally Baldwin. Sally worked in the University for over thirty years and was the director of SPRU from October 1987 until February 2002. In July we also planted a rowan tree in memory of Sally outside our new offices in Alcuin College.

During 2004, the Unit was successful in a national competition for Research Councils UK (RCUK) Academic Fellowships. These are five-year research posts that aim to improve the routes into permanent academic posts of contract research staff. Our successful application was for an Academic Fellow to develop research on pensioner poverty, to complement our existing strengths in child poverty.

Throughout the year covered by this report we received funding from a wide range of organisations. These included the Carnegie UK Trust, City of York Council, CLIC (Children with Cancer and Leukaemia), Department of Health, Department for Work and Pensions, Disability Rights Commission, Economic and Social Research Council, the European Commission, the Joseph Rowntree Foundation, the Nordic Research Council, and Save the Children. We are grateful to these organisations for supporting our work.

I hope you find our latest annual report interesting. More information about our research, publications and other activities is available on our website: *www.york.ac.uk/spru*

Special Feature

The Department of Health-funded Research Programme

Since 1996, the Department of Health has funded a programme of research in SPRU on the outcomes of social care. Research programme funding is expected to:

- Allow a coherent programme of research to be carried out, with additional opportunities for cross-project synergy
- Facilitate the development of research capacity and expertise, through continuity of staff and ideas. This expertise in turn is expected to provide the basis from which additional external research funding can be secured
- Meet DH needs for short-term ‘responsive’ research, advice and other expertise
- Enable research programmes to disseminate research findings more thoroughly and extensively than would be possible with project funding alone.

SPRU’s current Department of Health programme is focused on the outcomes of social care and has had two broad aims:

- To identify the outcomes of receiving services that are valued and desired by different groups of service users – frail older people, carers, working age disabled people, disabled children and young people and their families. In this context, ‘outcome’ includes the impact or effect of services on the lives of users and/or carers and the extent to which services enable users and carers to achieve desired ambitions, objectives or changes in their lives.
- Through development work with local service managers and front-line staff, to devise outcomes-focused approaches to purchasing, assessment, review and service delivery activities and to embed these into routine practice. This reflects the belief that research-based evidence cannot be simply applied but needs to be adapted and reconstructed to fit local contexts and practices in order to achieve maximum impact.

SPRU’s research programme has been primarily on the outcomes of social care services, although the multiple needs of many disabled people and the multi-agency responses that are required are increasingly acknowledged.

The research involves staff from both the Community Care for Adults Team and the Children and Families Team. The programme director is Professor Caroline Glendinning. Further details about the current projects being conducted within the Department of Health programme are provided elsewhere in the report.

Department of Health research programmes are subject to five-yearly assessment, and the latest review of our work was carried out in 2004 by an independent review panel comprising academic experts, service users and policy customers. The panel was chaired by Professor Marion Barnes from the Institute of Applied Social Science at the University of Birmingham. As well as reviewing the productivity, scientific merit, policy and practice relevance, impact and value for money of the research programme, the review panel also considers outline proposals for a future research programme. The assessment is based on supporting documentation provided by the Unit, reviews of our publications by external referees and by the review panel, and a two-day site visit. The review panel reports to the Department of Health’s Director of Research and Development.

We are very pleased to report that the review panel recommended that SPRU be funded for a new programme of research from January 2006. We will be focusing our new research programme on ‘choice and independence over the life course’.

Children and Families Team
Professor Patricia Sloper

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

The Team has a particular, and long-standing, interest in the needs of disabled or chronically ill children and their families. In the past, work in this area has largely concentrated on the accounts of adults, particularly parents. Yet, research has also shown that children's and adults' views differ, and adults cannot be used as proxies for children's views. A striking omission in research on childhood illness and disability has been the lack of attention paid to the views of the children themselves. Being a child and being ill or disabled appears to have created a double disadvantage in relation to true involvement in research. Recognising this gap in knowledge, we have conducted research that has focused on the views of children about their needs and experiences and the support they receive from services.

RESEARCH FUNDED BY THE DEPARTMENT OF HEALTH

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

Ongoing

Department of Health research programme
October 2001 to December 2005

Tricia Sloper, Bryony Beresford and Parvaneh Rabiee

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

The aims are:

- To identify desired outcomes of support services from the perspectives of disabled children and their parents

- To explore managers' and practitioners' perspectives on outcomes

- Working with local authority staff, 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, interviews and focus groups with disabled children and parents, and participatory workshops with key stakeholders amongst staff, were used to investigate views of outcomes. Using the research findings, the research team worked with local steering groups of staff and parents to develop tools by which information about outcomes for parents and children can be collected in practice. These tools are currently being piloted by practitioners, with researchers in SPRU conducting an independent evaluation of the tools from practitioner and parent perspectives.

Publications

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

Rabiee, P., Sloper, P. and Beresford, B. (in press) Doing research with children and young people who do not use speech for communication, *Children and Society*, DOI:10.1002/chi.841. *www.interscience.wiley.com*

Participation of disabled children and young people under *Quality Protects*

Ongoing

Department of Health
Quality Protects research initiative
April 2003 to June 2005

Anita Franklin and Tricia Sloper

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

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

The aims are:

- To identify participation work which includes disabled children

- To establish factors which can support and promote disabled children's effective participation.

The research has three stages. In stage one, Year 4 QP Management Action Plans (MAPs) were analysed to identify participation work with disabled children and provide a summary of the range and types of participation. Stage two was a survey of all Social Services Departments in England to identify and describe current work concerning disabled children's participation in decisions on their own care and in service development. Stage three is qualitative research with children (using verbal and non-verbal methods to facilitate communication), parents and staff in a sample of seven local authorities to find out 'what works' in respect of the processes and outcomes of disabled children's participation. The research will inform the development of guidelines to support services in promoting disabled children's participation.

Publications

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

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

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

Key worker services for disabled children: effectiveness and costs

Ongoing project

Funded by: Department of Health,
Department for Education and Skills,
HM Treasury, the Welsh Assembly Government.
October 2002 to January 2005

Tricia Sloper, Veronica Greco, Rosemary Webb, Jennifer Beecham

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

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

1. A UK-wide survey, to determine which areas had key worker services, and details of the service models
2. Seven areas with differing models of key worker services were identified for further investigation in case studies, and interviews were carried out with managers and staff in each of the services
3. Investigation of the effectiveness of the services in providing co-ordinated care and in meeting families' needs, through questionnaires to all families receiving the services and interviews with a sub-sample of these families.

Publications

Greco, V. and Sloper, P. (2004) Care co-ordination and key worker schemes for disabled children: results of a UK wide survey. *Child: Care, Health and Development*, 30, 1: 13–20.

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

OTHER FUNDED PROJECTS

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

Ongoing project

Funded by the Department for Education and Skills and the Welsh Assembly Government
October 2004 to June 2005

Wendy Mitchell and Tricia Sloper

The Integrated Children's System (ICS), as part of a wider Government programme to re-shape local services for children and their families, especially children in need, aims to redress some of the problems in previous recording systems and connect with other systems currently being implemented. However, there are many questions surrounding how the ICS will work with and its relevance to different groups of children. An evaluation of ICS is being carried out in collaboration between the social work section of the Department of Social Policy and Social Work, the Social Work Research and Development Unit, and SPRU. SPRU's part of the work will explore the implementation of the ICS for disabled children and their families.

The aims of the project are:

- To examine the application of ICS for disabled children and their families, in particular parents', children's and practitioner's views and experiences of information gathering, participation within and outcomes of the process

- To compare parents' and disabled children's own understanding of the information they are giving and services they expect to receive with the actual information recorded in the ICS system and the services received.

The study will draw upon a purposive sample of disabled children and their families from three pilot sites (two English local authorities and one Welsh local authority). The sample will encompass a range of ages, impairments and children at different stages of the assessment process. Individual interviews will be conducted with approximately 20 parents and at least 10 children. The children's interviews will draw upon a variety of verbal and non-verbal methods. Questionnaires will also be sent to social workers working with the disabled children in the sample. The questionnaire will explore social workers' views on the application and suitability of ICS for disabled children and their families.

Care and support needs of children with cancer and their families

Completed project

Funded by CLIC
(Cancer and Leukaemia in Childhood)
August 2002 to June 2004

Wendy Mitchell, Tricia Sloper, Susan Clarke

The diagnosis and treatment of cancer 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 investigated current patterns of provision, both statutory and voluntary, and how these meet children's and families' needs.

The aims of the study were:

- To explore patterns of psychosocial support service provision throughout the UK for children with cancer and their families

- To describe the needs of children, young people and their parents throughout the illness and post treatment

- To compare patterns of support with parents' and children's views of their needs, and develop recommendations for provision of services.

The project had three stages:

1 Postal survey of all 21 UK NHS paediatric oncology treatment centres and key voluntary agencies to gather information on service provision

2 Focus groups and interviews exploring children's and parents' experiences of psychosocial support

3 A questionnaire, based on themes identified in stage two, explored parents' and young people's views on the services they received and their unmet needs. The questionnaire was completed by 303 parents and 112 young people aged 10 and over.

Publications

Clarke, S., Mitchell, W. and Sloper, P. (2004) *Care and Support Needs of Children and Young People with Cancer and Leukaemia and their Families*, Social Policy Research Unit, University of York, Report to CLIC.

Clarke, S., Mitchell, W. and Sloper, P. (2005) Psychosocial support services for children and young people with cancer and their families, *Research Works*, 2005–01, Social Policy Research Unit, University of York.

Integrating services for disabled children and young people

Ongoing project

City of York Council
September 2004 to May 2005

Bryony Beresford, Sue Clarke, Tricia Sloper

The need to improve services for disabled children has moved up the policy agenda following the Audit Commission report on services for disabled children, The Green Paper *Every Child Matters* and the Children Act, and the National Service Framework for Children, Young People and Maternity Services. This project was commissioned by the City of York Children's Trust to consult with service providers, parents and children about improving the lives of disabled children and their families living in York.

The purpose of the consultation is:

- To identify changes that can be made to improve outcomes for disabled children, young people and their families in York; and
- To ensure that decisions made concerning changes to services are based on consultation with all stakeholders and wider research evidence.

The consultation covers children aged from birth to 19 years with a range of impairments and levels of severity. It will address service provision, delivery and organisation in mainstream as well as specialist services. A mixture of focus groups, questionnaires and individual interviews will be used to encourage widespread participation of children and young people, parents and professionals.

Consultation with children and young people will focus on the things they enjoy and the things they want to be able to do. Consultation with service providers and parents will have two stages. The first stage will examine what is good about existing services, gaps in services and areas in need of change. The second stage will consider ways in which identified gaps or problems can be addressed. This discussion will be informed by evidence from other areas where such difficulties have already been addressed and changes to services for disabled children have been implemented.

Care Co-ordination Network UK (CCNUK)

Ongoing development project

April 2001 to March 2006

Funded by Department for Education and Skills, Scottish Executive, Welsh Assembly Government, Joseph Rowntree Foundation.

Care Co-ordination Network UK (CCNUK) is an umbrella organisation promoting and supporting key working for disabled children and their families in England, Northern Ireland, Scotland and Wales. CCNUK developed out of a research project previously undertaken in the Unit. It is an independent registered charity currently based within SPRU.

Care Co-ordination Network UK's key achievements in 2004:

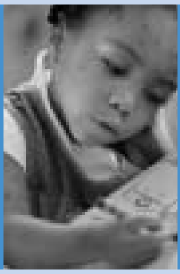
- Increase in membership to 270 members
- CCNUK held its third annual conference and AGM in London
- CCNUK advisory groups have been established in Northern Ireland, Scotland and Wales
- Appointment of a development worker in Scotland with funding secured from the Scottish Executive until March 2007
- Funding from the Welsh Assembly to appoint a development worker in Wales till March 2008
- Endorsement of the CCNUK key worker standards in the National Service Framework for Children in England
- A new logo and image for CCNUK
- An independent CCNUK website.

Publications

CCNUK *Key Worker Standards*
Care Co-ordination News issues 6,7, and 8
CCNUK *Annual Report* 2003–2004
CCNUK *Membership Pack*, March 2004
Website: *www.ccnuk.org.uk*

Special Feature

The National Service Frameworks



Researchers from SPRU have been involved in drawing up the National Service Framework for Children, Young People and Maternity Services and in reviewing evidence to inform both this and the National Service Framework for Long-Term Conditions.

The National Service Framework for Children, Young People and Maternity Services (NSF) was published by the government on 15 September 2004. It is an important 10-year national programme intended to stimulate long-term improvement in children's health and well-being in England. It sets national standards for the first time for children's health and social services, and the interface of those services with education. The aim of the NSF is that all children and young people will receive the services they need, wherever they live or whatever their circumstances. Central to the standards it sets is a fundamental change in services, leading to services that work together effectively and are centred around children and families' needs. Local authorities and the NHS will be assessed on the progress they make towards meeting these standards.

The NSF is based on reports prepared by eight External Working Groups (EWGs), each concerned with a different aspect of child health and well-being. The EWGs consisted of key people/specialists within the field of children's health and care. Two members of the Social Policy Research Unit, Professor Tricia Sloper and Dr Bryony Beresford, were members of the Disabled Children's EWG and played a key part in drawing up the group's report to ministers. The standards set out in the NSF, and the guidance on implementing these standards, are informed by research. Tricia and Bryony were also members of the NSF Research Group and carried out reviews of research on a wide range of topics, including multi-agency working, key workers, children's participation, early intervention, family support, information provision, transition to adult services, provision of housing adaptations, aids and equipment, and therapies. The purpose of the research reviews was to help identify what changes are required so that services can better meet the needs of disabled children and their families and to bring together evidence on what works. The programme of research carried out by the Children and Families Team at SPRU was a key contributor to this process.

The National Service Framework for Long-Term Conditions is due to be published early in 2005. The aim of the NSF is to improve the lives of people who live with neurological and other long-term conditions by providing them with better health and social care services. SPRU's work for this NSF involved a number of our own staff and staff from the universities of Lancaster, Sheffield and Leeds, led by Dr Jennifer Harris in SPRU. Two overviews of the literature were carried out: first, on user experiences of health and social care services, focusing on the experiences of people with epilepsy, Motor Neurone Disease, Parkinson's Disease, brain injury, spinal cord injury, polio and cerebral palsy; and secondly, of carers' experiences of supporting people with these conditions, including their relationships with health and social care services in their care-giving role.

Resources for the NSF work were provided by SPRU's Department of Health programme grant and the Joseph Rowntree Foundation with Contact a Family.

Community Care for Adults Team

Professor Caroline Glendinning

The Community Care for Adults Team is led by Professor Caroline Glendinning. It includes researchers working on the Department of Health funded outcomes programme and other researchers working on projects centred on carers. Our research is characterised by a focus on the individual and collective views and experiences of people coping with disability or chronic illness, and their families, across the life course, in particular their experiences and evaluations of public services. We are committed to the idea that research can influence, and be useful to, practice and policy. However the relationship is not always straightforward or easy. Current and recent projects include an emphasis on working with frontline staff, managers and policymakers to find useful and realistic ways in which existing practice, management and policy can be improved to systematically access, and take account of, insights and evidence from service users and their families.

RESEARCH FUNDED BY THE DEPARTMENT OF HEALTH

Outcomes for disabled service users

Ongoing project

Department of Health research programme
January 2002 to May 2005

Jennifer Harris, Michele Foster, Hannah Morgan, Karen Jackson

Disabled people of working age may receive services from a variety of personnel in social services. This project aimed to improve social service provision through the development and testing of tools that incorporate a focus on outcomes into assessment and review. Stakeholders included senior managers, care managers, occupational therapists, social workers, domiciliary services officers, community care workers, day care staff and service users. The implementation was evaluated, using computerised qualitative data analysis and took the form of interviews with staff and service users as well as documentary analysis (outcomes assessment documentation completed by staff).

Publications

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

Morgan, H. and Harris, J. (2003) *Social Care Outcomes Seminar: Issues for Professionals and Service Users, Woburn House, 8th May 2002*, Research Report DH1904 (10.02),

Social Policy Research Unit,
University of York, York

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

Morgan, H. & Harris, J. (forthcoming 2005) Involving disabled service users in research; barriers and challenges, in L. Lowes and I. Hulatt (eds.), *Service users' involvement in health and social care research*, London, Routledge.

Flexible, person-centred home care for older people

Ongoing project

Department of Health research programme
October 2001 to March 2005

Charles Patmore and Alison McNulty

The project aims to identify factors which enable home care services to help older people in a flexible, person-centred way, which can benefit their morale and quality of life as well as providing physical care.

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

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

Stage Two of the project examined six of these providers in depth. First, interviews with samples of older customers identified areas where person-centred practice was apparent and also each provider's shortcomings on this count. Subsequent interviews traced these issues through the different organisational and managerial levels of front-line home care staff, provider managers, care managers and senior social care commissioning managers. Explanations were sought for each provider's approach to care.

Publications

Patmore, C. (2004) Quality in home care for older people: factors to pay heed to, *Quality in Ageing* 5 (1).

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

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

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

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

A 'new vision' for adult social care: scoping service users' views

Completed

Department of Health research programme
September 2004 to November 2004

Caroline Glendinning, Melissa Dearey,
Bob Hudson (independent consultant)

As part of preparing a new Green Paper on adult social care services, SPRU was asked by the Department of Health to identify and collate the views of service user and similar organisations on how services should develop; and to consider how far these are compatible with the vision set out for children's services in *Every Child Matters*. An extensive list of service users and other organisations was contacted for recent relevant publications and reports. These were synthesised and the conclusions 'read across' to children's services. The report identified a set of common outcomes that user organisations and user-led research have identified as desirable objectives for social care and related services. It also identified a number of principles that are needed to inform service development and delivery, and issues for implementation at central, local, neighbourhood and individual levels, if these outcomes are to be achieved. The report also concluded that the scope for compatibility with the emerging changes to children's services is high.

Publications

Hudson, B., Dearey, M. and Glendinning, C. (2004) *A New Vision for Adult Social Care: Scoping Service Users' Views*, SPRU Working Paper.

Hudson, B., Dearey, M. and Glendinning, C. (2005) A New Vision for Adult Social Care: Scoping Service Users' Views, *Research Works* (forthcoming).

Measuring and understanding social services outputs: collaboration with Personal Social Services Research Unit, University of Kent

Ongoing project

Department of Health research programme
Start date: March 2004

Caroline Glendinning, Michael Hirst, Jennifer Harris

The Office of National Statistics is conducting a review of the future development of government outputs, productivity and price indices. SPRU is contributing to this work, led by PSSRU at the University of Kent, from the perspectives of personal social services activities with working age disabled people and informal carers. Work to date has involved collating information on the outcomes that are valued by working age disabled people, and informal carers, to complement the outcomes identified by PSSRU for older people. The work will continue by reviewing the range of available routinely-collected information on the activities of statutory social services in relation to working age disabled people and informal carers: the types and volume of services that are provided; the 'severity' of users needs (as a proxy indication of their 'capacity to benefit' from services); and the quality of the services that are provided.

Publications

Glendinning, C. (2005) *Research to Develop New Approaches to Measuring and Understanding Social Services Outputs and Productivity*, SPRU Working Paper DH (forthcoming).

Hirst, M. (2004) *Measuring Personal Social Services Outcomes: Services for carers*, SPRU Working Paper DH 2044.

Harris, J. (2004) *Measuring Personal Social Services Outcomes: Working age disabled people*, SPRU Working Paper DH 2046.

Health Inequalities and Informal Care: prospective, population-based study

Completed project

Department of Health Inequalities
in Health Research Initiative
October 2001 to January 2004

Michael Hirst

This study provides new evidence on the nature, extent, timing and persistence of health inequalities associated with the provision of unpaid care, and identifies high risk groups of carers. The findings increase knowledge of the diverse impacts of care-giving and help to disentangle the adverse effects of caring on health. They also begin to validate care-giving as an underlying social determinant in the creation of health inequalities, and to identify the circumstances in which care-giving might be an important variable in epidemiological analysis. The research is based on analysis of data from the first ten waves of the British Household Panel Survey covering the period from 1991 to 2000. Health-related measures include the General Health Questionnaire for assessing psychological well-being, and a widely used health status questionnaire (SF36). The study is relevant to the Strategy for Carers, National Service Frameworks, Health Improvement Programmes, Health Inequalities Agenda, and partnerships between Primary Care Trusts and councils with social services responsibilities.

Publications

Hirst, M. (2004) *Health Inequalities and Informal Care*, Social Policy Research Unit, University of York, York.
Available at: *http://www.york.ac.uk/inst/spru/pubs/pdf/healthinequalities.pdf*

Hirst, M. (2003) Caring-related inequalities in psychological distress in Britain during the 1990s, *Journal of Public Health Medicine*, 25, 4, 336–43.

Hirst, M. (2004) *Hearts & Minds: the health effects of caring*, Glasgow: Carers Scotland.
Available at: *http://www.york.ac.uk/inst/spru/pubs/pdf/Hearts&Minds.pdf*

Arksey, H. and Hirst, M. (in press)
Unpaid carers' access to and use of primary care services, *Primary Health Care Research and Development*, 6.

Hirst, M. (in press) Carer distress: a prospective, population-based study, *Social Science and Medicine*.

Hirst, M. (in press) Estimating the prevalence of unpaid adult care over time, *Research, Policy and Planning*.

OTHER FUNDED RESEARCH

Developing new approaches to funding long-term care for older people: lessons from other countries

Ongoing project

SPRU
Start date: August 2003

Caroline Glendinning

This work originated with a project commissioned by the Joseph Rowntree Foundation to investigate the lessons that could be learned from other countries' approaches to the organisation and funding of long-term care for older people. This project was conducted in collaboration with the Personal Social Services Research Unit at LSE. Subsequent work has built on this basis to develop methodological approaches to research on long-term care funding; to compare in depth developments in the UK and Germany; and to highlight policies to support informal and family carers within overall long-term care funding arrangements. Throughout, the project has relied on limited amounts of material published in English, supplemented by extensive contacts with key academics in relevant countries. Building on the original JRF project, more recent work has included:

- Preparation and presentation of a paper at the International Sociological Association RC 11 (Sociology of Ageing) conference at Roehampton, Surrey, on ways of evaluating long-term care funding arrangements

- Preparation and presentation of a paper (in collaboration with Professor Gerhard Igl, University of Kiel) comparing UK and German approaches to the organisation and funding of long-term care, to a invited seminar organised by the Anglo-German Foundation

- Collaboration with international collaborative research funded by the Social Sciences and Humanities Research Council of Canada, on policies in the UK and Germany for compensating care-givers of dependent adults in ten countries

- Contribution to the EU-funded Procare project end-of-project conference on health and social care for older people.

SPRU was also represented at the inaugural meeting of Eurocarers – a new EU network of carers' organisations and research partners intended to represent the voices of family carers at EU and national levels.

Publications

Glendinning, C., Davies, B., Pickard, L. and Comas-Herrera, A. (2004) *Funding Long-term Care for Older People: Lessons from other countries*, York, Joseph Rowntree Foundation.

Glendinning, C., Davies, B., Pickard, L. and Comas-Herrera, A. (2004) *Briefing: Funding Long-term Care for Older People: Lessons from other countries*, York, Joseph Rowntree Foundation.

Evaluation of People into Employment (PIE) project

Completed project

People into Employment/
Neighbourhood Renewal Fund
March 2003 to March 2004

Hilary Arksey

This is the second independent evaluation of the People into Employment (PIE) project based in Sunderland. PIE is a small project, which started in 2000. It specialises in finding employment specifically for disabled people, carers and former carers – groups that are known to be excluded and 'hard-to-reach'. The project is committed to supporting 'hidden' people who are not known to any of the statutory agencies. The evaluation sought to identify PIE's strengths and examples of good practice, as well as areas where there was scope for further development. It focused on the distance travelled by clients towards employability, so as well as examining qualifications and jobs obtained ('hard' outcomes) it looked at progress made in relation to key work skills and personal skills ('soft' outcomes).

The fieldwork for the evaluation comprised: a questionnaire survey of PIE clients, supplemented by three small discussion groups; one focus group with partner agencies; a joint interview with PIE's two development workers.

A report of the evaluation was produced in early 2004.

ESRC Research, Social Work and Social Care

Completed project

Social Care Institute for Excellence
September 2003 to February 2004

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

The role of the Economic and Social Research Council (ESRC) has been significantly expanded in recent years in order to promote the contribution of social science research to evidence-based policy and practice. At the same time, social work is increasingly being defined in terms of its relationship to research. The purpose of this project was to review the actual and potential coverage of social work and social care within ESRC programmes, and the implications of that review for social work and social care research in the UK. The review was conducted through a desk review of ESRC public domain documents; an electronic consultation of the social work research community; an e-mail questionnaire to grant holders on two recent ESRC programmes, a workshop and key informant interviews with senior ESRC staff and others.

The main report, *ESRC Research, Social Work and Social Care* written by Ian Shaw, Hilary Arksey and Audrey Mullender, was published in 2004. It is available on-line at: *www.scie.org.uk*

Public health: making community nurses count

Completed project

North and East Yorkshire and Northern Lincolnshire Strategic Health Authority
June 2003 to June 2004

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

The government's health strategy aims to improve the health of the general population and the health of the most disadvantaged in particular. Recently, the focus of public health activity has shifted to primary care. There is considerable scope for further involvement of nurses at all levels of public health activity, particularly within primary care settings. This study aimed to explore community nurses' emerging public health roles and the extent to which they offer evidence-based public health interventions in practice. Data collection methods included in-depth interviews with different groups of community nurses (health visitors; Sure Start health visitors; district nurses; practice nurses; school nurses) and public health managers, and over 100 hours of observational data.

The final report will document the findings from the primary research, as well as evidence from two reviews of systematic reviews published since 2000. Further dissemination will take place through journal articles and conference presentations.

Roles and expectations within a primary health care team

Completed project

Regional research practice funding
February to September 2004

Hilary Arksey (SPRU),
Ian Watt (Department of Health Sciences)

Primary care has changed over the last ten years. Demands on the primary care team have mushroomed and will continue to do so in a primary care-led National Health Service (NHS). The membership of the primary care team has broadened in line with recent government policy. As well as general practitioners, multi-professional teams include a range of nursing and other professionals such as counsellors or clinical pharmacist. New nursing roles such as nurse practitioners and clinical nurse specialists are blurring traditional boundaries, and old roles are being extended. The roles of practice managers, clerical and reception staff are also being continuously modified and extended. This pilot study was undertaken at a small urban general practice to explore how the roles of primary care professionals are understood by members of a primary care team, and team members' expectations of themselves and their colleagues.

The study adopted an 'action research' approach. All members of the primary care team were invited to take part in a face-to-face interview. A workshop was held at the end of the project to enable staff to come together to reflect on the findings. It was also the forum for developing change or action points to improve roles and enhance team working and patient care.

The findings are being disseminated through journal articles and conference presentations.

Special Feature
Sally Baldwin Memorial

In June family, friends and former colleagues of Sally Baldwin gathered to plant a tree in her memory. Sally had been the director of SPRU from 1987 to 2002, when she returned to work in the Department of Social Policy and Social Work. In 2003 she was killed in an accident whilst on holiday in Rome. The tree planting took place in the courtyard of the new Alcuin Research Resource Centre where the Social Policy Research Unit is now located, on Friday 11 June. A rowan tree was planted in memory of her contribution to SPRU and the University. The plaque is inscribed to Sally 'an inspirational leader and a good friend'.

Top

Peter Kemp, SPRU's director, spoke about Sally's contribution to SPRU and how much she is missed by those who knew her.

Bottom

Jonathan Bradshaw, Head of the Department of Social Policy and Social Work, planted the tree.

Social Security and Living Standards Team

Dr Roy Sainsbury

The Social Security and Living Standards Team is led by Dr Roy Sainsbury. Its research focuses on poverty, income maintenance and employment. The main streams of work being undertaken by the researchers within the Team are: the living standards of children and families; social security and the labour market, especially welfare to work policies in relation to people on incapacity benefit and other groups on the margins on employment; employment policies for disabled people; housing benefit; and the administration and delivery of benefits and tax credits, including the issue of social security fraud. Recently, we have begun to develop research on pensioner poverty, which complements our existing expertise in child poverty. The Team has a long track record of international comparative research.

Routes onto incapacity benefits

Ongoing project

Department for Work and Pensions
October 2004 – December 2005

Roy Sainsbury, Angela Meah, Naomi Finch

Little is known about the routes by which people become recipients of an incapacity benefit. Administrative data show that many claimants are unemployed before claiming incapacity benefit rather than in paid work. This qualitative study aims to explore the circumstances of claimants in the period leading up to claiming, whether their employment and benefit histories influence the decision to claim, and the roles played by key actors such as health professionals, Jobcentre Plus staff, other advisers, and family and friends. It is hoped that greater understanding of the factors leading to a claim will inform developments in disability and Welfare to Work policies.

Qualitative interviews will be carried out in 2005 with 60 recent claimants of incapacity benefits from areas of high, average and low rates of incapacity benefit claims. Follow-up interviews will be carried out after around six months to investigate people's exits from incapacity benefit in relation to their routes on to the benefit.

Evaluation of the incapacity benefit pilots

Ongoing project

Department for Work and Pensions
September 2003 to March 2007

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

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

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

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

Evaluation of the Job Retention and Rehabilitation Pilots

Ongoing project

Department for Work and Pensions
April 2003 to December 2005

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

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

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

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

Evaluation of the New Deal for Disabled People national extension

Ongoing project

Department for Work and Pensions
August 2001 to May 2005

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

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

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

Possible new work will be carried out to evaluate further changes to the New Deal for Disabled People introduced in 2004, and to explore the relationships between job brokers and the Incapacity Benefit pilots (also being evaluated by SPRU).

A report synthesising the first wave of qualitative and quantitative research was published in Stafford, B. *et al.* (including Corden, A., Thornton, P. and Sainsbury, R.)(2004) *New Deal for Disabled People (NDDP): First Synthesis Report*, DWP Research Management Report W199, Department for Work and Pensions Research Management, Sheffield.

By kind permission of the Disability Rights Commission

Employers’ management of long-term sickness absence

Completed project

Department for Work and Pensions
April to October 2004

Katharine Nice and Patricia Thornton

There is current policy interest in how best to support people on long-term sickness absence to return to work, and the Job Retention and Rehabilitation Pilot (JRRP) is underway. With funding from the JRRP evaluation, SPRU carried out with the National Centre for Social Research an in-depth study of what employers do to manage sickness absence and support return to work. It explored employers’ attitudes to sickness absence and why it was a problem; their policies and procedures; how short-term and long-term absence was actually managed; the resources they used; and what adjustments or adaptations were made on return to work. It also looked at whether employers knew about or needed external services to support or supplement what they do.

Publication

Job Retention and Rehabilitation Pilot: Employers' Management of Long-term Sickness Absence, by Katharine Nice and Patricia Thornton, was published by the Department for Work and Pensions in 2004.

User and provider views on desirable outcomes from WORKSTEP

Completed project

Department for Work and Pensions
January to October 2004

Angela Meah and Patricia Thornton

WORKSTEP is a national supported employment programme delivered by many provider organisations under contract to the Department for Work and Pensions. It is aimed at disabled people who face the most significant and complex barriers to getting and keeping a job. This qualitative study sought the views of participants and staff from provider organisations on what WORKSTEP ideally should be achieving for disabled people in terms of social, personal development, career and economic outcomes. It also explored views on the desirability and achievability of the WORKSTEP aims of individual development within supported employment and guided progression to staying in work without support from the programme. Thirteen focus groups were held with supported employees and nine with provider staff in locations in England, Scotland and Wales.

It is expected that the Department for Work and Pensions will publish a report from the project in 2005.

By kind permission of the Disability Rights Commission

Review of data and literature on employment of disabled people in the public sector

Completed project

Disability Rights Commission
June to October 2004

Michael Hirst, Patricia Thornton, Melissa Dearey and Sue Maynard Campbell (Equal Ability Ltd)

The review was commissioned in the context of the forthcoming new legal duty on public bodies to promote equality between disabled and non-disabled people. The Disability Rights Commission wanted a comprehensive picture of what is known about the situation of disabled people working in the public sector. Michael Hirst analysed longitudinal data from the Labour Force Survey to show recent trends and the employment circumstances and characteristics of disabled public sector employees. Patricia Thornton and Melissa Dearey's review of the research literature covered public sector employers' attitudes to their employment of disabled people; sickness absence and reasons for leaving public sector employment; disabled people's employment experiences; and the role of external services in promoting employment of disabled people in the public sector. Sue Maynard Campbell examined what is known about the effectiveness of what public sector employers do, based on unpublished employer documentation.

Publication

The report, *The Employment of Disabled People in the Public Sector: A Review of Data and Literature*, by Micheal Hirst, Patricia Thornton, Melissa Dearey and Sue Maynard Campbell, was published online by the Disability Rights Commission.

Trends in disability benefits recipiency rates

Ongoing project

Department for Work and Pensions
January 2003 to March 2005

Peter A. Kemp and Patricia Thornton

The aim of this International Social Security Association (ISSA) sponsored, six-country study is to understand reasons for growth in rates of receipt of disability benefits. The first stage of the project involved the preparation of a chapter on Great Britain for a book to be published for ISSA in 2005. Denmark, Israel, The Netherlands, Sweden and the USA are also participating in the study. The second stage involves writing a comparative chapter, contributing to a second comparative chapter, and contributing to the editing of the book.

Employability and problem drug users

Ongoing project

Unfunded

Peter Kemp and Joanne Neale (Oxford Brookes University)

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

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

Publication

Kemp, P.A. and Neale, J. Employability and problem drug users, *Critical Social Policy*, vol. 25, no.1, pp28–46.

Carers' aspirations and decisions around work and retirement

Ongoing project

Department for Work and Pensions
May 2004 to September 2005

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

There is increasing government recognition of the contribution and needs of people who provide unpaid, informal care for chronically sick, disabled, or elderly people. The importance of helping carers who wish to remain in employment was recognised in the National Strategy for Carers, published by the government in 1999. Paid employment can be important for carers' well-being and can help protect against poverty in later life. Since 1997 the Government has introduced a wide range of measures aimed at moving people from welfare to work and tackling poverty and social exclusion. The purpose of the study is to understand the relationship that carers have with the labour market and in particular their attitudes to, and decisions about, caring, paid work and retirement.

There are two elements to the study: a literature review and primary research. The literature review examines the existing evidence on carers in relation to employment and retirement published in the UK since 1985. The primary research comprises (a) in-depth interviews with carers in four different areas of England, and (b) focus groups in the same geographical areas with front-line staff whose work involves providing carers with information, advice or support from Jobcentre Plus offices, social services departments and carers' organisations.

The final report is expected to be available in early 2006.

Lone parents, childcare and work

Completed project

Department for Work and Pensions
February 2004 to September 2004

Naomi Finch, Roy Sainsbury and Christine Skinner with Alice Bell and Ivana La Valle (Natcen)

In 1997, as part of its welfare reform and child poverty strategy, the new Labour Government set a target to increase the lone parent employment rate to 70 per cent by 2010. A major barrier to work for lone mothers in the UK is considered to be lack of good quality, convenient and affordable childcare. This qualitative study aimed to increase understanding of lone parents' attitudes towards and experiences of childcare, their decisions about childcare and work, and their views and experiences of recent and imminent policy initiatives and changes. Seventy-eight face-to-face interviews and eight focus groups were conducted with lone parents with at least one child aged ten or under living in the household. The sample included lone parents who were both in and out of paid employment.

Publication

Bell, A., Finch, N., La Valle, I., Sainsbury, R. & Skinner, C. (2005) *A Question of Balance: Lone parents, childcare and work*, published by Department for Work and Pensions.

Welfare policy and employment in the context of family change

Ongoing project

Nordic Council of Ministers
May 2002 to April 2005

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

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

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

Use of the Social Fund among families with children

Completed project

Department of Work and Pensions
May 2003 to February 2004

Peter A. Kemp, Naomi Finch and Julie Williams

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

Publication

The report, *The Use of the Social Fund by Families with Children*, by Naomi Finch and Peter Kemp was published by the Department for Work and Pensions in 2004.

Poverty in large families

Ongoing Project

Joseph Rowntree Foundation
October 2004 to September 2005

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

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

1 by establishing the current extent of child poverty within large families in the UK

2 by comparing how different countries treat families of different sizes in their tax benefit packages

3 by examining how this relates to the relative child poverty rates of large and small families in different countries.

The well-being of children in the UK

Ongoing Project

Save the Children UK
March 2001 to March 2006

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

This project draws on the expertise that exists in the wider Department on children. The second volume of the book currently in press contains 15 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. The impact of poverty is another focus of this project.

Publication

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

Babies of the new millennium

Completed project

Unfunded
January 2004 to January 2005

Jonathan Bradshaw and Emese Mayhew

The project focuses on information collected in the new Millennium Cohort Study containing a sample of 18,700 babies born in 2000–2001 in the UK. The end result of the project is published in a book, which is a collection of chapters focusing on particular aspects of starting out on life in the 21st century, including experiences of pregnancy, and birth; child and parental health; household structure and socio-economic circumstances; characteristics of mothers and fathers as well as their attitudes towards parenting and employment. Jonathan Bradshaw and Emese Mayhew's contribution focused on poverty during pregnancy and its outcomes for both mother and child.

Publication

Dex, S. and Joshi, H. (eds) (2005) *Babies of the New Millennium*, Centre for Longitudinal Studies, London, Policy Press.

COST Action 19: children's welfare in ageing Europe

Completed project

European Union
September 2001 to June 2005

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

COST Action 19 is a comparative project involving 13 countries that seeks to understand children's welfare in ageing societies. The project explores the interplay of material, social and institutional forces through emphasising theoretical and methodological approaches to children's welfare. Three areas of welfare are highlighted:

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

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

Publication

Jensen, A.M., Ben-Arieh, A., Conti, C., Kutsar, D., Phadraig, M.N.G. and Warming Nielsen, H. (eds.) (2005) *Children's Welfare in Ageing Europe*, Volume 1, Trondheim, Norwegian Centre for Child Research.

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

Ongoing project

Economic and Social Research Council
November 2002 to June 2005

Anne Corden and Roy Sainsbury

In presenting findings from applied social research, one technique is to include respondents' verbatim quotations within the author's written text. However, in research methods texts, more attention has been paid to data collection and analysis than to the way qualitative researchers write up findings. This study attempts to redress this imbalance.

The aims of the project 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:

1. A review of what the theoretical and methodological textbooks say about using quotations
2. A review of recent social research texts, to identify different types of use of quotations
3. Selection of illustrative texts, and exploration of preferences about using quotations with the authors, and research users (policy makers, funders, other researchers)
4. Testing the impact of different approaches, with alternative versions of a report from a small study of people participating in a volunteering project.

In 2004 progress was made with all stages of the project including the completion of the small study on volunteering. Findings from the whole project will be disseminated in a book and academic papers. This study is funded as part of the ESRC Research Methods Programme.

Publication

Corden, A. and Sainsbury, R. (2005)
Volunteering for Employment Skills – A Qualitative Research Study,
Social Policy Research Unit, York.

SPRU Seminar Series

The Unit organises a series of public seminars each year. In 2004, the seminars were held on the theme of

**Supporting the family:
policy and practice developments
across the life course.**

SPRU is grateful to the following people for making presentations to the seminar series:

Tuesday 6 April 2004
*'Family support:
Where do disabled parents fit?'*
Dr Richard Olsen – Nuffield Community Care Studies Unit, University of Leicester

Tuesday 4 May 2004
'Sure Start: Has it gone astray?'
Professor Norman Glass – Chief Executive, National Centre for Social Research, London

Tuesday 8 June 2004
'Making sense of health and social care for minority ethnic populations: Implications for research policy and practice'
Dr Karl Atkin – Director of the Centre for Research in Primary Care, University of Leeds

Tuesday 22 June 2004
*'Funding long term care:
Lessons for the UK from other countries'*
Professor Caroline Glendinning – Social Policy Research Unit, University of York

Tuesday 6 July 2004
'Developing policies for post divorce family life: The case of shared residence and children'
Professor Carol Smart – Director of the Centre for Research on Family, Kinship and Childhood, University of Leeds

Wednesday 29 September 2004
'Getting the message across'
Derek Kinrade – National Information Forum, London

Tuesday 5 October 2004
'Into paid work: The experiences of lone mothers and their children'
Professor Jane Millar – Director of the Centre for the Analysis of Social Policy, University of Bath

Tuesday 9 November 2004
*'Family carers:
Towards better assessment practice'*
Professor Mike Nolan – Professor of Gerontological Nursing, University of Sheffield

Tuesday 30 November 2004
'Unmarried parenthood: Does it Matter?'
Professor Kathleen Kiernan, Professor of Social Policy and Demography, Department of Social Policy and Social Work, University of York

Tuesday 7 December 2004
*'Children's family circumstances:
Tracing across time using the
ONS Longitudinal Study'*
Linda Clarke – Centre for Population Studies, London School of Hygiene and Tropical Medicine

External Activities and Advisory Positions held by SPRU Staff in 2004

Hilary Arksey

Chair of the Advisory Group for the *Changing Lives Project* (Scarborough and Ryedale Carers Resource)

Jonathan Bradshaw

UK expert on national action plans on social inclusion for the European Commission

Consultant to the University of Oxford project Poverty in South Africa

Advisor to the Department of Work and Pensions Committee Inquiry on Child Poverty

Chair of York Welfare Benefits Unit

Anne Corden

Bereavement Research Forum Steering Committee member

Caroline Glendinning

Member of Research Committee 11 (Ageing) of the International Sociological Association Advisory Group

Member of the ESRC Research Evaluation Committee

External examiner in MSc in Health and Social Care, City University

Jennifer Harris

Member of the Scientific Committee of the 2005 Conference on Qualitative Evidence in Health Care

Member of the Joseph Rowntree Foundation Project Advisory Group for Housing and Related Services for Refugees and Asylum Seekers

Member of Care Centre Review Panel, Motor Neurone Disease Association

External Examiner for MSc in Advanced Practice Management, St Martin's College, University of Lancaster

Michael Hirst

Member of the Stakeholder Steering Group of the Scottish Executive Unpaid Carers Futures Exercise

Advisory Board of the Nuffield Community Care Studies Unit, University of Leicester

Peter Kemp

General Secretary of the Foundation for International Studies of Social Security

Member of International Social Security Association Advisory Board

Member of Department for Work and Pensions Housing Benefit Reform Group

Member of the Joseph Rowntree Foundation's Housing Benefit Reform Forum

Office of the Deputy Prime Minister nominee on the Hull Partnership Liaison Board

Patricia Sloper

External PhD examiner at Monash University, Australia and University of British Columbia, Canada

UK independent expert for the Peer Review of Disability Management Policy in The Netherlands

Member of The National Association for Colitis and Crohn's Disease Social and Psychological Research Committee

Member of York Health Services NHS Trust Research Ethics Committee

Member of City of York Children's Trust Board

Peer Reviewing

During 2004, staff in SPRU refereed articles for the following academic journals:

Archives of Disease in Childhood Benefits

British Journal of Educational Psychology

British Journal of Learning Disabilities

Child and Adolescent Mental Health

Child and Family Social Work

Child: Care, Health and Development

Children and Society

Critical Public Health

European Journal of Housing Policy

Health Expectations

Health Policy

Health and Social Care in the Community

Housing Studies

The International Journal of Aging and Human Development

Journal of Child Psychology and Psychiatry

Journal of Disability and Society

Journal of Gender Studies

Journal of Social Policy

Journal of Social Security Law

Journal of Youth Studies

Psycho-Oncology

Qualitative Social Work: Research and Practice

Social Policy and Administration

Social Policy and Society

Social Science and Medicine

Urban Studies

Membership of Editorial Boards

During 2004, staff in SPRU belonged to the editorial boards of the following journals:

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

Jennifer Harris
Health and Social Care in the Community, *Social Work and Social Services Review*

Peter Kemp
Journal of Social Policy

Parvaneh Rabiee
Journal of Disability and Society

Roy Sainsbury
Journal of Social Security Law, *Benefits*

Patricia Thornton
Research Matters

Other editorial activities for journals in 2004 included:

Jennifer Harris
Review Editor of *Journal of Psychiatric and Mental Health*; Editor of *Disability and Society*

Peter Kemp
Guest editor for a special issue of the journal *Benefits*

Angela Meah
Social Science Editor for the *Journal of Gender Studies*

Patricia Sloper
Guest editor for a special issue of *Child: Care, Health and Development*

Research Staff Profiles

Hilary Arksey's research during 2004 included an action research project looking at the roles and expectations of members of a primary care team, as well as a study of community nurses' perceptions of public health. Both studies, in their different ways, feed into current debates about the impact of modernisation of the NHS. Hilary's current work concentrates on a study into carers' aspirations and decisions around paid work and retirement, which have the potential to inform the development of the Department for Work and Pensions' strategy on carers, and the Department for Trade and Industry's strategy on workplace policies for carers. In autumn 2004, Hilary undertook a series of seminars in universities, government departments and carers' organisations in Australia and New Zealand.

Bryony Beresford is currently working on a project looking at the outcomes disabled children and their families desire from support services and how information about outcomes can be collected and used by services. Recent policy initiatives, such as the Children Act and Children's National Service Framework, are requiring statutory agencies to look to improve the way these families are supported. In response to this a new project with the aim of improving services for disabled children, young people and their families in York began towards the end of the year. Bryony is also involved in researching children's access to space and their use of time in a European project that seeks to understand children's welfare in ageing societies. Bryony's on-going interests include developing methodologies for research with children, children's experiences of illness and disability, and the issues and processes surrounding the implementation of research findings into practice.

Jonathan Bradshaw has been Associate Director of SPRU since 1994 and is a member of the Social Security and Living Standards Team. He is Head of the Department of Social Policy and Social Work at the University of York. His research interests include social security policy; family policy; poverty and living standards; comparative social policy; demography and social policy; well-being of children. Currently his research includes child poverty in large families; welfare policy and employment in the context of family change; COST Action 19 Child Well-being; the multi-national project measuring and monitoring children's well-being and deprivation and variations in teenage conceptions and abortions in England.

Sue Clarke has worked on projects in both health and social care during 2004. She is currently working on a project consulting with service providers, parents and children about improving services for disabled children and their families in York. This initiative ties into recent national policy developments, such as the Children Act and Children's National Service Framework, to provide better services for disabled children and their families. Sue is also helping to set up a local consultation group of young people who have an illness or disability themselves, to guide the research of the Children and Families Team.

Research Staff Profiles

Anne Corden's interests in qualitative methodology have continued this year, in her exploration of theoretical and practical issues in using verbatim quotations from research participants in reporting social research. Findings about the impact of quotations on those who read and use research reports, and the views of those who speak the words will be important for people across a wide range of social science disciplines and policy arenas. Anne has also continued working on a number of large, government-commissioned evaluations of labour market programmes for disabled people. Findings will be immediately relevant to the Government's commitment to 'welfare to work' and the proposed major changes to incapacity benefits. Drawing on her overall knowledge of benefits and tax credits, Anne has also contributed to a comparative study of social security benefits for sick and disabled people, to provide information from other countries to inform US government interest in temporary, short-term and partial disability benefits.

Naomi Finch has expertise in both quantitative and qualitative data collection and analysis, but is mainly a quantitative researcher. She has undertaken research on poverty, living standards, employment and family policy. Naomi's work over the last year has focused on the work–family life balance, a key area in the Government's child poverty strategy. Her work also has relevance to wider debates about gender equity in paid and unpaid work. Her research has included a comparative analysis of childcare and parental leave policies to understand the extent that welfare states support gender equity in paid and unpaid work. She has also explored the outcomes of these policies by examining gender divisions of labour within the household using the Multi-national Time Use Survey. Naomi has also undertaken a qualitative study exploring lone parents perceptions and experiences of different kinds of childcare and how these are balanced with decisions about employment.

Michele Foster worked on the outcomes for disabled service users project during 2004, as a secondment from her research fellowship in Australia. Building on previous DH Outcomes Programme work, this project seeks to develop and test a goal-orientated approach to social services assessment and review with disabled people of working age. Michele's research interests include: equity and access to services for people with long-term disabilities and factors influencing professional decision-making, and the implications for social and health policy.

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

Caroline Glendinning's main priority during 2004 involved preparing for and successfully leading the review of SPRU's Department of Health research programme. She also had overall responsibility for the remaining projects in the DH-funded Outcomes programme. As part of the DH programme, she has contributed evidence to support a new Green Paper on Adult

Social Care Services and has also contributed to work led by the Personal Social Services Research Unit on the development of methods to measure the productivity of social services. She is responsible for the management of a DWP-funded study on the experiences of family carers in relation to paid work, retirement and pension planning. In October she participated in a meeting in Maastricht of carers' organisations and research institutes; this laid the foundations of a new EU-wide organisation to promote policy and research on informal care. Meanwhile, Caroline has continued to give conference presentations and publish papers on direct payments, comparative approaches to funding long-term care and health and social care partnerships, arising from previous research carried out at the University of Manchester.

Veronica Greco has conducted research on key worker and care co-ordination services, exploring which models or types of key working lead to the best outcomes for families of disabled children and for the children themselves. The research project has used both qualitative and quantitative methods and has also comprised a section on the cost-effectiveness of the services and on the key worker's links with education and schools. The research is timely since recent policy initiatives, such as the National Service Framework for Children, have placed increasing emphasis on multi-agency collaboration, both in general and specifically in relation to disabled children.

Jennifer Harris leads research within the Department of Health research programme on disabled adults of working age. This year has seen the culmination of her research into the outcomes for disabled service users project, which seeks to develop and test a goal-orientated approach to social services assessment and review with disabled people of working age. Jennifer also led a team of researchers working on the National Service Framework for Long-Term Conditions. They investigated user and carer experiences of health and social care services for people with neurological and other long-term conditions. Jennifer's research interests are in the fields of cultural deafness, disability studies and qualitative research methods.

Janet Heaton has been examining the extent to which NHS Patient Advice and Liaison Services (PALS) have enabled children, young people and parents to access and use this service, which provides information and advice to people of all ages on healthcare issues. The findings will enable policymakers and service providers to improve PALS so that they are more easily accessible to and usable by this group who previous research has shown have been poorly involved in healthcare decision-making. Before this, Janet's work at SPRU involved carrying out a range of empirical studies involving children, young people, adults and older people with physical and/or complex disabilities or who care for relatives. She has also done work exploring the epistemological, methodological and ethical issues surrounding the re-use of qualitative data in social research.

Michael Hirst has conducted research evaluating policy, the delivery of benefits and services, and outcomes as they affect disabled people and carers. He has considerable experience of quantitative research methods and the analysis of complex datasets. In 2004, Michael completed a study of carers' health, highlighting the importance of adopting a temporal perspective and producing key recommendations for supporting carers in their caring role. The findings also have relevance for health improvement programmes, the health inequalities agenda, and partnerships between primary and social care. Michael also worked on a project examining trends in, and inequalities between, disabled and non-disabled people working in the public sector, providing a benchmark for the new Disability Discrimination Act, which places a duty on public authorities to eliminate discrimination against disabled people. Latterly, he began work on measuring the contribution of personal social services to achieving the outcomes valued by carers and disabled working age people.

Karen Jackson has been working with Jennifer Harris and Michele Foster on the outcomes for disabled service users project. Building on previous Outcomes Programme work, this project seeks to develop and test a goal-orientated approach to social services assessment and review with disabled people of working age. Karen's interests are in service user involvement in the research process and systematic review methods.

Peter Kemp has a long-standing interest in the implementation of policy and the outcomes that result from it. Having spent many years studying housing policy, his research is now focused on social security, welfare reform, employment and carers. He also maintains a long-term research interest in housing benefit. During 2004 he completed a review of research on routes out of poverty and a research project on use of the Social Fund by families with children. His current projects include a comparative study of trends in incapacity benefits, a study of carers' aspirations and decision-making about work and retirement, and a four-country study of housing benefit and income support. He is also editing a comparative book on housing benefit.

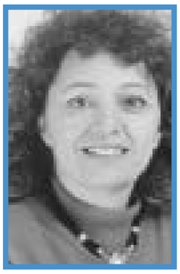
Emese Mayhew's primary skills include using large-scale surveys and collecting and analysing cross-national data. She has worked on a variety of projects, focusing on issues of child demography; child and youth poverty; gender inequality and comparative social policy. In the context of the Government's target to abolish child poverty by 2020, her current project concerns exploring poverty in large families in the UK, from both an historical and a comparative perspective. She is also contributing to a comparative project on welfare policy and employment in the context of family change involving the comparison of five Nordic and three European countries. She has recently completed a project exploring poverty during pregnancy using the Millennium Cohort Study which is a new child cohort study containing information on over 18,000 babies born in 2000 in the UK.

Angela Meah has undertaken research focusing on issues relating to sickness and employment, and supported employment for disabled people funded by the DWP. As a qualitative researcher and a sociologist, she has experience of collecting and analysing data via focus groups and individual interviews and has experience of teaching focus group methodology. Completed work within SPRU includes a study examining the non-take-up of Job Broking services by people eligible to participate in the New Deal for Disabled People. Her principle area of interest has been with the WORKSTEP programme, and she has completed a study involving both service users and providers, which explores what they perceive to be the desirable outcomes of the programme. She is currently working on a project that will examine claimants' routes onto Incapacity Benefit, one of the aims of which is to identify key transitions points at which current or future interventions may help people toward work or active job seeking.

Wendy Mitchell's research this year has involved a study for CLIC examining the care and support needs of children with cancer and their families. This study, via two postal surveys, explored patterns of psychosocial support service provision throughout the UK. It also described and compared the needs of children and their parents throughout the illness and post treatment. Recommendations for future service provision were made, which have helped to inform standards and guidelines currently being developed by NICE. Wendy is presently working on an evaluation of the Integrated Children's System, examining the experiences of families with disabled children, via qualitative interviews with both parents and disabled children. Wendy's first work with SPRU was to develop a directory and website of services that families with disabled children valued and nominated as 'quality' services.

Katharine Nice has been working on DWP-funded projects evaluating current welfare-to-work initiatives for sick and disabled people. The projects have used qualitative research methods to explore the roles, experiences and views of key stakeholders such as benefit recipients, GPs, employers and service providers. Her work on the Incapacity Benefit Pathways to Work pilots reports on the new work-focused interviews and packages of support that aim to help benefit recipients into work, measures that are planned to continue under government proposals. She has also undertaken work evaluating an innovative programme that has been piloted as a randomised controlled trial and which aims to help people keep their jobs and return to work when they become ill or have a disability. As part of this project she worked on a study investigating employers' roles in managing sickness absence, which helped to inform the Government's new Framework for Vocational Rehabilitation.

Charles Patmore joined SPRU in 1997 to work on community care for older people. Prior to joining SPRU, he was a research officer in Social Services. His interests are in ways of adjusting social care for older people to reflect individuals' values and aspirations, and ways of supporting morale and quality of life for older people who suffer disability or long-term illness. Currently he is concluding a research project on factors which enable home care for older people to be flexible and person-centred. This is part of the Department of Health research programme.



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

Roy Sainsbury's research interests include social security and the labour market, sickness and disability benefits, housing benefit, and the administration and delivery of benefits, in particular the appeals system and social security fraud. This year Roy has worked on all aspects of incapacity benefit and job rehabilitation. His work looks at how people find themselves on incapacity benefits; projects to help new applicants for incapacity benefit get back to work; evaluating the success of different methods of support in job rehabilitation; and assessing the job broker service in the New

Deal for Disabled People National Extension. All these are issues at the heart of recent government concern and action about the rising levels of incapacity benefit claimants. A separate strand of work explores the theoretical and practical issues around using verbatim quotations from research participants in reporting social research.

Tricia Sloper's research interests include the needs of children and young people with chronic illness or disability and their families; stress and coping in children, young people and families affected by illness or disability; developing methods for research with children; and the implementation of research findings in practice. Tricia's background is in psychology and she has long-standing interests in the application of knowledge from developmental and social psychology to issues affecting the lives of disabled children and their families. Current work includes studies of the effectiveness of different models of key workers for families with disabled children; implementing an outcomes approach in services for disabled children and their families; disabled children's participation in decisions that affect services they receive; children and young people's use of Patient Advice and Liaison Services; and support needs of children with cancer and their families.

Patricia Thornton's research continued in the highly topical policy area of how to support disabled people's participation in work. Government initiatives are focused not just on programmes to assist people into work and support them there – such as the New Deal for Disabled People and WORKSTEP which Patricia has been involved in evaluating – but also on preventing people from leaving work through ill health. To inform a pilot job retention project, Patricia and Katharine Nice undertook an in-depth study of what employers do when an employee is off sick. Disability discrimination legislation is evolving too, with new duties on public bodies to actively promote equality between disabled and non-disabled people, and Patricia led a review of what is known about public sector employment of disabled people. Her interest in comparative policy continued too this year, through involvement with Peter Kemp in a study looking at trends in disability benefits receipt.

Support Staff Profiles

CCNUK Staff Profiles

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

Christine Carpenter is personal assistant to Caroline Glendinning and provides secretarial and administrative support to the Community Care for Adults Team.

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

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

Lisa Goode is personal assistant to the Director and is responsible for administration of the Senior Management Group.

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

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

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

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

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

CCNUK

Katy Barton's background is in social work with over 20 years experience as a manager and practitioner in both the statutory and voluntary sector. Her interests are in disabled children and their families and her work over the last four years has been a development role to set up an umbrella organisation, Care Co-ordination Network UK, that promotes key working for disabled children and their families. Over the last 12 months CCNUK has produced a set of standards for the key workers' service and there has been a significant increase in interest from policymakers and practitioners in the principles of key working and its implementation.

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


MB


CC


RD


TF


LG


CB

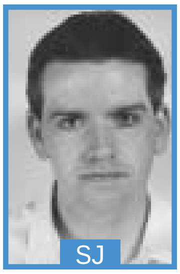

KB

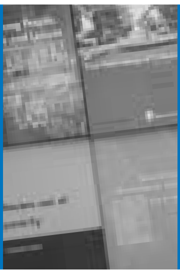

JWi


JWh


SP


RP


SJ



Publications

ARTICLES IN ACADEMIC JOURNALS 2004

Arksey, H. and Weatherly, H. (2004) Respite care and short breaks: what works and at what cost?, *Journal of Dementia Care*, 12, 5, 33–7

Beresford, B. (2004) On the road to nowhere? Young disabled people and transition, *Child: Care, Health and Development*, 30, 6, 581–87

Beresford, B., Tozer, R., Rabiee, P. and Sloper, P. (2004) Developing an approach to involving children with autistic spectrum disorders in a social care research project, *British Journal of Learning Disabilities*, 32, 4, 180–85

Bradshaw, J. (2004) How has the notion of social exclusion developed in the European discourse?, *The Economic and Labour Relations Review*, 14, 2, 168–86

Bradshaw, J. and Finch, N. (2004) Housing benefits in 22 countries, *Benefits*, 12, 2, 87–94

Bradshaw, J. and Mayhew, E. (2004) Public attitudes to dependency and the welfare state, *International Journal of Market Research*, 46, 1, 49–63

Cavet, J. and Sloper, P. (2004) The participation of children and young people in decisions about UK service development, *Child: Care, Health and Development*, 30, 6, 613–21

Cavet, J. and Sloper, P. (2004) Participation of disabled children in individual decisions about their lives and in public decisions about service development, *Children & Society*, 18, 4, 278–90

Coleman, A. and Glendinning, C. (2004) Local authority scrutiny of health: making the views of the community count?, *Health Expectations*, 7, 1, 29–39

Corden, A. and Ellis, A. (2004) Volunteering and employability: exploring the link for incapacity benefit recipients, *Benefits*, 12, 2, 112–18

Corden, A., Sainsbury, R. and Sloper, P. (2004) Money matters and bereavement support, *Bereavement Care*, 23, 2, 19–21

Crawshaw, M., Glaser, A., Hale, J., Phelan, L. and Sloper, P. (2004) Professionals’ views on the issues and challenges arising from providing a fertility preservation service through sperm banking to teenage males with cancer, *Human Fertility*, 7, 23–30

Dowling, B., Powell, M. and Glendinning, C. (2004) Conceptualising successful partnerships, *Health and Social Care in the Community*, 12, 4, 309–17

Eiser, C., Greco, V., Vance, Y., Horner, B. and Glaser, A. (2004) Perceived discrepencies and their resolution: quality of life in survivors of childhood cancer, *Psychology and Health*, 19, 1, 15–28

Glendinning, C. and Means, R. (2004) Rearranging the deckchairs on the Titanic of long-term care – is organizational integration the answer?, *Critical Social Policy*, 24, 4, 435–57

Greco, V. and Sloper, P. (2004) Care co-ordination and key worker schemes for disabled children: results of a UK wide survey, *Child: Care, Health and Development*, 30, 1, 13–20

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

Hockey, J., Robinson, V. and Meah, A. (2004) A Heterosexual Life: older women and agency within marriage and the family, *Journal of Gender Studies*, 13, 2, 227–38

Kemp, P.A. (2004) Housing and social security, *Benefits*, 12, 2, 83–5

Kirk, S. and Glendinning, C. (2004) Developing services to support parents caring for a technology-dependent child at home, *Child: Care, Health and Development*, 30, 3, 209–18

Mihaylov, S., Jarvis, S., Clover, A. and Beresford, B. (2004) Identification and description of environmental factors that influence participation of children with cerebral palsy, *Developmental Medicine and Child Neurology*, 46, 5, 299–304

Mitchell, W. and Sloper, P. (2003) 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*, 33, 8, 1063–80

Patmore, C. (2004) Quality in home care for older people: factors to pay heed to, *Quality in Ageing*, 5, 1, 32–40

Priemus, H. and Kemp, P.A. (2004) The present and future of income-related housing support: debates in Britain and the Netherlands, *Housing Studies*, 19, 4, 653–68

Qureshi, H. (2004) Evidence in policy and practice: what kinds of research designs?, *Journal of Social Work*, 4, 1, 7–23

Qureshi, H. and Rowlands, O. (2004) User satisfaction surveys and cognitive question testing in the public sector: the case of personal social services in England, *International Journal of Social Research Methodology*, 7, 4, 273–87

Robinson, V., Hockey, J. and Meah, A. (2004) "What I used to do on my mother's settee": spatial and emotional aspects of heterosexuality in England, *Gender, Place & Culture*, 11, 3, 417– 35

Sainsbury, R. (2004) Whatever happened to the reform of decision making and appeals?, *Benefits*, 12, 1, 8–12

Sloper, P. (2004) Facilitators and barriers for co-ordinated multi-agency services, *Child: Care, Health and Development*, 30, 6, 571–80

Sloper, P. and Statham, J. (2004) The National Service Framework for children, young people and maternity services: developing the evidence base, *Child: Care, Health and Development*, 30, 6, 567–70

Soutter, J., Hamilton, N., Russell, P., Russell, C., Bushby, K., Sloper, P. and Bartlett, K. (2004) The golden freeway: a preliminary evaluation of a pilot study advancing information technology as a social intervention for boys with Duchenne muscular dystrophy and their families, *Health and Social Care in the Community*, 12, 25–33

Titzmann, P., Roger, D., Olason, D. and Greco, V. (2004) A new approach to assessing optimism: the development of a German version of the positive and negative expectancies questionnaire (PANEQ-G), *Current Psychology: Developmental, Learning, Personality, Social*, 23, 2, 97–110

REPORTS AND BOOKS

Arksey, A., Jackson, K., Croucher, K., Weatherly, H., Golder, S., Hare, P., Newbronner, E., Baldwin, S. (2004) *Review of Respite Services and Short-Term Breaks for Carers of People with Dementia*, National Health Service, Service Delivery and Organisation, London (Online)

Alborz, A., McNally, R., Glendinning, C. and Swallow, A. (2004) *From the Cradle to the*

Grave: A literature review of access to health care by people with learning disabilities across the lifespan, National Health Service Service Delivery and Organisation, London, (Online)

Bradshaw, J., Kemp, P., Baldwin, S., and Rowe, A. (2004) *The Drivers of Social Exclusion: A review of the literature*, Social Exclusion Unit, Office of the Deputy Prime Minister, London

Clarke, S., Mitchell, W. and Sloper, P. (2004) *Care and Support Needs of Children and Young People with Cancer and Leukaemia and Their Families*, Social Policy Research Unit, University of York, York

Finch, N. and Kemp, P.A. (2004) *The Use of the Social Fund by Families with Children*, Department for Work and Pensions In-house Report 139, Social Research Division, Department for Work and Pensions, London

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

Glendinning, C. (2004) *Research to Develop New Approaches to Measuring and Understanding Social Service Outputs and Productivity*, Social Policy Research Unit, University of York, York (Online)

Glendinning, C. (2004) *Support for Carers of Older People – Some Intranational and National Comparisons: A review of literature prepared for the Audit Commission*, Audit Commission, London (Online)

Glendinning, C., Davies, B., Pickard, L. and Comas-Herrera, A. (2004) *Funding for Long-term Care for Older People: Lessons from other countries*, Joseph Rowntree Foundation, York

Harris, J. (2004) *Measuring Personal Social Services Outcomes: Working age disabled people*, Social Policy Research Unit, University of York, York (Online)

Heaton, J. (2004) *Reworking qualitative data*, Sage, London

Hirst, M. (2004) *Health Inequalities and Informal Care*, Social Policy Research Unit, University of York, York

Hirst, M. (2004) *Measuring Personal Social Services Outcomes: Outcomes for carers*, Social Policy Research Unit, University of York, York (Online)

Hirst, M., Thornton, P., Dearey, M. and Maynard Campbell, S. (2004) *The Employment of Disabled People in the Public Sector: A review of data and literature*, Disability Rights Commission, Stratford Upon Avon (Online)

Hudson, B., Dearey, M. and Glendinning, C. (2004) *A New Vision for Adult Social Care: Scoping Service Users' Views,* York: Social Policy Research Unit, University of York, (Online)

Kemp, P.A. (2004) *Private Renting in Transition*, Chartered Institute of Housing, Coventry

Kemp, P.A., Bradshaw, J., Dornan, P., Finch, N. and Mayhew, E. (2004) *Routes Out of Poverty: A research review*, Joseph Rowntree Foundation, York

Mitchell, W., Bunton, R. and Green, E. (eds.) (2004) *Young People, Risk and Leisure: Constructing identities in everday life*, Palgrave Macmillan, Basingstoke

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

Ormrod, S., Glendinning, C., Stanmore, E. and Waterman, H. (2004) *Evaluation of Rehabilitation Assistants in East Cheshire*, National Primary Care Research and Development Centre and School of Nursing, Manchester

Overbye, E. and Kemp, P.A. (eds.) (2004) *Pensions: Challenges and Reforms*, Ashgate, Aldershot

Sainsbury, R. and Corden, A. (2004) *Medical Evidence and Incapacity Benefit Appeals: Evaluation of a pilot study*, Department for Work and Pensions In-house Report 129, Social Research Division, Department for Work and Pensions, London

Shaw, I., Arksey, H. and Mullender, A. (2004) *ESRC Research, Social Work and Social Care*, Social Care Institute for Excellence, London

Stafford, B. … (et al.) incl. Corden, A., Sainsbury, R. and Thornton, P. (2004) *New Deal for Disabled People (NDDP): First synthesis report*, Department for Work and Pensions Research Report W199, Research Management, Department for Work and Pensions, Sheffield

Thornton, P., Banks, P., Riddell, S. and Beyer, S. (2004) *A Study of Providers New to WORKSTEP*, Department for Work and Pensions Research Report W195, Research Management, Department for Work and Pensions, Sheffield

CHAPTERS IN BOOKS

Arksey, H. (2004) Semi-structured and unstructured interviewing, in S. Becker and A. Bryman (eds.), *Understanding Research for Social Policy and Practice*, Policy Press, Bristol, pp.268–75

Corden, A. (2004) Research with recently bereaved parents, in S. Becker and A. Bryman (eds.), *Understanding Research for Social Policy and Practice: Themes, methods and approaches*, Policy Press, Bristol, pp.167–69

Bradshaw, J. (2004) Comparative research on poverty, in S. Becker and A. Bryman (eds.), *Understanding Research for Social Policy and Practice: Themes, methods and approaches*, Policy Press, Bristol, pp.127–29

Bunton, R., Green, E. and Mitchell, W. (2004) Introduction: young people, risk and leisure – an overview, in W. Mitchell, R. Bunton and E. Green (eds.), *Young People, Risk and Leisure: Constructing Identities in Everyday Life*, Palgrave Macmillan, Basingstoke, pp.1–24

Glendinning, C. and Coleman, A. (2004) Joint working: the Health Service agenda, in S. Snape and P. Taylor (eds.), *Partnerships Between Health and Local Government*, Frank Cass, London

Harris, J. (2004) Incorporating the social model into outcome-focused social care practice with disabled people, in C. Barnes and G. Mercer (eds.), *Disability Policy and Practice: Applying the social model*, Disability Press, University of Leeds, Leeds, pp.116–29

Harris, J. and Roberts, K. (2004) "Not our problem": the provision of services to disabled refugees and asylum seekers, in D. Hayes and B. Humphries (eds.), *Social Work Immigration and Asylum: Debates, dilemmas and ethical issues for social work and social care practice*, Jessica Kingsley, London

Hirst, M. (2004) The British Household Panel Survey: a longitudinal perspective on informal care, in S. Becker and A. Bryman (eds.), *Understanding Research for Social Policy and Practice*, The Policy Press, Bristol, pp.190–93

Kemp, P.A. (2004) Young people and unemployment: from welfare to workfare?, in M. Barry (ed.), *Youth Policy and Social Inclusion*, Routledge, London, pp.139–56

Mayhew, E., Uprichard, E., Beresford, B., Ridge, T. and Bradshaw, J. (2004) Children and childhood in the United Kingdom, in A. Jensen, et al. (eds.), *Children's Welfare in Ageing Europe*, Norwegian Centre for Child Research, Trondheim, pp.401–57

Meah, A., Hockey, J. and Robinson, V. (2004) Narrating Heterosexual Identities: Recollections, Omissions and Contradictions, in D. Robinson, C. Horrocks, N. Kelly and

B. Roberts (eds.), *Narrative, Memory and Identity: Theoretical & Methodological Issues*, University of Huddersfield Press, Huddersfield, pp.85–93

Mitchell, W. (2004) Risk, motherhood and children's play spaces: the importance of young mothers' experiences and risk management strategies, in W. Mitchell, R. Bunton and E. Green (eds.), *Young People, Risk and Leisure: Constructing Identities in Everyday Life*, Palgrave Macmillan, Basingstoke, pp.180–202

Overbye, E. and Kemp, P.A. (2004) Introduction, in E. Overbye and P.A. Kemp (eds.), *Pensions: Challenges and Reforms*, Ashgate, Aldershot, pp.xvii–xxi

Sainsbury, R. (2004) Policy ignoring research: The case of housing benefit appeals and a new deal, in S. Becker and A. Bryman (eds.), *Understanding Research for Social Policy and Practice: Themes, methods and approaches*, Policy Press, Bristol, pp.26–8

Thornton, P. (2004) New directions in disability employment policy, *Proceedings of the Conference on Creation of New Employment Strategy: Full participation and Opportunity, Seoul, South Korea, 13 and 14 October*, Korea Employment Promotion Agency for the Disabled, Seongnam-City, pp.199–214

Thornton, P. (2004) United Kingdom, in European Commission-DG EMPL Peer Review Programme of the European Employment Strategy (ed.), *Disability Management in the Netherlands*, OSB Consulting, Vienna, pp. 105–10

ARTICLES IN PROFESSIONAL JOURNALS

Arksey, H. and Wagstaffe, G. (2004) Uphill struggle, *Care and Health*, April 6th, 60, 36–7

Patmore, C. (2004) Are payment regimes precluding best care?, *The Homecarer*, January 2004

Thornton, P. (2004) Disability, *Research Matters*, Special Issue, 17–22

RESEARCH SUMMARIES

Arksey, H., Jackson, K., Mason, A., Wallace, A., Weatherly, H. (2004) Support services for carers: methodological issues in evaluating the literature, *Research Works*, 2004–03, Social Policy Research Unit, University of York, York

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

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

Hirst M. (2004) *Hearts & Minds: The health effects of caring*, Carers Scotland, Glasgow

Kemp, P.A., Bradshaw, J., Dornan, P., Finch, N. and Mayhew, E. (2004) Routes out of poverty, *Findings*, N94, Joseph Rowntree Foundation, York

S | P | R | U

SOCIAL POLICY RESEARCH UNIT

Social Policy Research Unit
University of York
Heslington
York
YO10 5DD
England

Telephone: 01904 **321950**
Text: 01904 **321951**
Fax: 01904 **321953**

Email: spru@york.ac.uk
Website: www.york.ac.uk/spru

THE UNIVERSITY *of York*