Annual Report **2012**

The Queen's Anniversary Prizes
For Higher and Further Education
2009

The University *of York*

spru

Excellence in social care,
health and welfare research

Geoff Mulgan, Chief Executive of NESTA, with Professor Gillian Parker on the occasion of his lecture ***Know your impact: Is it possible to know what works?*** *November 2012.*

A project team from the Norwegian Labour and Welfare Directorate visited SPRU in January 2012 to investigate and discuss the latest UK back to work initiatives with our experts.

Every summer the young people from our consultation group at Applefields School come to the University. This year they visited the Music Research Centre and recorded a track called 'The Haunted House'.

Officials from Chengdu City, Sichuan Province, China visited SPRU to hear Professor Roy Sainsbury brief them on the changes that the UK Government is making to our welfare and benefits systems.

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Introduction by the Director

This annual report sees SPRU moving into its 40th anniversary year. The unit began with a single research project in 1973, examining the needs of severely disabled children and their families. Since then it has grown into one of the most successful, and longest-established, groups of applied social policy researchers in the UK.

I suppose we might hope that the factors that stimulate our research would improve over time and that we would eventually put ourselves out of business! However, policy and practice do not always move forwards in a consistent way, or for all groups, and political and demographic change can throw up new challenges that require good quality evidence to underpin intervention. The report this year is full of examples of how we continue to inform best practice to tackle long-standing issues as well as generate knowledge for emerging topics. Charities and third sector organisations are increasingly commissioning research to explore how they can best support the groups they serve in the light of welfare reform, austerity in the public sector and demographic change. We have been pleased to establish partnerships with the Carers Trust, the Thomas Pocklington Trust and Crohn's Colitis UK this year, exploring a range of new and challenging topics (see pages 32, 34, 27).

Our partnerships with dementia organisations have seen fruit with the start of a large, NIHR funded project on the role of life story work in dementia care (see page 5). Another new research area flagged-up last year - work-related stress in the children's health care workforce has attracted significant international interest, and colleagues are now collaborating with clinicians and academics in Canada and Australia on this issue (see page 7). Other international links include academic visits from Norwegian researchers and new collaborative relationships with academics and policy makers in the EU. These have borne fruit with an EU funded project starting in 2013. We have also had visits from Chinese and Norwegian policy makers, interested in learning about 'what works' in employment and welfare policy (see page 9).

We have worked on 35 different projects through the year. Funders include: National Institute of Health Research (NIHR) School for Social Care Research (see page 6), NIHR Health Services and Delivery Research Programme, Department of Work and Pensions, Department of Health, Department for Education, Ataxia-Telangiectasia (A-T) Society, Big Lottery, Cancer Research UK, Carers Trust, Children's Society, Crohns and Colitis UK, Joseph Rowntree Foundation, Thomas Pocklington Trust, National Society for the Prevention of Cruelty to Children, Centre for Excellence and Outcomes in Children and Young People's Services (C4EO), and Economic and Social Research Council. Our thanks go to them all.

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

Gillian Parker
Director

People with dementia and their carers play key role in new study

People with dementia and their family carers will play a pivotal role in a pioneering study led by SPRU into the use of life stories to influence their care and improve their quality of life.

Life story work involves helping people to record aspects of their past and present lives along with future hopes and wishes, often in a book or folder and, increasingly, in music, film and multi-media formats. Life story work may have the potential to improve care for people with dementia in a range of settings including hospitals and residential care homes, to support smooth transitions between care settings, and improve quality of life for those with dementia and their carers. The project aims to find out how, and in what circumstances, life story work could make a difference.

SPRU's partnership with voluntary and community organisations, academic departments and service providers has facilitated new and successful approaches to user involvement, including the creation of a network of research advisers with experience of dementia and dementia care. This involvement of people with dementia and their carers is a key feature of the project: the advisers, who include five people with dementia and five family carers, will draw on personal experiences to inform the project throughout. Kate Harwood, a family carer involved as an adviser on the project, explained:

When you can't remember what happened last month, week or even half an hour ago, what can you find to talk about? Life stories with photos and words can be shared together, act as a reminder and gives others insight into the person with dementia. This is why I have become involved in the York University Life Story Project and am pleased that family carers and people with dementia are being involved in the project from the very start.

Researchers will carry out a systematic review of literature on life story work and gather qualitative data through focus groups involving people with dementia, family carers and professionals. They will then develop a theoretical good practice model of life story work as well as surveying the current use of life story work in dementia care across England. Finally, the researchers will assess the potential effects and costs of using the technique in specialist inpatient and long-term care settings, and consider further evaluation. A short film, designed and created with the help of people with dementia and their carers, will be produced to showcase the study's key messages.

Lead researcher Kate Gridley, of SPRU, said:

Collaboration is proving central to the success of this project. SPRU's experience in research methods has been pooled with the expertise of specialist organisations to produce a project that is well informed, linked in and robust. The connections that we have developed through these partnerships will also help our findings to reach those people most affected by the issues.

Partnership

This is a partnership project being led by SPRU with involvement from the University of York Department of Health Sciences, the Hull York Medical School, Dementia UK, Innovations in Dementia, Anchor Trust, the Life Story Network, the University of Hull and Pennine Care NHS Foundation Trust.

Funding and disclaimer

This project is being funded by the National Institute for Health Research Health Services and Delivery Research Programme (HS&DR). The views and opinions expressed in any reports and other outputs will be those of the authors and will not necessarily reflect those of the HS&DR Programme, National Institute for Health Research, NHS or the Department of Health.

See the project web page here: bit.ly/lsDem

NIHR School for Social Care Research in SPRU

In 2008 the National Institute for Health Research announced the establishment of a new School for Social Care Research (SSCR), with a ring-fenced budget of £15 million over five years. SSCR's mission is to develop the evidence base for social care practice in England: by commissioning and conducting world-class research; contributing to the development of research capacity in social care; and disseminating research findings through a range of knowledge transfer activities.

With a long-established track record in high quality adult social care research, SPRU was selected as a member of SSCR, along with five other research centres. Funding from SSCR has enabled SPRU to build on its past research reputation and experience; develop future expertise and capacity in adult social care research; and explore new approaches to sharing research knowledge with social care practitioners.

SPRU's SSCR-funded studies take forward a number of earlier research interests, including the development and implementation of outcomes-focused approaches in social care; research into disabled and older people's experiences of choice in social care; the national evaluations of the social care and health personal budget pilots; and successive studies of transition to adult social care by young disabled people. Our SSCR studies all focus on different aspects of personalisation, which earlier research had shown to be in some way problematic.

- ***Good support for people with complex needs: a scoping study***. What are the features of the service and support arrangements desired by adults and older people with severe and complex needs? What robust evidence is there of service models with these desired features? (page 26)
- ***Personalisation and carers***. What roles do carers play in assessing, planning and managing personal budgets? How far does practice recognise and balance the separate, but interdependent, needs and outcomes of service users and carers? (page 29)
- ***Managed personal budgets***. What choice and control is available to older people who use their personal budget to pay for council-commissioned home care services? (page 30)
- ***Taking On and Taking Over: Physically disabled young adults and their support arrangements***. What support is available for young adults to exercise desired levels of choice and control? (page 13)

These projects aim to be widely inclusive, particularly through involving service users with communication difficulties or who use non-verbal communication techniques.

All the studies focus on aspects of social care practice. We have been fortunate in that local adult social care departments have offered us opportunities to shadow practitioners for a few days; the researchers have found this very helpful in understanding the pressures of real, day-to-day practice. Regular meetings, with SSCR-funded researchers across the country, are also proving helpful in developing and consolidating expertise in adult social care research.

All the projects are working hard to develop new approaches to dissemination and knowledge transfer that go beyond simply publishing in academic journals (though this is still important). Each project has an Advisory Group of service users, carers and practitioners from statutory and voluntary sectors. In addition, projects often have feedback workshops, where provisional research findings and dissemination plans are discussed with a much wider range of interested stakeholders. Local authority shadowing has provided further opportunities for informal discussions with front-line practitioners about research findings. Meanwhile, we are working with the Making Research Count (MRC) partnership so that MRC workshops on SSCR projects are extended to relevant voluntary and private sector service providers, as well as local authority staff.

Workforce stress and burnout: development of a new research stream in SPRU

The need to tackle work-related stress is a priority within health services due to mounting evidence that, not only does it take its toll on the individuals, but has consequences for patients and colleagues.

There are also economic reasons for intervening: work-related stress is a major cause of sickness absence and presenteeism (going to work whilst sick), both of which are costly to organisations and put patient care and safety at risk.

A few years ago professionals working in paediatric oncology asked SPRU to collaborate with them on a project looking at stress, burnout and well-being within the paediatric oncology workforce. This marked the start of a series of projects which have taken SPRU into a new, but complementary, area of research.

Key outputs of the work to date are two self-completed measures (ie. questionnaires) that gauge the work-related stressors (WSS-PO) and work-related rewards (WRS-PO) experienced by clinical and non-clinical staff working in paediatric oncology. They have been developed using a standardised approach to developing and testing measures. The project work was funded by Cancer Research UK and the University of York. The measures are essential building blocks to further work such as:

- exploring the 'black box' between exposure to stressors and rewards and outcomes, and the factors which moderate and mediate this relationship
- identifying the stressors causing most difficulties for staff in a particular setting, therefore informing the focus of any staff support interventions
- evaluating staff support interventions.

Interest in these measures has been very high, both in the UK and elsewhere, particularly in terms of the way such measures can inform support interventions that prevent staff burnout. The evidence base on effective ways to support staff is extremely limited and exploring it is a natural next step for our work. To this end, in collaboration with colleagues at Great Ormond Street Hospital, we have recently conducted an audit of staff support provision and practices in all UK paediatric oncology primary treatment centres (findings to be published in 2013). We are using the audit data to inform the design of a study to evaluate preventive staff support interventions that will extend into other paediatric health care settings which carry a high emotional load. We are also looking forward to collaborating with colleagues in Australia who will be administering the WSS-PO and WRS-PO to staff in a number of their paediatric oncology treatment centres in the coming year.

Concerns about workforce stress and burnout are not restricted to the health care workforce, and similar concerns have been raised about sections of the social care workforce and hospice staff. Extending our research into these settings is a further possibility.

An important secondary outcome has been the development within the team of expertise in scale development and psychometrics, including Rasch analysis. We have been fortunate to have had the support and supervision of Professor Alan Tennant (University of Leeds) with this aspect of the projects.

Further details, manuals and application forms for the WSS-PO and WRS-PO are available from this web page: www.york.ac.uk/lipop

Details of the collaborative work mapping paediatric oncology centres in the UK is available on this web page: bit.ly/SPRUmss

Know your impact: is it possible to know what works?'

Some reflections on whether we are entering a golden age for evidence, data and knowledge about what's working.

Geoff Mulgan, Chief Executive of NESTA, Founder of DEMOS

Queen's Anniversary Prize Lecture 2012

Do we help those around us to be healthier, happier, more prosperous?

What is our accountability to the people we share a planet with?

Why is research evidence overlooked?

We enjoyed an excellent, thought-provoking and challenging evening with Geoff Mulgan who spoke on the subject of 'impact' for this year's Queen's Anniversary Prize lecture. Geoff's lecture was wide ranging, encompassing anyone, in any position, who has some knowledge to share. He discussed the moral questions of daily life: whether we help those around us to be healthier, happier, more prosperous, as well as our accountability to the people with whom we share the planet. Geoff illustrated his lecture with many interesting examples from around the world, where great leaps forward came from 'borrowing' others' ideas and reshaping them to improve our world, and examples of the beneficial application of research and the instances where evidence is overlooked and why that happens. He described 'a circle of questioning, discovery, and experiment, generating new questions and hypotheses as well as knowledge'. The lecture can be read or listened to on this web page: bit.ly/2012qap

Geoff Mulgan is Chief Executive of NESTA (National Endowment for Science, Technology and the Arts). From 2004-2011 he was the first Chief Executive of the Young Foundation, a leading centre for social innovation. Between 1997 and 2004 Geoff had various roles in the UK government including director of the Government's Strategy Unit and head of policy in the Prime Minister's office. Before that he was the founder and director of the think-tank Demos. He is a visiting professor at LSE, UCL, Melbourne University and a regular lecturer at the China Executive Leadership Academy. He is an adviser to many governments around the world. His recent books include *The Art of Public Strategy - Mobilising Power and Knowledge for the Public Good* (OUP, 2008) and *Good and Bad Power: the ideals and betrayals of government* (Penguin, 2008).

The lecture was the culmination of the 2012 SPRU seminar series, **Social Policy: Making an Impact**, which explored the growing need for social policy research to be able to demonstrate an impact on practice. Research funders want proposals to set out clearly how project findings will influence the way practitioners work, or the way policy is designed and implemented. The Government and research councils are requesting more evidence of the benefits of our research to the economy, society, culture and quality of life. Speakers in the series went on to engage with these fundamental questions:

- How can we ensure that the research we do makes an impact?
- Who and what are we trying to influence, and why?
- What are the best ways of doing this?

Over the course of the series we heard from academic colleagues with a track record of influencing policy and practice, as well as key practitioners and policy makers who have used research outputs to bring about real change.

Slides from most of the lectures are on the web page: bit.ly/sprusem12

The new seminar series is on the topic of **Social Research in the Digital Age**.
Details of future talks are available here: bit.ly/sprusem

Widening our influence

This year SPRU was privileged to host a number of visitors which in turn led to a mutual exchange of views and widened the impact of our work abroad. This, together with an extensive list of presentations around the globe in 2012, displays the far-reaching influence of SPRU's research.

SPRU International Presentations 2012 (see page 43 for details)

In January we welcomed a project team from the Norwegian Labour and Welfare Directorate who are looking at research in the UK in order to enrich their knowledge base. They wished to meet SPRU experts evaluating the latest Government interventions to help people back into work.

The visit led to an interesting exchange of views, as in Norway the 'back to work' process is led by social workers. One of SPRU's strengths, and a reason that the Norwegians found this a fruitful place to visit, is our cross-group breadth of expertise. Our Social Work Research Group was able to add value to the debate with our Welfare and Employment Research Group.

Later in the year we were pleased to host a visit from the Deputy Chief of the Bureau of Human Resources and Social Security, Chengdu City in Sichuan Province and a party of officials. Professor Roy Sainsbury briefed them on the changes that the UK Government is making to our welfare and benefits systems.

Chengdu City is an experimental area in China. They are aiming to build a sustainable welfare system for residents and they are exploring options from the UK and other countries.

SPRU was also happy to welcome visiting scholars from the Centre for the Study of Professions at Oslo and Akershus University College, Norway. Professor Lars Inge Terum runs the Centre and twice visited SPRU during the year to consult with colleagues here. His PhD student, Heidi Moen Gjersøe, also visited for a few months, in order to compare the emergence, role, aims and the implementation of work capability assessment systems in the UK and Norway.

Health and Social Care for Children and Young Adults Research Group

Contents:

A new name and a 'new' topic

Transition is a widely used but ill-defined term describing both the transfer from children's to adult services, and a developmental stage spanning adolescence to adulthood.

Over the past few years, research on 'transition' has constituted a significant part of the work of the Children and Families Team. During 2012 we changed the name of our team to the Children and Young Adults Research Group in order to reflect this aspect of our work and expertise.

The use of 'young adults', as opposed to 'young people' was deliberate, signalling our interest in and commitment to researching all stages of transition, particularly issues related to being a 'young adult' in adult services.

The notion of 'young adulthood' (or 'emerging adulthood') as a distinct developmental stage, spanning 18 to around 25 years, is gaining increasing attention. It was first used by researchers within the fields of social and developmental psychology and neurology. However, there are clear policy and practice implications. For example, adult services do not typically recognise, or adjust their practice, to accommodate the relative immaturity of this age group. Equally, there is little understanding of parental/family involvement in young adults' lives, and their role in decision-making.

To date, the majority of research, policy development and practice on 'transition' is located at the 'child' end: on the planning and preparation which takes place in the mid- to late teenage years, and the transfer of care to adult services. We are beginning to build a body of evidence on the range of factors which support achieving positive outcomes in young adulthood, and what constitutes 'young adult' friendly services and practice. These projects also contribute to conceptual work on 'young adulthood', illustrating the diversity of experiences and desired outcomes held by young adults with long-term conditions and disabilities, including degenerative conditions.

Within this portfolio of work (see bit.ly/ygadult) we have investigated a range of topics across health and social care:

- systems and service models which support young people as they leave school and move out of children's services
- service models and practice which support positive outcomes in young adulthood
- aspirations for, and the experiences of, young adults with long-term conditions
- being a 'young adult' service user
- the dynamics of family decision-making in late adolescence and young adulthood
- parents' experiences and needs during this life-stage.

We are looking forward to extending and developing work on this topic in the forthcoming year.

Bryony Beresford
Research Director

Professor Beresford can be contacted on (01904) 321960 or email bryony.beresford@york.ac.uk

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

This study concerned young people with autistic spectrum conditions (ASC) on the cusp of leaving school and moving into early adulthood. This is a period of significant change and presents particular challenges for those with ASC. Young people with a diagnosis of 'high functioning autism' (HFA) or Asperger's syndrome (AS) are a particular concern: they may not be eligible for statutory services yet can have significant support needs.

Findings
Some local authorities had configured their services to ensure all young people with ASC received help with planning for leaving school. Elsewhere, young people with HFA/AS were moving on from school with no specialist advice or support.

Many reported their time at college as more positive than their school years. However, having ASC increased the chances of suspension or dropping out. Colleges' failures to support and, particularly, manage behavioural issues were identified as reasons for this. Families lacked advice as they anticipated leaving further education. Those who left college 'prematurely' were identified as being particularly vulnerable. The lack of post-education options was a key concern. The absence of any meaningful daytime occupation was an enormous worry for parents who had witnessed firsthand a negative impact on their children's well-being.

I've got visions of him being on the dole for years and years and years…can't get an apprenticeship, can't get a job 'cos he's got special needs. He'll be fed up, upset, his self-esteem will go through the floor again and I won't even be able to get him out of his bedroom.

Parents were typically very involved in 'managing' the young adults' lives. Yet many did not want to assume this role and, indeed, felt ill-equipped to deal with the task.

The absence of any meaningful daytime occupation was an enormous worry for parents who had witnessed firsthand a negative impact on their children's well-being.

There were examples of positive practice from ASC-specific services supporting young people into work. Negative employment outcomes were ascribed to a lack of understanding of ASC among Job Centre/Job Centre Plus staff, or withdrawal too early of employment support.

In terms of low-level social or mental health support, the young adults consistently reported a preference for HFA/Asperger-specific support. In some localities specialist 'Asperger's teams' acted as the first port of call. Autism-specific outreach services were very positively endorsed, particularly those which offered opportunities for peer support. Access to these was, however, extremely variable.

Implications for policy and practice

This study provides evidence that can inform the changes and developments required by the Autism Strategy (2010) and NICE (2012) guidelines.

- It demonstrates that service models can be developed to ensure continuity of support to all young people with ASC as they leave school and become young adults.
- It reiterates the need for autism-specific services, delivered by autism-trained professionals.
- It identifies the services valued and endorsed by young adults with HFA and Asperger's syndrome, including: opportunities to spend time with peers; help with facing, and planning for, adult life; specialist, and on-going, employment support; settings and activities which provide meaningful day-time occupation.
- The lack of planning/advice at the stage of leaving further education is of concern.
- Access to specialist employment support did not appear adequate. Experiences of mainstream employment support suggest a lack understanding of ASC among frontline staff though implementation of the Autism Strategy may have improved this situation.

Further information and access to the report and summary is available on this webpage: bit.ly/TranASC

Funder: Department of Health
Duration: November 2009 to April 2012

Taking On and Taking Over (ToTo): physically disabled young adults and their care and support arrangements

Personalised adult social care emphasises the aspirations and preferences of service users. Providing opportunities and support for service users to exercise their preferred level of choice and control over their support arrangements is central. This is particularly important for young people as they transfer to adult services, move towards adulthood and seek increasing independence. Developments in practice/services and research surrounding personalisation within adult social care have, to date, tended to focus on older people and adults with learning disabilities. Little is known about the experiences of physically disabled young adults. This is an important omission because the group includes young adults with complex support needs, including life-limiting conditions, but who are nevertheless perhaps most likely to aspire to independent management of their care and support arrangements.

This study is identifying what support is needed for these young adults to achieve their aspirations for choice and control over their support arrangements, including the facilitators and barriers to exercising choice and control. The roles of statutory and independent sector care services, including specialist planning/brokerage services and transition support services are being explored in depth. The research will inform practice and future research on how services can help physically disabled young adults achieve their desired level of control over these aspects of their lives.

Further information is available on this web page:
bit.ly/SPtoto

Funder: National Institute for Health Research, School for Social Care Research
Duration: July 2012 to October 2013

It is important to identify what support is needed for these young adults to achieve their aspirations for choice and control.

The 'My Life' project: growing up and living with Ataxia-Telangiectasia (A-T)

Ataxia-Telangiectasia (A-T), is a rare, complex and progressive genetic disorder. It affects a number of different systems within the body including:

- increasing difficulty in controlling and co-ordinating movements
- reduced efficiency of the immune system leading to more frequent infections
- an increased risk in developing cancers, in particular leukaemia and lymphoma.

In Spring 2012, the A-T Society commissioned SPRU to conduct a piece of research about young people/young adults with Ataxia-Telangiectasia. The A-T Society was seeking to understand more about the lives of young people and to hear their views about the support the Society provided to them.

Eleven young people (aged 16 – 27 years) and ten parents were interviewed. The parents and young people were not all related; thus a total of 12 families were represented, around a third of young people with A-T in the UK.

Findings

A strong theme in young people's accounts describes the way different facets of young people's lives are inter-connected. For example, taking part in activities can be pleasurable and can also be a means of making friends; both also have an impact on emotional well-being. Similarly, participation in activities is dependent on transport or being independently mobile, and this can require having sufficient finances to purchase, for example, a motorised wheelchair.

These accounts illustrate such interconnections and highlight the crucial importance of an holistic approach to supporting young people with A-T. Whilst statutory services may be good at delivering support and care related to a specific need, having the support and expertise of an organisation which is concerned with all aspects of a young person's life adds another 'layer' of support for families, as well as providing services which may not be available from statutory agencies.

All the young people we interviewed considered having a meaningful daytime occupation (for example, paid or unpaid work) and friendships were central to a good quality of life. Many were not currently satisfied with those aspects of their lives. Almost all wanted more opportunities for social contact/peer support from others with A-T or similar conditions.

We have developed two measures that gauge work-related stressors and rewards for staff working in paediatric oncology.

Two characteristics of A-T presented particular challenges for young people living with the condition:

- diagnosis follows a period of normal, healthy development and is followed by on-going deterioration
- it is a very rare condition.

These features permeated the young people's accounts and offered at least partial explanations for why certain areas of their lives were unsatisfactory. The fact that, within adult social care, physically disabled young adults (without learning disabilities) are a minority group was another important explanatory factor.

In Spring 2013 the A-T Society is hosting a workshop for young people with A-T which the research team will also attend. Ways in which the A-T Society can best support young people/young adults with the condition will be discussed at the event.

Funder: The A-T Society
Duration: April 2012 to September 2012

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

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

Over the past four years Dr Mukherjee has been funded by Cancer Research UK and CLIC Sargent to carry out research on this topic, with a focus on the paediatric oncology workforce. The anniversary lectureship has allowed Dr Mukherjee to develop this work. Further information is available on this web page: bit.ly/sbhealth

Please go to page 7 to read more about our work in this area of research.

Managing behaviour and sleep problems in disabled children: an investigation into the effectiveness and costs of parent-training interventions

Parents of disabled children, and particularly those with learning disabilities and/or autistic spectrum conditions, are more likely to report difficulties managing their child's sleep or behaviour problems compared to parents of non-disabled children. Typically, these problems do not resolve themselves.

Daytime behaviour problems threaten children's safety and can interfere with participation in school and community activities and/or access to services. Poor sleep increases the risk for daytime behaviour problems. Sleep and behaviour problems are both associated with increased levels of parental stress and mental health difficulties. Parents report high levels of unmet need for skills to manage their child's sleep or day-time behaviour.

The aims of this study were, through a portfolio of effectiveness investigations and qualitative research, to:

- evaluate parent-training interventions for parents of disabled children with sleep problems or behaviour problems
- calculate the costs of these interventions and explore their cost effectiveness
- identify factors which hinder or support effectiveness
- describe parents' experiences of receiving, and professionals' experiences of delivering, these interventions.

Key findings

- practitioners and parents desire disability and/or autism specific parenting support interventions
- parents' trust and confidence in the practitioner directing or referring the parent to an intervention are important factors affecting the decision to attend a programme

Parents report high levels of unmet need for skills to manage their child's sleep or day-time behaviour.

- parental 'readiness' to address their child's sleep or behaviour problems affects take-up, on-going engagement and intervention outcomes
- overall, the evidence shows the interventions yielding, to a greater or lesser extent, positive outcomes both post-intervention and at later follow-up time points for parents and children
- strategies for providing on-going or 'top-up' support need to be developed and tested
- further work may need to be done on the existing interventions to make them more effective for parents of children with autism at the more severe end of the spectrum
- the group-delivery mode, whilst a powerful tool, is not suitable (and has the potential to be harmful) for all parents. It can also be a barrier to take-up.

Informing future practice and commissioning decisions: key messages from the research

- Preventive or early intervention support to parents of disabled children which helps them to manage their child's sleep or behaviour needs to be 'disability- (or autism-) specific'.
- Group-delivered interventions can be an effective mode of delivery. However, it is not suitable for all parents, nor will all parents find this an acceptable mode of delivery.

- A 'menu' of parenting support options is required. The specific needs and situation of the parent, and the severity of the sleep/behaviour problem, are factors which will determine the suitability of delivery mode.
- Support with managing sleep problems is less common. Its availability needs to be expanded.
- Preliminary work with parents so that they feel 'ready' to address their child's sleep or behaviour problem may need to be integrated into the intervention approach.
- Finding an effective and appropriate way to provide follow-up or 'top-up' support is an important consideration.

Information on methods and access to the report and summary is on this web page: bit.ly/sbinter

Funder: Centre for Excellence in Outcomes in Children and Young People's Services - C4EO
Duration: August 2008 to October 2011

Transforming community health services for children and young people who are ill (Traccs): a quasi experimental evaluation

Current policy for children and young people who are ill advocates that care should be provided in the community and close to the home. In response to this, health communities in England are redesigning their services to include comprehensive children's community nursing (CCN) teams that can deliver this type of care. In three health communities undergoing these service redesigns this project is evaluating the impact of introducing or expanding CCN teams.

We are using mixed methods to assess the impact of introducing or expanding CCN teams on: hospital activity, costs, and families' experience of quality of care. We will also explore the perceived benefits and challenges of redesigning and implementing the CCN teams from the perspectives of NHS commissioners, managers and practitioners.

The evidence gathered from this project will be valuable for helping to inform the development of CCN teams, in line with the current policy agenda around bringing care closer to home.

Further information about the methods used is available from: bit.ly/traccs

Funder: NIHR Health Services and Delivery Research Programme
Duration: June 2012 to June 2015

Supporting health transitions for young people with life-limiting conditions (STEPP): researching positive practice.

Advances in the treatment of many life-limiting conditions mean that children are living longer and many now survive into adulthood. Managing the transfer of their health and other care needs to adult services has proved challenging. Adult services can also struggle to provide appropriate services for young adults.

The STEPP project is investigating condition management pathways which have 'cracked the nut' of providing health care to young people and young adults with life-limiting conditions, including managing the transfer from paediatrics to adult health services, adult health care, and palliative and end-of-life care. A range of non-malignant, life-limiting conditions are represented in the project. Interviews with practitioners, young adults and parents will be used to identify core components and principles of good practice.

Findings from the study will be disseminated through a range of media, included 'pocket-size' practice resources and materials to support clinical teams to discuss and review their practice or develop new provision.

Research findings relating to palliative care services were reported at a meeting of the All Party Parliamentary Group on Hospice and Palliative Care at the House of Commons on 27th November 2013. A paper setting out the issues and the findings from the research, as well as recommendations to professionals and the Department of Health, is available here: bit.ly/appgBP

Further information is available here: bit.ly/steppLLC

Funder: Big Lottery Research Programme
Duration: April 2010 to August 2013
Partners: Together for Short Lives, Help the Hospices, the National Council for Palliative Care

External research

Professor Bryony Beresford is involved in research for several external projects:

- The CHUMS project: what outcomes of NHS care should be measured for children with neurodisability?, NIHR, Health Services Research Programme

As well as looking at which outcomes should be measured, this project is researching the extent to which they can be measured by existing instruments. It is a mixed methods project led by the Peninsula Medical School. Professor Beresford is providing expert input on qualitative research methods and data analysis.

- Fuel poverty and disabled people: the impact of policy change, EAGA Charitable Trust

  This project is seeking to address the limited and fragmented evidence base surrounding the relationship between disability and fuel poverty. It has three key aims:

  - to consolidate existing knowledge and understanding in the field
  - to consult with key organisations/stakeholders in order to understand the different dimensions of disability and fuel poverty, and the potential impacts of welfare reforms
  - to hear disabled people's and parents of disabled children perceptions of the impact of policy changes.

Professor Beresford is providing expertise related to disabled children, their housing and welfare/benefits issues. It is lead by colleagues in the Department of Social Policy and Social Work at the University of York.

- MeASURe: measurement in Autism Spectrum Disorder Under Review, NIHR, Health Technology Assessment Programme

The MeASURe project is tackling two main questions:

  - What is the validity of tools and outcome measures used in measuring and monitoring autism spectrum disorder in young children?
  - How well do these reflect and measure issues of importance for children, young people and their parents/carers?

This project is led by the University of Newcastle. Professor Beresford is contributing to a review of the qualitative evidence on the views of children, young people and their parents/carers regarding which outcomes they regard as important.

- Translation of the Strengths and Difficulties Questionnaire (SDQ) into British Sign Language, NIHR, Health Services Research Programme

Deaf children and young people are more likely to have reading and comprehension difficulties compared to their hearing peers. This means that written versions of self-report measures of mental health and psychological well-being cannot be used in epidemiological or service evaluation research. This project is translating a widely-used measure of child mental health (SDQ) into British Sign Language. The project is being led by clinicians working for the Child and Adolescent Mental Health Services (CAMHS). Professor Beresford is providing expert input on research design and methodological issues.

Social Work with Children and Young People Research Group

Contents:

Evaluation of Multi-dimensional Treatment Foster Care for Adolescents (MTFC-A)

Multi-dimensional Treatment Foster Care (MTFC) was developed in the USA as an intervention for young people with challenging behaviour. The British government introduced it in 2004, originally as a national pilot programme, in 18 English local authorities. The aim was to improve placement stability and outcomes for adolescents in the care system. MTFC was originally developed as an alternative to custody for adolescent boys and has a strong evidence base, as its use with various groups of children has been positively evaluated by the programme developers.

The English MTFC programme was an exciting new development, as MTFC had never before been tried with adolescents who were already in care. SPRU's evaluation of MTFC-A was not only the first evaluation of the programme's use with this population of children, but also the first independent evaluation of this well-known, evidence-based programme. Furthermore, it was one of only a handful of randomised controlled trials of services for looked after children in the UK. A discussion of the issues will be available from the *British Journal of Social Work* soon (see web page, address below).

What is MTFC-A?
MTFC-A is a highly structured behavioural programme, providing wraparound, multi-professional support and including daily communication between carers, the team and school. It provides older children with a short-term placement with specially-trained foster carers usually intended to last around one year, followed by a short period of aftercare to support the transition to a new placement or return home.

What was the impact of MTFC-A?
The young people in the sample were aged 11-16 years, all had considerable difficulties. Nearly all had experienced abuse or neglect, two-thirds had mental health difficulties and over half had statements of special educational needs. Nearly half had been excluded from school in the previous three months and over one-third had recently committed a recorded offence.

We used a global measure of social functioning to compare outcomes for the group receiving MTFC to those for similar young people in 'usual care' placements, and also compared a range of specific outcomes including participation in school, offending and mental health. For the sample as a whole, placement in MTFC-A showed no statistically significant benefit over the usual care placements.

However, for the subgroup of young people with serious antisocial behaviour problems, MTFC-A showed improved reduction in these behaviour problems over usual care and also in overall social adjustment.

Young people's engagement was a key issue, as some were reluctant to 'buy in' to the structured nature of the programme. However, the development of strong relationships with foster carers facilitated engagement. MTFC-A foster carers found the displacement of discipline on to a 'points and levels' system to be helpful, and valued the training and intensive support provided by the MTFC-A teams.

This evaluation therefore found MTFC to be less effective than the previous studies conducted by the programme developers in the UK. It raises a number of questions about how best to implement evidence-based programmes developed in other national contexts.

Further information and access to the report and summary is on this web page: bit.ly/MTFCA

Funder: Department for Children, Schools and Families
Duration: December 2004 to July 2010, report released 2012
Partner: University of Manchester

Fostering unaccompanied asylum-seeking young people

Unaccompanied asylum-seeking young people form a small but significant part of the population of children in public care. This study focused on the fostering experiences of these young people and of their foster carers. It involved a survey of foster carers, and interviews and focus groups with young people, foster carers and social workers.

Welcoming an unaccompanied young person into a foster family is complex, especially where language, culture and religion are different, as was the case for most young people in this study. Young people had little, if any, understanding of foster care on arrival. Foster carers had very little information about their particular needs and often felt unprepared. Arrival was often late at night and foster carers focused on providing hospitality and refuge.

There was this boy, his face covered in mud, his shoes, everything, with this plastic bag with all his dirty things, belongings and whatever. He said: 'Hello'.

Over time, most young people were able to settle, build new attachments with their foster families and re-establish an ordinary rhythm to their lives through school or college, religious and community activities and by developing stronger friendship networks. Most were thought by their foster carers to be doing very well (77 percent).

Three broad models of family placement were identified:

Family-like relationships – where new 'family-like' connections were established that were expected to endure beyond placement end. Most young people spoke of such experiences.

Temporary home bases – where good relationships existed, the placement worked well, but lacked a tight bond, and was seen as time limited.

Lodgings – where foster carers delivered a contracted service (not always well), but the young person never felt at home, more like a 'lodger' in someone else's house.

A minority of young people who lodged had negative experiences of foster care, often feeling excluded, living in segregated parts of the home, unable to access food freely or invite friends back. For the majority, however, experiences were much more positive and their presence influenced and transformed the everyday lives of their foster families. Feelings of trust, respect and belonging grew and young people felt strengthened in their relationships outside the home.

We were taking some photos and we said: 'Oh yeah, let's get the family' (together)'and they (our foster children) stood apart and everyone else said: 'Oh no, no, no, (get) in, in.' It was just one of those moments when you think: Oh yeah, that's it, you are (family).

Most foster carers were satisfied with their role (95 per cent) and felt it had enriched their lives (90 per cent). Most had a high commitment to the young people in their care, would appreciate opportunities for continuing training (especially in culture and immigration) and valued reliable and consistent support from social workers working together with them to form a team around the child.

The study shines a light on key issues in fostering today. In particular, it provides a focus on the quality of relationships in foster care, the variability in relationships that are evident, and identifies factors associated with high quality foster care. A focus on relationships is timely, not least because that is what matters most to young people themselves.

Further details and access to the final report and summary are available on this web page:
bit.ly/FosterU

Funder: Big Lottery
Duration: June 2009 to February 2012
Partners: British Association for Adoption and Fostering, University of Bedfordshire

Investigation of special guardianship

Special guardianship (SG) represents a major legislative initiative to increase the range of permanent placements for children unable to live with their birth parents. It provides legal permanence for those children for whom adoption is not appropriate, and gives a special guardian clear responsibility for all aspects of caring for the child and for taking decisions to do with his or her upbringing. It was introduced in December 2005.

This study is investigating how the policy and practice of local authorities is evolving, charting the experiences of guardians and their children, and assessing the progress of the children three to six years after the Special Guardianship Order (SGO) has been granted.

The project is also undertaking a national survey of all local authorities in England and an intensive study in seven local authorities that participated in our earlier study of the Implementation of Special Guardianship.

Further information about the methods used is available on this web page: bit.ly/SpecialG

Funder: Department for Education
Duration: March 2012 to May 2014
Partners: British Association for Adoption and Fostering

Allegations concerning the maltreatment of looked after children

Although there have been a number of descriptive reports in the UK of foster carers' experiences of allegations of abuse or neglect, very little evidence exists on the frequency of such allegations or the extent of confirmed maltreatment involving looked after children in their care. We are exploring these issues through a survey of local authorities across the UK. We are focusing on both fostering and residential sectors to provide firm evidence on the scale of the problem for looked after children as a whole.

The disruptive effects of maltreatment allegations can be high for looked after children and foster families, perhaps especially where they prove to be unfounded. An improved understanding of the scale, nature and consequences of allegations will help local authorities to safeguard children, manage their allegation cases and target support services more effectively. This study is being undertaken in partnership with The Fostering Network.

Details on the methods involved and further information are available on this webpage: bit.ly/LACma

Funder: National Society for the Prevention of Cruelty to Children
Duration: July 2012 to June 2013

The disruptive effects of maltreatment allegations can be high for looked after children and foster families.

Peer research: opportunities and challenges

I was interviewing care leavers as a care leaver myself – and knowing that through this, young people were given a voice, a chance to share their opinions on the transition from care to independent living.

(Peer researcher)

A recent innovation in relation to leaving care research is the involvement of young people from care as peer researchers. This development resonates with recent policy themes, including children's rights, the participation of young people in policy making, and peer mentoring.

There is evidence from research carried out by Jo Dixon and Professor Mike Stein that well-managed peer research can give selected young people from care an opportunity to participate in the research process, in partnership with professional researchers. Using the model developed by the National Care Advisory Service (NCAS), our research involves peer researchers in all aspects of the process: drawing on their personal experience to increase awareness of the topic being researched; helping to identify, comment upon and revise the research questions and interview schedules; carrying out interviews; reflecting upon the research findings; contributing to the policy and practice implications; and, participating in the presentation and dissemination of the findings.

Successful peer researchers are often those young people who have made sense of their own journey from care to adulthood: by having some emotional distance they can balance empathy and objectivity.

Overall, in these studies, professional researchers see peer researchers as an important source of insight, bringing something different – an 'in care' and 'leaving care' perspective - to the stages of the research process. This is underpinned by recognition of the centrality of the voice of young people in research, including reducing power differences between young people and adults through reciprocity. Also, by participating in peer research young people are given the opportunity, through training and the research experience, to acquire new knowledge and skills and develop confidence which may help them in the future.

There are also many challenges. Peer research is not for all young people from care – for example, very vulnerable young people who still need help with their own problems. Successful peer researchers are often those young people who have made sense of their own journey from care to adulthood: by having some emotional distance they can balance empathy and objectivity - being able to focus on the interviewees' experiences and not being inhibited by interviewees' revelations whilst exploring sensitive issues.

Neither is peer research a cheap or time-saving option. A well-managed and ethical peer research programme requires: a rigorous selection process; training (addressing issues such as informed consent; confidentiality, ethical dilemmas); the availability of support at the time of the interview; debriefing; and, ongoing preparation and support during the different stages of the process identified above.

All of which raises a paradox: to what extent does the professionalisation of peer research reduce its strengths? Drawing on the two studies we have carried out, using peer researchers from England and from Albania, the Czech Republic, Finland and Poland, suggests that if the process is well managed and attention is paid to the issues identified above, qualitative research can benefit greatly from the resulting partnership between professional and peer researchers.

See Corporate parenting: Making the difference, Jo Dixon (Research Manager) Mike Stein (Consultant) in collaboration with the National Care Advisory Service (details below)

See Stein, M. and Verweijen-Slamnescu, R. (2012) (Eds) When Care Ends, Lessons from Peer Research, insights from young people on leaving care in Albania, the Czech Republic, Finland and Poland, SOS Children's Villages International

See National Care Advisory Service (NCAS) peer research booklet

For information on current peer research studies see Jo Dixon's profile at: bit.ly/SpruDixon

or contact us at jo.dixon@york.ac.uk and mike.stein@york.ac.uk

Corporate parenting: making the difference?

In England around 67,500 young people are looked after in the care of their local authorities. The local authority has a responsibility to provide the kind of support and opportunities that any good parent would provide for their own child. However, young people from care tend to have poorer outcomes than their non-care peers. This research is focusing on how 'corporate parenting' operates across local authorities and how it impacts upon the experiences and progress of young people in and from care. The study is being carried out by Catch22's National Care Advisory Service (NCAS) in collaboration with researchers from SPRU. It includes data from young people, support workers and policy staff.

Young people are central to the research process; as participants, members of the research reference group, and as peer researchers. Care-experienced young people have received training and support in research skills to interview their peers about their care experiences. This is currently one of the largest UK studies of care-experienced youth to utilise a peer research approach.

The recommendations arising from the research will be used to inform further policy and practice developments and will inform the further development of training workshops delivered by NCAS to the sector.

Read more about the research and methods on this web page: bit.ly/CorParent

Funder: Big Lottery
Duration: September 2010 to June 2014
Partners: Catch22, National Care Advisory Service

Transitions to adulthood of young people leaving public care international research group (16 countries)

The move to adulthood is a big step for all young people. However, young people leaving care face a high risk of social exclusion and marginalization. Professor Mike Stein and Harriet Ward (Loughborough University) have established an international research group to outline and compare the range of legal and policy frameworks, welfare regimes and innovative practice across 16 countries.

The group meets annually and to date a book, research reports and three special editions of journals have been produced. Work this year involves ongoing research, including building on related research work on transitions in post-communist societies. This was the first comparative study using peer researchers, *When Care Ends, Lessons from Peer Research, insights from young people leaving care in Albania, the Czech Republic, Finland and Poland.*

Further information and access to publications from the group is available here: bit.ly/LPCint

Duration: 2003 onwards
Partners: Loughborough University, Queen's University Belfast, Chapin Hall Centre for Children, Chicago

Living in children's residential homes

This short, descriptive study was commissioned by the Department for Education to inform current debates about the role and future development of residential care. It provides an insight into the nature of children's residential homes, the characteristics, circumstances and views of those young people who live in them and the short-term outcomes for these residents. The study included a total sample of 16 homes, from which we drew an intensive sample of ten homes for more detailed, qualitative study.

The use of residential care for looked after children has declined sharply over the last 30 years. Today, only ten per cent of children are placed in children's homes. A number of factors have led to this decline, including negative perceptions of residential care deriving from its previous history of punitive separation of children from the poorest families as well as concerns about outcomes, residents' safety, levels of professionalism and costs. Children's homes now cater mainly for troubled adolescents, who cannot be contained in foster care and who often have a history of multiple placement breakdowns.

Most of the young people living in the homes were in middle adolescence, with an average age of 15½. They were certainly a troubled and troublesome group. Over half had become looked after due to abuse or neglect. No doubt at least partly due to their previous experiences, they were six times more likely to have mental health difficulties than adolescents in the wider population. Many displayed significant behavioural problems, including aggression and violence, as well as putting themselves at risk, and two-thirds had been in trouble with the police during the previous six months. Their difficulties were compounded by their late entry to care, as nearly two-thirds were age ten at admission. Many had therefore been exposed to maltreatment and other adversities for a large portion of their childhood.

We found that there was a high degree of turnover in the homes, although a small group had been in the same home for several years. Most homes accommodated a diverse group, including emergency- and longer-stay admissions, which complicated their task. Among those who moved on during the study period, around one-third left due to the breakdown of the placement, which was often due to the young person's violent behaviour.

Children's residential care in England remains under-professionalised compared with much of continental Europe, despite catering for an older, very challenging core of young people. For most staff, their highest qualification was an NVQ Level 3 or 4. However, they were a very experienced group.

Our periods of observer participation revealed that only half of the homes provided a consistently warm and caring environment throughout the day and across the staff group. However, the young people were mostly complimentary about the residential experience and most were positive towards staff. They especially valued listening skills, reliability, a sense of humour and relationships that resembled family. On the other hand, the peer group was a source of anxiety to many of them and they were often wary of their co-residents.

Managing residents' behaviour in the community is very complex. Behaviours included: going missing, offending, drug misuse, intimate relationships and exploitation. We need to consider what is realistic, and how staff can be supported to address anti-social behaviour and keep young people safe.

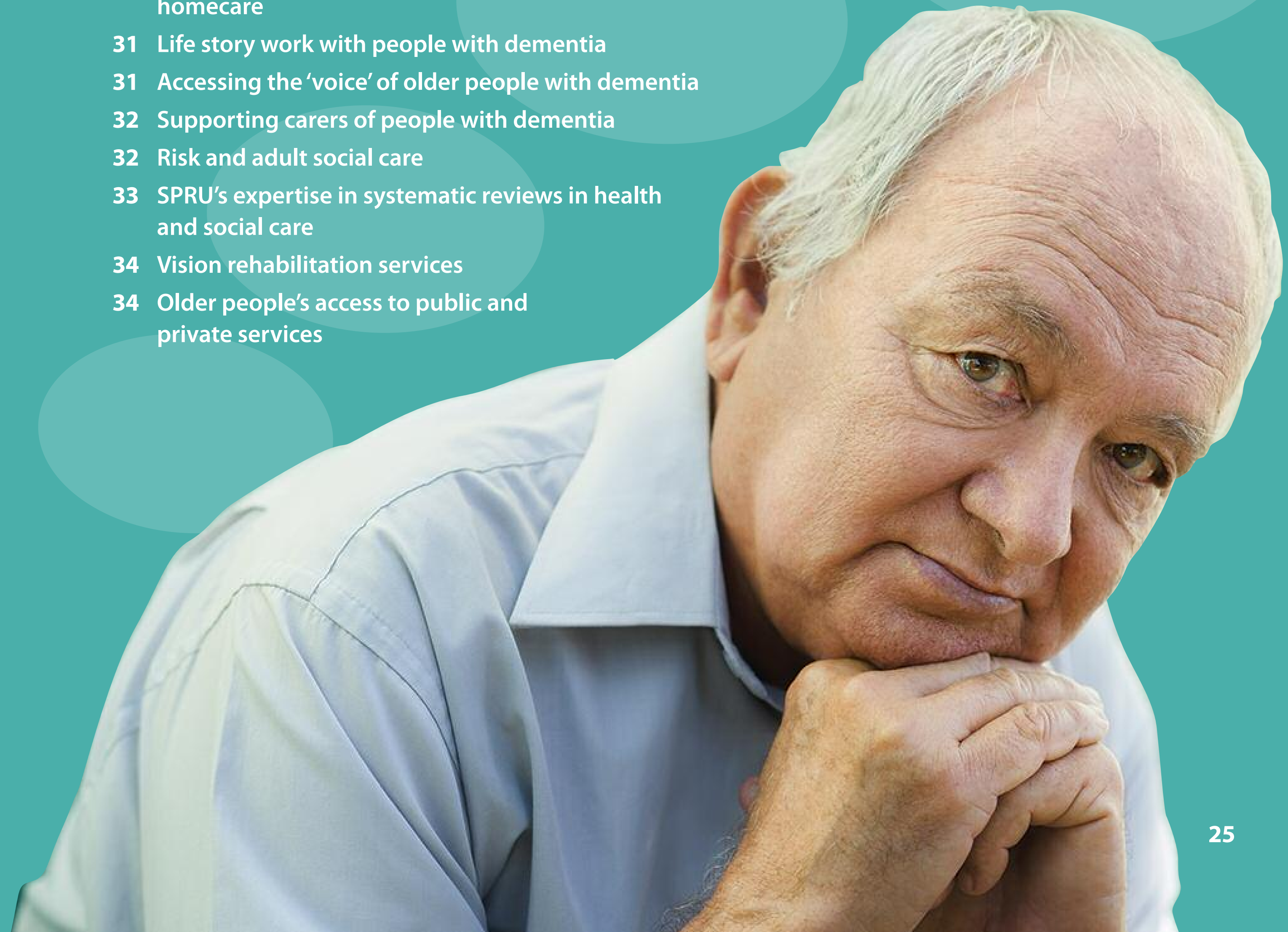
Important questions to ask as a result of this research are: whether the rapid turnover of residents is acceptable and what implications does this have for the work undertaken? There is also a need to consider exactly what are the respective contributions of residential care and specialist foster placements for adolescents.

Further information and access to the report and summary is available on this web page: bit.ly/Rhomes

Funder: Department for Education
Duration: April 2011 to October 2011, report released 2012
Partner: University of Bristol

Health and Social Care for Adults Research Group

Contents:



Good support for people with complex needs: what does it look like and where is the evidence?

This study looked for evidence on good practice in social care for disabled and older people with severe and complex needs. The aims were to find out what this group considered to be key features of good support, and what robust evidence existed to support different approaches. The study also identified examples of potential good practice and made recommendations for future evaluation.

People with severe and complex needs will make up an increasing proportion of adult social care service users in the coming years. Developments in medicine and surgery mean increasing numbers of younger people are surviving previously catastrophic illnesses or accidents with severe impairments. As the population grows and ages, older people are increasingly living with multiple conditions. The numbers of older people in England living with complex needs are estimated to have increased in a decade from 551,000 to 631,000.

These demographic changes present challenges to commissioners and providers of services which have not yet been satisfactorily addressed, resulting in a lack of appropriate services, poor coordination and poor outcomes. At the same time, English local government is facing spending cuts. There is thus a considerable need for evidence about how to run services in the most efficient and effective way.

Some promising evidence was found on the effectiveness of organizing services: multidisciplinary specialist teams; intensive case management; specialist social work; and interprofessional training.

Key points from the research

- People with complex needs emphasise the importance of individually tailored support and value a range of person-centred approaches to social care. Staff should have the time, and services the flexibility, to respond to each individual's unique needs and preferences. Support should be holistic, addressing social and emotional, not just personal care, needs.
- Findings highlight the importance of good practice in service organisation, including flexible systems and coordination via case management. Getting it right at this level could be the key to achieving true personalization.
- Many publications advocated person-centred support, covering a wide range of approaches, but there was no robust evidence to support any specific model.
- Some promising evidence was found on the effectiveness of organizing services: multidisciplinary specialist teams; intensive case management; specialist social work; and inter-professional training.
- There was a dearth of evidence about the outcomes and costs of models of social care considered to be good practice for people with complex needs.
- Several examples of services and support arrangements were identified that appeared to illustrate key features of good practice, but they had not been formally evaluated.

With the pressures building in demand for these services, there is an urgent need for rigorous evaluation of models of support. In particular, there is a lack of robust evidence on how best to personalise support for this group. Studies should have comparison groups, and clearly report both the costs and outcomes of services.

A summary and examples of potential good practice are available from this webpage: bit.ly/CompNeed

Funder: NIHR School for Social Care Research
Duration: June 2010 to February 2012

Assessing outcomes of integrated care for long-term neurological conditions

This research is investigating the outcomes that people with long-term neurological conditions (LTNCs) value and whether integrated approaches to service delivery can help achieve them. It is evaluating practice in four case areas where innovative models of integrated care are being developed. The different models of care will be explored and also how outcome assessment is used to influence practice.

The project aims to produce messages about integrated health and social care that can be used elsewhere. Being younger than most long-term users of services and have roles as partners, parents and economically active adults.

People with LTNCs are younger than most long-term users of services and have roles as partners, parents and economically active adults. They thus pose complex challenges for the integration of services. The knowledge gained from 'getting it right' for this group of people will be transferable to other conditions and situations.

Read more about the project and access its publications: bit.ly/LTNCoutcomes

Funder: The National Institute for Health Research Service Delivery and Organisation (NIHR SDO)
Duration: April 2010 to January 2013

Living with inflammatory bowel disease (LISA): the experiences of adults of South Asian origin

Over recent years, increasing numbers of South Asians (SAs) living in the UK are being diagnosed with inflammatory bowel disease (IBD). Research on the illness experience of SA people in the UK with IBD is extremely limited. A much broader and more comprehensive understanding of the experiences of people with IBD from the SA communities is needed if the NHS and organisations such as Crohn's and Colitis UK are to provide appropriate, or 'culturally competent', care and support.

This study aims to describe what living with IBD is like for SA adults, including their experiences as health service users, and to understand whether ethnicity impacts on this experience and, if so, how. In addition, the study will specifically identify ways that Crohn's and Colitis UK can develop its support for this population.

Further information on the methods used in the study are available from this web page: bit.ly/infSA

Funder: Crohn's and Colitis UK
Duration: November 2012 to May 2014

Meaning of independence for older people

This is a PhD study funded by the Sally Baldwin Studentship. Taking a qualitative approach, the study aims to develop an understanding of the meaning and perceptions of independence for older people. As part of the study, a scoping literature review and a review of relevant policy have been completed. Informed by these findings, a first round of semi-structured interviews has been conducted with a small sample of older people. Analysis of the interviews will shape the focus of a subsequent round of interviews, in line with the principles of grounded theory.

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

Further information about the project is available here: bit.ly/indepop

Funder: SPRU, Sally Baldwin Studentship
Duration: January 2008 to December 2013

Evaluating personal health budgets: evidence from interviews with patients and carers

Personal health budgets (PHB) are central to the English government's ambition to create a more responsive health service, in which patients are at the heart of decisions about the care and services they receive. Twenty PHB pilots participated in a multi-method evaluation, led by the University of Kent. SPRU contributed by finding out how a subsample of 52 patients and 13 carers had experienced personal health budgets, three and nine months after being offered one. What had they expected of their budget and how it had actually impacted on their health and health care? The interviewees either were, or cared for, people with long-term health conditions, including chronic obstructive pulmonary disease, diabetes, neurological conditions, mental health problems or were eligible for NHS continuing healthcare.

Widespread satisfaction and benefits from personal health budgets were reported:

- Health improvements were far wider than the condition for which the budget had been given: people given budgets for a mental health condition reported improvements in their physical health; people with physical illnesses reported improvements in overall well-being.
- Personal health budgets offered greater choice and flexibility over healthcare, particularly for people employing their own carers: ***It's made a massive difference to me […] being able to tell the carers when I want them to come in and how long I want them to stay.***
- Improvements in health led to better relationships with partners or families: it was possible to do more things as a family and partners worried less, with gains to their own well-being. Carers of people with severe disabilities reported benefitting from more time off and greater flexibility over breaks from caring.

How personal health budgets were used

Broad areas	***Specific examples***
Personal care	Employing carers/personal assistants, respite care
Health/personal care equipment	Nebuliser, sanitary equipment, aprons, rubber gloves
Psychological therapies sessions	Neuro-linguistic counselling
Alternative /complementary therapies	Acupuncture, Reiki, yoga, bio-neuro therapy
Physical exercise home	Gym membership, exercise equipment
Dietary management	Frozen meals delivered, dietetics sessions
Computers/technology	Laptop, mobile phone, emergency telecare system
Aids and adaptations	Wheelchair, adjustable armchair, adjustable table
Social activities and hobbies	Musical instrument, driving lessons, childcare, theatre
Travel/transport	Travel to/from gym, travel for husband to visit hospital

However, these benefits could be reduced by some of the implementation problems experienced in the pilot projects. Although not widespread, they included:

- Lack of information about the level of the personal health budget and how this had been calculated.
- Lack of clarity on what budgets could and could not be used for – it was disheartening to be told a budget could not be used for a particular purpose, particularly when patients knew that others had been able to do so. People with newly-diagnosed conditions particularly needed help to plan how to use their budget.
- Delays in the NHS procuring approved items or services.

- Lack of regular reviews.
- Confusion between local NHS and social care services about funding responsibilities where people had very complex needs.

These experiences provide important lessons for the wider implementation of personal health budgets. Following the completion of the pilot programme and publication of the full evaluation report, personal health budgets are now being extended across England.

Further information and the final report and summary are available on this web page: bit.ly/phbe3

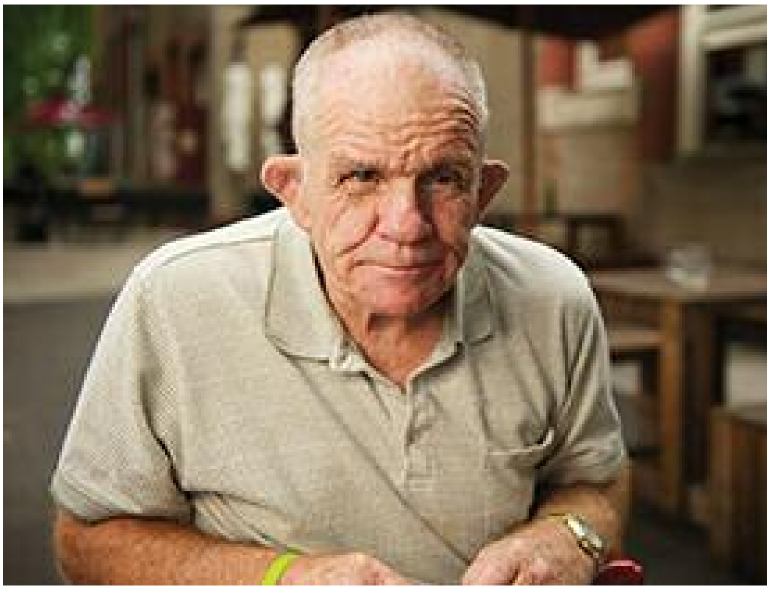
Funder: Department of Health
Duration: November 2009 to October 2012
Partners: Personal Social Services Research Unit, University of Kent; Imperial College, London

Personal budgets, direct payments and self-directed support for people with severe mental health problems

Personalised care can comprise of a personal budget or direct payment, and self-directed support. However, take-up of these initiatives is particularly low among people with mental health problems and we still have limited evidence of their effectiveness for this group of people.

Seventy-five Primary Care Trusts are currently piloting personal health budgets for people with long-term conditions such as mental health problems to explore how the principles of personalisation may be extended into the NHS. With all of these initiatives for personalised care in place, it is important to have gold standard evidence of their effectiveness for people with mental health conditions.

This project will carry out initial research to test the feasibility and inform the development of a full evaluation programme of personalised care. It will also develop an exemplar of good practice in personalised care from the perspective of mental health services users, carers, clinicians and policy makers.



Clarifying the role of carers within personalisation is particularly important for people with communication or cognitive impairments, who depend on carers to communicate their needs and wishes.

This project is led by Martin Webber at the University of York in collaboration with multiple partners. Professor Parker is providing input on issues around the role of personal budgets in supporting parenting.

Further details can be found on this web page: bit.ly/pbudmh

Funder: The National Institute for Health Research, Programme Development Grant
Duration: January 2012 to December 2013

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

Personalised adult social care emphasises the aspirations and preferences of service users. Carers have also secured rights to assessments and support. These developments have largely occurred separately and may overlook the close relationships between disabled and older people and the family/friends (informal carers) who support them. Clarifying the role of carers within personalisation is particularly important for service users with communication and/or cognitive impairments who depend on carers to communicate their needs and wishes. People with dementia, and adults with learning disabilities and their carers have been recruited to explore this aspect.

The study is identifying the range of practice currently promoted and used by front-line staff. This practice will be compared with service users' and carers' own experiences. These insights will be used to inform guidance on assessment and support planning processes and management of personalised support arrangements that more accurately reflect both service users' and carers' wishes. The study generally seeks to explore the views of an often-overlooked group of service users, as well as those of their carers.

More details on the methods and aims of the project are available here: bit.ly/carersP

Funder: The National Institute for Health Research, School for Social Care Research
Duration: January 2011 to February 2013

Risk, safeguarding and personal budgets: exploring relationships and identifying good practice

One of the main forms of enabling personalisation is through personal budgets (PBs), whereby people are given real budgets (cash direct payments) or virtual budgets with which to arrange their own services.

However, there are fears that people using PBs to purchase unregulated care, or relying on relatives to manage PBs, may be at greater risk of abuse and neglect than people using conventional services.

The project aims to generate robust evidence to support practice developments. It is bringing together statistical evidence with the perspectives and accounts of people with direct payments, as well as their carers and relatives, and practitioners. We will draw out clear practice messages for care coordinators, social workers and practitioners in provider and safeguarding roles, specifically in the areas of support planning, monitoring and reviewing people who use cash direct payments.

Read more about the project and access its publications on this web page: bit.ly/risksp

Funder: National Institute for Health Research, School for Social Care Research
Duration: November 2012 to March 2014

Personalisation of home care for older people using managed personal budgets

Personal budgets (PBs) are a mechanism for facilitating personalisation of social care services and are being rolled out to all adults in England who are eligible for social care. Some people manage their own PBs and others use PBs managed by local authorities or providers. It is important that people using managed PBs are not excluded from receiving personalised and flexible support, or from having control over that support, merely because they do not wish to manage their budget.

This study is exploring the factors affecting the delivery of personalised support to older service users who opt for managed personal budgets. It is using a range of qualitative methods of data collection and analysis from three study sites in England.

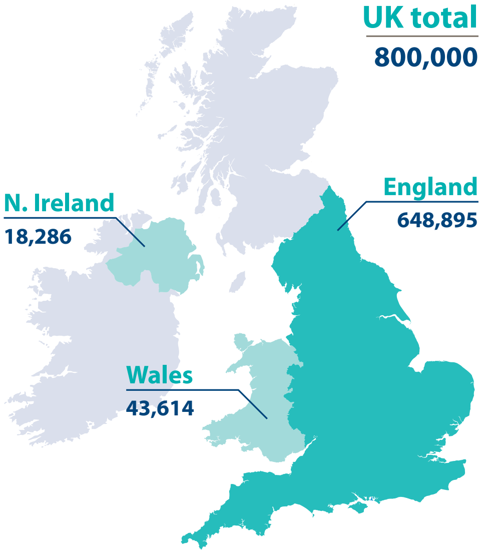
The study's findings will be of direct relevance, not just for local authority-based practitioners, but for all practitioners of social care (including independent support planners and managers of provider organisations), as well as holders of managed PBs. It will inform practice about the most effective ways to enable choice and flexibility of social care support for this group of PB holders.

Further information including methods and publications are available here: bit.ly/mpbudget

Funder: NIHR School for Social Care Research
Duration: January 2011 to February 2013

Dementia: the size of the challenge

The breakdown of the population with dementia across the UK.



Graphic courtesy of the Alzheimer's Society

Life story work with people with dementia: an evaluation

Everybody has a life story. Such stories are rich and varied and can be used to communicate who we are to the people around us. People with dementia sometimes need help to communicate their histories and identities, and 'life story work' might provide a way for them to do so.

Networks of practitioners, carers and user groups tell us that life stories are growing in popularity as a tool in the care of people with dementia but there have been no large-scale, rigorous studies of their use. SPRU is undertaking the development and initial feasibility stages of an evaluation of life story work. The involvement of people with dementia and family carers will be central to the success of this research. They will be involved throughout the project as expert advisers, helping to ensure that all research materials and strategies are fully inclusive. They will validate findings, using their personal experience to put interpretations in context.

The research will provide dementia care providers, service planners and policy makers with evidence-based information on the use and outcomes of life story work. It will also provide an assessment of how it might be possible to further evaluate the costs and outcomes of life story work for research planners and commissioners.

Information on our research partners, objectives and methods is on this web page: bit.ly/lsDem

A special feature on the project is on page 5 of this report.

Funder: NIHR Health Services and Delivery Research
Duration: July 2012 to December 2014

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

This project is looking at the increasing numbers of people who live with dementia and impaired cognition or communication. Traditionally this group has been without a strong 'voice' in research and therefore health services and policy makers require a deeper understanding their lives and needs.

One main group of methods to elicit views from people with impaired cognition or communication are the non-verbal techniques generally referred to as augmented and alternative communication (AAC). However, there is little methodological research about how these alternatives have been tested and applied and whether they do, indeed, increase 'voice'. This studentship project is scoping and systematically reviewing the literature on AAC methods in research amongst people living with dementia.

The findings will be used to understand the contribution of such methods for capturing and analysing the views of participants. The study will determine when and how AAC methods can be applied. Greater understanding of the contribution of AAC methods, including how they have been tested and applied and the data generated, will lead to the creation of good practice guidelines for the use of such methods in research.

Further information on the research is available here: bit.ly/voiceD

Economic and Social Research Council, White Rose Studentship
October 2011 to September 2014

Supporting carers of people with dementia

Carers Trust is the new charity formed in April 2012 from the merger of The Princess Royal Trust for Carers and Crossroads Care. It has commissioned research into the caring 'journeys' of carers of people with dementia in order to inform the planning and delivery of information, advice and other support services for this group of people.

In the next 40 years the number of people with dementia is projected to double to 1,700,000. There are 670,000 carers of people with dementia in the UK at present.

The project will review recent UK research literature, interview carers in four localities across the UK, and undertake a survey of carers from across the whole of the UK. There will be a feedback workshop to review the provisional findings. The research team will be working closely with local Carers Centres throughout the study.

For further information please see this web page: bit.ly/CarersDem

Funder: Carers Trust
Duration: July 2012 to June 2013

Research review of risk and adult social care: focused update

This review was a focused update of an earlier SPRU review of the research into the incidence and management of risk in adult social care. The updated review concentrated on identifying evidence from UK based empirical research published between 2007 and 2011 in the following areas:

- social care service users' and carers' experiences and perspectives on risk
- the effectiveness of mechanisms to prevent or reduce risk
- experiences, incidence and the management of risk within personalised adult social care.

Databases were searched (alongside hand-searching of relevant journals and website checking) for research involving different groups of adult social care service users (such as older people, disabled people, mental health service users, service users from black and minority ethnic groups) and social care service providers (public, private, voluntary and informal). The search identified 49 relevant papers.

The review highlighted that:

- Some gaps identified in the previous review had been addressed, particularly the experiences of people with mental health problems and those with learning disabilities in relation to risk. However, there is still very little research on the risk-related experiences of some other groups of service users, such as those from black and minority ethnic communities.
- Tensions and dilemmas for professionals were apparent, as they try to balance positive approaches to risk-taking alongside professional and statutory duties to protect service users. These tensions are particularly apparent in relation to personalisation and personal budgets in adult social care.
- Research into ways of managing risk largely reported practitioners' and managers', rather than users', perspectives.
- Overall, the research review demonstrated that there is still little evidence on what constitutes good practice or how to balance rights and protection.

More research is clearly needed; recognising this, the Joseph Rowntree Foundation has used the review to inform their research programme called 'Risk, Trust and Relationships' where they explore what would help people to feel confident when making decisions about supporting and caring for each other, as well as how to encourage communities to be kinder.

The review can be accessed from this web page: bit.ly/riskasc

Funder: Joseph Rowntree Foundation
Duration: August 2011 to October 2011, report released 2012

SPRU's expertise in systematic reviews in health and social care

Researchers in SPRU have an established record of carrying out systematic reviews in complex areas of health and social care, with a particular emphasis on service delivery and organisation.

There have been arguments about the need for accumulated knowledge to be identified systematically, tested for quality, analysed, and synthesised since at least the eighteenth century, when James Lind tried to sift good evidence about preventing scurvy from the indifferent or positively bad.

Systematic reviews attempt to do this by finding and bringing together most of the good quality evidence about a topic and then synthesising the findings. The underlying rationale for doing this is that we can rarely rely upon a single piece of research as a guide to intervention, and that research is not always as rigorous as it might be.

As the name suggests, all elements of a review are done systematically – searching for publications, deciding whether they should be included in a review, assessing the quality of the underlying research, selecting data to be analysed, and then bringing it all together. This involves being transparent about how material was searched for and selected for a review, and leaving an audit trail for all the decisions made as a review progresses. Data are 'extracted' into forms that can be shared, and allow others to judge whether the conclusions drawn by the reviewers are supported by the data.

The past 20 years in the UK have seen an increasing role for systematic reviews in health services. However, the early development of methods for research synthesis or systematic reviewing owes much to social science, and recent developments – especially the government's need for 'rapid evidence appraisal' in order to support policy making - have brought social scientists back into the fray. This has led to a rich stream of methods development that has extended systematic review techniques far beyond a focus on clinical intervention research and randomised controlled trials, and into the realms of theory development and synthesis of qualitative research. 'Rapid' reviews, reviews that scope out an area of evidence, and meta-reviews (reviews of reviews) are also now parts of the systematic review armoury.

Recent and current examples of subjects that SPRU has tackled include reviewing the evidence on:

- delivering care 'closer to home' for children and young people who are ill
- models of continuity of care for people with long-term neurological conditions
- interventions to support parents with mental health problems
- interventions to deal with sleep and behavioural problems for disabled children
- the impact of Life Story Work in dementia care
- rehabilitation services for people with visual impairment
- interventions to support carers.

We also have a PhD student who is using systematic review techniques to explore how researchers use alternative and augmented communication methods in research with people with dementia.

These often complex topics raise interesting methodological challenges that belie the systematic review's reputation as a 'bit boring'. And there is nothing more exciting than finishing a review with the sensation that one now knows as much (if not more than) anyone else in the world about the evidence base for the topic.

Gillian Parker

Professor Parker has been leading and contributing to systematic reviews in health and social care for over 15 years. To contact her to discuss your project needs please telephone (01904) 321951 or email: spru-director@york.ac.uk

It is important the people with visual impairment receive appropriate interventions that promote their independence for as long as possible.

Vision rehabilitation services: increasing the evidence base

Age-related eye conditions are the most common causes of visual impairment. With the increase in the number of older people in England, the number of people with visual impairment is also expected to rise considerably. This will in turn increase demands on health and social care provision and their associated economic costs. It is important that people with visual impairment receive appropriate interventions that could improve their well-being and promote their independence for as long as possible.

The study is using mixed methods including: a review, workshops, a national survey, focus groups and interviews to access a range of information, views and experiences from those who have visual impairments and those who help them.

The research will provide an initial evidence base for rehabilitation service models for people with visual impairment. The extent and models of current provision and gaps in rehabilitation interventions are being explored. This will help to identify key features to be tested in a future evaluation studies. Service managers, care providers and policy makers will be able to use the guidance on 'good practice' in their services.

Further information about the project is available on this web page: bit.ly/visionTPT

Funder: Thomas Pocklington Trust
Duration: October 2012 to June 2014

Older people's access to public and private services

There have been radical changes within the last 20 years in the ways in which both public and private sector services are provided and positioned. There is a trend to conglomeration and movement away from the local level. Local shops and post offices have closed, retail outlets have conglomerated, transport patterns have changed and the internet is used for shopping. There appears to be little research that systematically examines and tracks changes to these 'everyday' services or explores the possible impact on older people's ability to live independently in the community. At a time of far-reaching changes to both public and private sector services, the need to explore these interactions is urgent.

The aim of this project is to:

- identify and track change in the UK in the provision and positioning of selected, 'everyday', public and private services using longitudinal, secondary data sources
- hypothesise about the ways in which these changes might have affected the ability of older people to maintain independence
- explore these hypotheses through a mixed methods approach, including secondary data analysis and primary, qualitative research with older people
- set the acquired knowledge within a social policy context.

Further information about the project is available on this web page: bit.ly/olderp

Funder: Economic and Social Research Council, White Rose Studentship
Duration: October 2011 to September 2014

Welfare and Employment Research Group

Contents:

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

The 2008 report by Dame Carol Black *Working for a Healthier Tomorrow*, was a landmark publication in the development of policy towards improving health in the workplace. Among the many responses of the government of the time, two linked initiatives were set up as pilot schemes:

- Eleven Health, Work and Well-being Co-ordinators in Scotland, Wales and the nine English Regions were appointed to develop partnerships between employment and health networks, co-ordinate health work and well-being strategies and activities within and across regions and countries, and promote best practice and innovation within firms.
- A Health, Work and Well-being Challenge Fund was established to provide funding for initiatives to improve workplace health and welfare, particularly in small and medium sized enterprises (SMEs) and local partnerships.

SPRU evaluated these initiatives in 2010 and 2011.

Co-ordinators

Our study showed that Co-ordinators had made considerable progress in meeting the strategic aims of the post. Co-ordinators worked to develop and encourage partnerships between employment and health networks. Public sector engagement was wide ranging, including working with primary care trusts to help them assess needs in the workforce, set goals and measure outcomes, and advising strategic health authorities, local enterprise partnerships and emerging Health and Well-being Boards in England.

However the extent of direct contact with small and medium enterprises (SMEs) did not match the aspirations of government. There was some activity relevant to SMEs such as developing charters and accreditation schemes but there was relatively little direct contact with them. There was far more contact with large public sector organisations (particularly in the NHS).

Overall most organisations with whom the Co-ordinators had dealings valued the contact with 88 per cent saying it was useful or very useful.

Although central government funding for Co-ordinators ended in March 2012, some regional authorities continued to fund the posts from other resources.

Challenge Fund

The findings from the evaluation of the Challenge Fund were particularly interesting. Receiving an award stimulated a wide range of activities in individual firms and partnerships. Firms tended to introduce activities aimed at individual employees, while partnerships concentrated more on corporate activities (such as health promotion and education). Physical exercise and mental health initiatives were the most common.

A survey of Challenge Fund winners showed that there were perceived to be positive impacts on workplace culture and increased knowledge about work and health, with the greatest impact reported on mental well-being. There was also evidence that merely knowing about the Fund (but not receiving an award) could have a positive effect on health and well-being activity, a 'halo effect'. Overall it appeared that relatively small amounts of money could kick-start new activity that had a good chance of being sustained beyond the funding period. However, the evaluation was unable to provide evidence of the effect of health and well-being initiatives on levels of sickness, a key government objective.

Overall this research highlighted that there are both direct and indirect means by which workplace health and well-being can be effectively promoted and that responsibility for further development lies in the hands of both government and health bodies, and employers of all sizes.

Further information and access to the final report is available on this webpage: bit.ly/HealthWWB

Funder: Department for Work and Pensions
Duration: January 2010 to November 2012
Partners: Ipsos MORI

Most clients had multiple needs. These other concerns in addition to health problems together presented significant risks to staying at work.

Evaluation of the Fit for Work Service pilots

Spru was involved in an initiative that sprang from Dame Carol Black's review of the health of Britain's working age population – the Fit for Work Service (FFWS). It was piloted in 11 areas throughout Great Britain. The pilots provided a service to people in work with a health condition, including workers on a period of sickness absence from their job (sickness absentees), and those who were attending work but at risk of sickness absence (presentees).

Pilots were formed by partnerships of health, employment and local community organisations, and offered biopsychosocial assessments of need and case-managed support to aid a quick return to work. The biopsychosocial model is an approach which explores biological, psychological (thoughts, emotions, and behaviours), and social factors, as they all play a significant role in disease or illness. This approach was favoured because it was found that most clients had multiple needs. These other problems and concerns, in addition to health problems, together presented significant risks to staying in work.

SPRU was involved in the qualitative longitudinal study of users' experiences and the focused study of GPs' views and use of the Fit for Work Service.

Clients

When surveyed about their participation, FFWS clients were generally positive about their overall experience of the service. The vast majority of respondents agreed that the service had been responsive to their needs, well coordinated with other health and employment services, personalised, and provided relevant referrals or signposting. It was found that nearly all the clients who were at work when they were first supported by the pilots, and who left the pilot during the first year, remained employed.

Our qualitative evidence from the clients interviewed in the panel indicates that the FFWS provided significant support to return to work, without which the return would not have happened.

Others said that the service had helped by:

- accelerating a return to work
- easing or supporting a return to work
- sustaining employment after a return to work.

GPs

The pilots tried different ways of encouraging access to the scheme. Some encouraged GPs to refer their patients when they saw that they were in danger of leaving work through illness. The GP route was found to be a difficult one, requiring a lot of effort to get the GPs involved and active in recommending the service.

GPs who used the FFWS reported several benefits from their perspective including:

- the holistic assessment of patients' capabilities
- the provision of expert workplace assessments
- the saving of GP resources.

Further information and access to the final report is available on this webpage: bit.ly/fitfw

Funder: Department for Work and Pensions and the Department of Health
Duration: February 2010 to April 2012
Partners: Institute for Employment Studies, University of Liverpool, National Institute of Economic and Social Research, Gfk NOP

UK expert on National Action Plans for Social Inclusion

All member states of the European Council have drawn up National Action Plans to make a decisive impact on the eradication of poverty and social exclusion. The European Commission established a group of non-government experts responsible for providing an independent critical review of member states' NAPs/inclusion. The UK experts Jonathan Bradshaw and Fran Bennett (University of Oxford), have produced a series of reports each year on the progress being made. In 2012 they reported on:

- Active Inclusion: A study of national policies in the United Kingdom
- United Kingdom Country Profile
- United Kingdom Assessment of Progress Towards the Europe 2020 Objectives. A Study of National Policies

Previous reports are available on this webpage: bit.ly/naps12

Funder: European Union
Duration: 2003 onwards

The independent experts assist the European Council in monitoring and evaluating the situation with regard to poverty and social exclusion in each country.

Evaluation of the Work Programme

The Work Programme is the Coalition Government's flagship welfare-to-work programme for benefit claimants, replacing previous programmes.

Distinctive features of the Work Programme include contracting out delivery to prime contractors in the private and third sectors and an innovative 'Payment by Results' funding model.

A consortium of research organisations, including SPRU, is evaluating the Work Programme over a period of three years, looking at the commissioning, provider and claimants' experiences of the scheme. The evaluation package will test the success of the Work Programme as a novel method of delivering welfare-to-work services.

Findings will be used to inform the evolution of the Work Programme, as it progresses, by generating lessons about what works, for whom and in what circumstances.

The findings will also be used by other government departments to inform decisions about the commissioning of other public services beyond welfare to work.

A report on the first phase of programme delivery was released in 2012. It identifies some of the critical themes that will be tracked at future stages of the evaluation such as: 'creaming and parking', personalisation of support, addressing barriers to work, conditionality and sanctions, in-work support and sustainability.

Further information and access to the report and summary is available on this webpage: bit.ly/WorkPro

Funder: Department for Work and Pensions
Duration: December 2011 to December 2014
Partners: Institute for Employment Studies, National Institute of Social and Economic Research, Centre for Social and Economic Inclusion and GfK NOP

Self-employment and Universal Credit

From 2013, Universal Credit will replace the main out-of-work social security benefits and the main in-work benefit, Working Tax Credit. The intention is to have a more simplified benefit system that will be easier to understand and administer, and which will incentivise people to enter and progress within the labour market. Universal Credit will be paid to everyone with a low income regardless of whether they are in work or unemployed and will also apply to self-employed people.

New procedures for claiming Universal Credit and keeping claims up to date on a monthly basis will also be introduced. This will be a major change for self-employed people who currently only have to make an annual claim for tax credits. The Department for Work and Pensions wishes to have a greater understanding of how Universal Credit will affect the lives of self-employed people.

The research comprises in-depth, qualitative interviews with 45 self-employed people. Data will be collected on their working patterns, the flows of their income and outgoings, and the likely impact of the Universal Credit reporting requirements.

The research is intended to generate data that will help the Department for Work and Pensions to design reporting arrangements for self-employed people that are feasible, effective and efficient.

Further information is available on this webpage:
bit.ly/Selfemp

Funder: Department for Work and Pensions
Duration: July 2012 to January 2013
Partners: Institute for Employment Studies

The subjective well-being of children

The growth of interest in subjective well-being is partly due to recognition that existing social and economic indicators do not fully capture what matters for the quality of people's lives. Subjective well-being is one of the least developed areas of well-being measurement and contains a good deal of conceptual and empirical confusion.

From 2007, SPRU and the Children's Society collaborated in a study of the subjective well-being of children in England. This study is part of an ongoing research programme which aims to make a significant contribution to understanding what affects young people's well-being, and to monitor changes in well-being over time. In 2010 a report analyzing the national survey of children aged 10, 12 and 14 was published. In 2012 *The Good Childhood* report was released, revealing that half a million children across the UK are unhappy with their lives. Six priorities for policy-makers to help improve the situation for children and young people were suggested.

Further details of the survey and access to the publications is available on this webpage:
bit.ly/swbchild

Funder and research partner: The Children's Society
Duration: January 2007 onwards

Half a million children across the UK are unhappy with their lives - The Good Childhood Report 2012.

Unit Information

Staff list

Director

- Professor Gillian Parker

Health and Social Care (Adults) Research Group

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

Health and Social Care (Children and Young Adults) Research Group

- Research Director - Professor Bryony Beresford
- Mairi Harper
- Wendy Mitchell
- Nicola Moran
- Suzanne Mukherjee
- Gemma Spiers
- Lucy Stuttard

Social Work (Children and Young People) Research Group

- Research Director - Professor Nina Biehal
- Linda Cusworth
- Jo Dixon
- Visiting Associate - Gwyther Rees
- Emeritus Professor - Ian Sinclair
- Research Professor - Mike Stein
- Jim Wade

Welfare and Employment Research Group

- Research Director - Professor Roy Sainsbury
- Associate Director - Professor Jonathan Bradshaw
- Anne Corden
- Jacqueline Davidson
- Annie Irvine
- Katharine Weston

Research Support Group

- Finance Officer - Simon Johnson
- Information Officer - Rachel McAllister
- Information Assistant - Ruth Dowling
- Office Manager and PA to the Director - Sally Pulleyn
- Research Support Administrator - Teresa Frank
- Research Support Administrator - Dawn Rowley
- Research Support Administrator - Rebecca Thompson

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All publications can be found on our website at: bit.ly/SPRUpubs

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Brooks, J., It's like having a friend around, in M. Davies (ed.) *Social Work with Adults: Policy, law, theory, research and practice*, Palgrave Macmillan.

Corden, A., An example of semi and unstructured interviews, in S. Becker, A. Bryman and H. Ferguson (eds.) *Understanding Research for Social Policy and Social Work*, 2nd ed., The Policy Press, Bristol, pp.294-295.

Corden, A., Research with recently bereaved parents, in S. Becker, A. Bryman and H. Ferguson (eds.) *Understanding Research for Social Policy and Social Work*, 2nd ed., The Policy Press, pp.77-78.

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Gridley, K., A good arrangement - now under threat, in M. Davies (ed.) *Social Work with Adults: Policy, law, theory, research and practice*, Palgrave Macmillan.

Hoelscher, P., Richardson, D. and Bradshaw, J., A snapshot of child well-being in transition countries: exploring new methods of monitoring child well-being, in A. Minujin and S. Nandy (eds.) *Global Child Poverty and Well-being: Measurement, concepts, policy and action*, The Policy Press, pp.179-206.

Irvine, A., Semi-structured and unstructured interviewing, in S. Becker, A. Bryman and H. Ferguson (eds.) *Understanding Research for Social Policy and Social Work*, 2nd ed., The Policy Press, pp.291-297.

Irvine, A. Telephone interviewing in qualitative research, in S. Becker, A. Bryman and H. Ferguson (eds.) *Understanding Research for Social Policy and Social Work*, 2nd ed., The Policy Press, pp.297-302.

Newman, J., Glendinning, C. and Hughes, M. (forthcoming) Beyond modernisation? Social care and the transformation of welfare governance, in C. Pierson, F. Castles and Naumann (eds.) *The Welfare State Reader*, 3rd ed., Polity Press.

Stein, M. [Transitions from care to adulthood: messages from research for policy and practice], in P. Bastianoni and F. Zullo (eds.) *[Young Adults and Personal Autonomy]*, Carocci editore, Rome, Italy, pp.18-33.

Stein, M. [Promoting the resilience of young people from care to adulthood: messages from research], in M. L. Raineri (ed.) *[The Protection of Children]*, Erickson, Gardolo, Italy, pp.119-128.

Van Mechelen, N. and Bradshaw, J., Child poverty as a government priority: child benefit packages for working families, 1992-2009, in I. Marx and K. Nelson (eds.) *Minimum Income Protection in Flux*, Palgrave Macmillan, pp.81-107.

Other Publications 2012

Bradshaw, J. Does cash or services have the biggest impact on child poverty? *New Statesman blog*, 27 June 2012.

Corden, A., Hirst, M. and Sainsbury, R. *Bereavement Benefit for the 21st Century: Public consultation by the Department for Work and Pensions 2011-2012: Response to the consultation from the Social Policy Research Unit, at the University of York*, Social Policy Research Unit.

Huby, M. and Bradshaw, J. Water poverty set to soar, *Poverty and Social Exclusion* website.

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

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

Stein, M. *Corporate Parenting from Care to Adulthood: A research perspective*, National Care Advisory Service.

International presentations 2012

Biehal, N. (2012) Implementing Multidimensional Treatment Foster Care for adolescents in England. Keynote., *11th International Conference on Child Maltreatment*, Oviedo, Spain, 18 October 2012.

Biehal, N. (2012) Outcomes of adoption: findings from research in England. Keynote., *What are the Outcomes for Adopted Children Conference?*, Zurich, Switzerland, 1 March 2012.

Bradshaw, J. (2012) Child poverty and social exclusion, *The State of the Art of Measuring Poverty and Social Exclusion in the UK and Japan Research Seminar*, Institute for Population and Social Security, Tokyo, Japan, 6 January 2012.

Bradshaw, J. (2012) Child poverty, Is Japan an Equal Society? *Policies Against Poverty and Social Exclusion Public Symposium*, Keio University, Tokyo, Japan, 7 January 2012.

Bradshaw, J. (2012) Family related benefits in the UK, *Tackling Child Poverty: Lessons from the UK and New Frontiers in Japan Open Seminar*, Doshisha University, Kyoto, Japan, 9 January 2012.

Bradshaw, J. (2012) Child well-being and the impact of the crisis in advanced economies, *UNICEF Regional Social and Economic Policy Network CEECIS Meeting*, Tblisi, Georgia, 27 March 2012.

Bradshaw, J. (2012) Social protection for children in advanced economies and other middle income countries: lessons for CEECIS, *UNICEF Regional Social and Economic Policy Network CEECIS Meeting*, Tblisi, Georgia, 28 March 2012.

Bradshaw, J. (2012) Comparing states' contribution to the costs of children, *Richard Titmuss Memorial Lecture*, The Hebrew University of Jerusalem, Jerusalem, Israel, 14 May 2012.

Bradshaw, J. (2012) Subjective well-being research, *Harum Institute Seminar*, Harum Institute, Jerusalem, Israel, 16 May 2012.

Bradshaw, J. and Tokoro, M. (2012) The end of universality? The abolition of universal child benefits in Japan and the United Kingdom, *Challenges for Social Protection, Foundation for International Studies on Social Security Annual Conference*, Sigtuna, Sweden, 19 June 2012.

Bradshaw, J. (2012) The structural determinants of child subjective well-being, *UNICEF Innocenti Centre Seminar*, Florence, Italy, 22 June 2012.

Bradshaw, J. (2012) Engineering happiness in childhood. Can policy influence well-being?, *Flinders Institute for Public Policy and Management Seminar*, School of Policy Studies, Flinders University, Adelaide, Australia, 2 July 2012.

Bradshaw, J. (2012) Engineering happiness in childhood. Can policy influence well-being?, *Promoting Children's Well-being and Happiness: What Role for Social Policy? Seminar*, Children's Centre, Crawford School of Public Policy, Australian National University, Canberra, Australia, 4 July 2012.

Bradshaw, J. (2012) The international context of research on child well-being, *Are the Kids Alright? Meeting*, Canberra, Australia, 5 July 2012.

Bradshaw, J. (2012) The UK experience of the National Reform Programme and the Social Report Programme and the crisis, *European Union Network of Independent Experts on Social Exclusion Meeting*, Nicosia, Cyprus, 11 July 2012.

Bradshaw, J. (2012) Child poverty, family policy and the crisis, *Nordwel Summer School*, University of Helsinki, Helsinki, Finland, 17 August 2012.

Bradshaw, J. (2012) The subjective well-being of children, *Defining and Measuring Poverty in Heterogeneous Societies Colloqium*, Human Sciences Research Council, Cape Town, South Africa, 29 November 2012.

Dixon, J. (2012) Leaving care in England. Invited. *School of Social Work Lecture*, The Hebrew University of Jerusalem, Jerusalem, Israel, 26 May 2012.

Glendinning, C. (2012) Social services reform (and its absence) in England. Invited. *Social Services, Crisis and Solutions International Seminar*, San Sebastian, Spain, 31 October 2012.

Sainsbury, R. (2012) Cross-national research in social security - is there a case for greater use of qualitative methods? Keynote. *Challenges for Social Protection, Foundation for International Studies on Social Security Annual Conference*, Sigtuna, Sweden, 18-20 June 2012.

Stein, M. (2012) When care ends: lessons from peer research. Insights from young people on leaving care in Albania, the Czech Republic, Finland and Poland. Invited. *Young People Making a Difference in Leaving Care.* Launch of the European Peer Research Report to a meeting of the European Parliament, Brussels, Belgium, 6 November 2012.

Stein, M. (2012) [Promoting the resilience of young people from care to adulthood: messages from research]. Keynote. [*4th International Conference on Quality Welfare, The Protection of Children*], Riva del Garda (Trento), Italy, 9 November 2012.

Stein, M. (2012) Transitions from care to adulthood: messages from international research for policy and practice. Keynote. [*Norwegian National Conference on Young People Leaving Care*], Stavanger, Norway, 22 November 2012.

Stein, M. (2012) A journey of ideas: from theory to practice in leaving care. Keynote. [*Norwegian National Conference on Young People Leaving Care*], Stavanger, Norway, 22 November 2012.

Wade, J. (2012) Fostering unaccompanied asylum-seeking young people in England. Invited. *International Day*, University of Zurich, Zurich, Switzerland, 12 November 2012.

External advisory positions and activities

Fiona Aspinal

Proposal refereeing

National Institute for Health Research, School of Social Care Research

Kate Baxter

Proposal refereeing

National Institute for Health Research, School of Social Care Research

Nina Biehal

Expert witness, House of Lords Select Committee on Adoption Legislation

Member, Expert Working Group on Returning Looked After Children Home, Department for Education

Member, Expert Working Group on Permanence for Looked After Children, Department for Education

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

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

Expert witness, Education Select Committee on Child Protection

PhD Examiner, School for Policy Studies, University of Bristol

Bryony Beresford

Member, Advisory board, Children's Policy Research Unit, Department of Health

Academic Advisor, National Autistic Society

Member, Research Group, Martin House Children's Hospice

Member, Research Group, CHILLI (children with life-limiting illnesses)

Member, Psychosocial Group, Childhood Cancer and Leukaemia Group (CCLG)

Member, Research Group, Together for Short Lives/ Association of Paediatric Palliative Medicine

Member, Ethics Taskforce, Research Group, Together for Short Lives/ Association of Paediatric Palliative Medicine

Member, Transitions Taskforce (Together for Short Lives, National Council for Palliative Care, Help the Hospices)

Proposal refereeing

National Institute for Health Research (Programme Grants)

Together for Short Lives Legacy Research Programme

HSC Public Health Agency, Northern Ireland

Great Ormond Street Hospital Children's Charity, Local Investigator Research Awards

The Nuffield Foundation

Jonathan Bradshaw

Fellow, British Academy

Member, International Committee British Academy

Member, Standing Committee S4 British Academy

Academician, Learned Societies for the Social Sciences

Honorary Research Fellow, South African Human Sciences Research Council

Honorary Fellow, UNICEF UK

Honorary Visiting Professor, University of Oxford

Consultant, UNICEF Namibia

Consultant, UNICEF Regional Office for the CEE/CIS

Consultant, UNICEF Innocenti Centre in Florence

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

Member, Board, Foundation for International Studies in Social Security

Trustee, Social Research Unit Dartington

Member, Research Committee of the International Social Security Association

Trustee, Child Poverty Action Group

Chair, York Welfare Benefits Unit

Member, Board, International Society for Social Indicators

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

Member, Research Advisory Committee, Future Labour Markets Programme, Joseph Rowntree Foundation

Member, Advisory Committee, Are the Children Alright?, Australia

---

Anne Corden

Invited member, Parliamentary Round Table on Social Fund Funeral Payments

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

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

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

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

Member, Steering Group, 'Do-Well' trial of impact of welfare rights advice on health of elderly people, Institute of Health and Society, Newcastle University

Proposal refereeing

Chief Scientist's Office, Scotland

Jo Dixon

Research Manager (secondment), National Care Advisory Service

Co-investigator, Evaluation of Head, Hearts and Hands - Bringing up children in foster care: a social pedagogic approach, Loughborough University

Member, Starting Blocks Working Group, York Cares

Proposal refereeing

The Israel Science Foundation Individual Research Grants Programme

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Caroline Glendinning

Associate Director, National Institute for Health Research, School for Social Care Research

Member, Advisory Group, Approaches to Assessment of Eligibility for Adult Social Care in Other Countries, Centre for Health Services Economics & Organisation, Nuffield College, Oxford

Member, Research Advisory Committee, Research into Ageing, Age UK

Member, Technical Advisory Group, Genio Dementia Demonstration projects, Ireland

Member, Nordic Network for Research on Marketisation in Eldercare

Trustee, Thalidomide Trust

Proposal refereeing

National Institute for Health Research, Research for Patient Benefit Programme

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Kate Gridley

Proposal refereeing

National Institute for Health Research, Health Services and Delivery Research Programme

---

Annie Irvine

Member, Economic and Social Research Council Peer Review College

---

Wendy Mitchell

Member, Eurocarers: European Organisation on Informal Care

Co-ordinator, Carers Special Interest Group, University of York

---

Nicola Moran

Awards Officer, Social Policy Association (SPA)

Member, Judging Panel, Best Postgraduate Paper, SPA Annual Awards

Proposal refereeing

National Institute for Health Research, Health Technology Assessment Programme

---

Gillian Parker

Pan Yorkshire Lead, Dementia, North & East Yorkshire & Northern Lincolnshire Comprehensive Local Research Network (NEYNL CLRN)

Speciality Groups Chair, NEYNL CLRN, Dementias & Neurodegenerative Diseases Research Network (DeNDRoN)

Social care expert, Quality Standard Advisory Committee (QSAC), National Institute for Clinical Excellence (NICA)

Member, Steering Group, ESCAPE85+, University of Leicester

Critical Friend, REF process, External University

Proposal refereeing

Alzheimer's Society

NIHR, School of Social Care Research

Medical Research Council

Report refereeing

National Institute for Health Research, Service Delivery and Organisation Programme

Department of Health Policy Research Programme

Economic and Social Research Council

Roy Sainsbury

Member, Department of Work and Pensions Ministerial Advisory Group on the Evaluation of Universal Credit

Treasurer, Foundation for International Studies on Social Security (FISS)

Member, Advisory Panel on 'Intergenerational worklessness', Joseph Rowntree Foundation

International Adviser, 'Social Regulaton in the Nordic Countries' project, Norwegian Social Research Institute, Oslo

External examiner, Stirling University

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

---

Ian Sinclair

Academic Advisor, Care Inquiry on Permanence for Looked After Children, Eight National Children's Charities

Consultant, Rees Centre for Research in Fostering and Education, University of Oxford

Consultant, Southwark Children's Services

Mike Stein

Member, International Advisory Board, UNESCO, Children and Youth Programme

Invited member, Children's Society consultation event, Troubled and Troublesome Young People

Invited member, Ministerial consultation event, Leaving Care Services

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

Chair, Research Advisory Group, Corporate Parenting: Making the difference, Big Lottery

Chair, Passport to Parliament, North East Event, Who Cares? Trust

Member, Research Advisory Group, Care Leavers' Stories Research Project

Member, Research Advisory Group, Recognition and Telling, Developing Earlier Routes to Safety for Children and Young People

Consultant, 'I Matter Peer Research Project', SOS Children's Villages International

Consultant, Evaluation of the Springboard Project, Big Lottery

PhD examiner, Loughborough University

Jim Wade
Member, Advisory Group, Contested Adoption, Department for Education

Member, Expert Working Group, Returning Looked After Children Home, Department for Education

Member, Expert Working Group, Permanence for Looked After Children, Department for Education

Member, International Research Network on Leaving Care (INTRAC)

Member, European Migration Network

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

Member, Advisory Group, Beyond the Adoption Order, Department for Education

Member, Advisory Group, Working with Families of Children Placed Away from Home: Perspectives from four European countries, Nuffield Foundation

Adviser, Children's Society Research Unit

Member, Reunification External Reference Group, National Society for the Prevention of Cruelty to Children

Invited Participant, Care Inquiry on Permanence for Looked After Children, Eight National Children's Charities

Report reviewing
Social Care Institute for Excellence

Editorial Boards

Kate Baxter
Member, *Social Policy and Society*

Bryony Beresford
Co-editor, special issue, *Children and Society* 26:3

Nina Biehal
Member, *Child and Family Social Work*
Member, *Children and Youth Services Review*

Jonathan Bradshaw
Member, *Child Indicators Research*
Member, *International Social Security Review*

Jo Dixon
Member, *Child and Family Social Work*

Caroline Glendinning
Co-editor**,** special issue, *Health and Social Care in the Community* 20:3

Gillian Parker
Member, *Health and Social Care in the Community*

Roy Sainsbury
Member, *Journal of Social Security Law*
Editor, 'Research Highlights' section, *Journal of Poverty and Social Justice*

Jim Wade
Member, *Child and Family Social Work*

Peer Reviewing

Bereavement Care
Biomed Central
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Developing Practice (Association of Children's Welfare Agencies)
Disability and Society
Diskurs Kindheits und Jugendforschung [Discourse of Childhood and Youth Research]
European Journal of Social Policy
European Journal of Social Security
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spru

Social Policy Research Unit
The University of York
Heslington
York YO10 5DD
United Kingdom

Tel: +44 (0)1904 321950
Fax: +44 (0)1904 321953
Email: spru@york.ac.uk

www.york.ac.uk/spru

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