

## RESEARCH AND POLICY UPDATE

### ISSUE 70 January 2012

Welcome to the seventieth Research and Policy Update from **research in practice for adults**. Each month we will seek to highlight key policy activity within the previous month and to identify major research reports that have been released. We hope that this will provide ready access to the emergence of key initiatives and research findings. The balance across different service user groups and across different types of reports will vary from issue to issue. However in January, April, July and October each year there will be a particular focus on recent journal articles. At the request of Link Officers there is an abstract to help identify the main contents. Any queries and comments should be sent to [rachel@ripfa.org.uk](mailto:rachel@ripfa.org.uk).

### ABSTRACT

This month's RPU has a focus on journal articles, but also includes some government activity including headline findings from the telecare and telehealth **Whole System Demonstrator Programme**, an announcement about the **NHS Whistleblowing Helpline** now extended to cover social care and new **Autism training resources**. The ASCOF Handbook of Definitions is also highlighted. There is one consultation, from the Office for Disability Issues **Fulfilling potential: Working together to empower disabled people** and one research report looking at the evidence from the National Carers' Strategy Demonstrator Sites **New approaches to supporting carers' health and well-being**.

The journal articles included are as follows:

- Can we move beyond burden and burnout to support the health and wellbeing of family caregivers to persons with dementia?
- The impact of dementia on care transitions during the last two years of life
- Constructing Moral Responses to Risk: A framework for hopeful social work practice
- The Definition of Social Work in the United Kingdom 2000–2010
- Goal setting as a feature of homecare services for older people: does it make a difference?
- Carers' responses to challenging behaviour: A comparison of responses to named and unnamed vignettes
- Living the High Life? Residential, social and psychosocial outcomes for high-rise occupants in a deprived context
- What does vulnerability mean?
- The characteristics of residents in extra care housing and care homes in England

### GOVERNMENT ACTIVITY

#### [Whole System Demonstrator Programme: headline findings](#)

The Whole System Demonstrator Programme is the largest randomised control trial of telehealth and telecare anywhere in the world, and it is being carried out for the Department of Health in Kent, Cornwall and Newham. The programme started in May 2008 and is ongoing, however headline findings (from 12 months data) have now been published which show that, if delivered

properly, telehealth has big impacts on reducing mortality (45% reduction in mortality rates), reducing hospital admissions, reducing the time spent in A&E and lowering the amount of time spent in hospital.

The findings show that the most important factor in making this work is ensuring that telehealth technologies are integrated in care services. The Department of Health has committed to working across industry, the NHS, social care and other partners to collaborate and support them to introduce telehealth and telecare technologies. The workplan to support this is associated with the *Three million lives* campaign, which is in early stages of development. The campaign will seek to improve the lives of 3 million people over the next five years, through the introduction of telehealth and telecare technologies. Further information will be published as plans are established.

#### [NHS Whistleblowing helpline extended to social care](#)

From 1<sup>st</sup> January 2012, the free Whistleblowing Helpline number for NHS staff has been extended to staff and employers in the social care sector. The helpline operates between 0800 and 1800 on weekdays, and there is also an answering service available at weekends and on public holidays. The service was previously funded by the government, but will now become a free-phone service provide by the Royal Mencap Society. This will allay fears people may have had about raising their queries. The new number is 08000 724 725.

#### [Autism training resources](#)

The Department of Health is promoting a series of on-line training resources and booklets to increase awareness and understanding of autism across all public services. These resources are developed in response to the Autism Strategy, *Fulfilling and Rewarding Lives* (RPU52).

There are:

- a set of [resources from the Royal College of Nursing](#)
- an [Autism in General Practice course](#) from the Royal College of General Practitioners
- links to resources from the Royal College of Psychiatrists
- links to the [Skills for Health and Skills for Care knowledge list](#) for autism training for social care workforces
- two [videos from SCIE](#) looking at the skills that care workers and social workers need to support people with autism
- three [e-learning modules on autism from the British Psychological Society](#)
- access to [Healthtalkonline from the University of Oxford](#) where people share their experiences of living with autism
- and links to the [National Autistic Society website](#).

#### [Adult Social Care Outcomes: handbook of definitions](#)

The government has published a handbook setting out the technical detail of each measure used in the Adult Social Care Outcomes Framework (ASCOF). Each outcome is listed with rationale, definition, formula, a worked example, frequency of collection and data sources amongst other features. The handbook is offered as a support to minimise confusion and inconsistency in reporting and interpretation of measures. The intention is that an updated handbook will be published alongside each year's ASCOF (in March) and an update issued in Autumn if required. The ASCOF and the handbook will be co-produced by the DH, LGG and ADASS.

## **CONSULTATIONS**

### [Fulfilling potential: Working together to empower disabled people](#)

The government is putting together a new cross-government disability strategy and the Office for Disability Issues has put together [a discussion document](#) to enable people with disabilities, the people and organisations that support them to contribute to this discussion.

Responses are due by 9 March through the online form, by emailing [fulfilling.potential@dwp.gsi.gov.uk](mailto:fulfilling.potential@dwp.gsi.gov.uk) or by post to Office for Disability Issues (Disability Strategy Team), Ground Floor, Caxton House, 6-12 Tothill Street, London, SW1H 9NA.

## **RESEARCH REPORTS**

**[New approaches to supporting carers' health and well-being: Evidence from the National Carers' Strategy Demonstrator Sites programme](#)** (2011) Sue Yeandle and Andrea Wigfield

This report from the CIRCLE centre at Leeds University shares key findings from the national evaluation of the Department of Health's National Carers' Strategy Demonstrator Sites programme that aimed to improved carers' health and well-being. As part of that programme, the 25 demonstrator sites each had 18 months to develop new, creative and innovative approaches to offer personalised support to carers, or to extend existing provision if effective arrangements were already in place.

Key findings from the national evaluation are as follows:

- Services which are flexible and accessible at different points of a carer's journey, and on a regular basis when needed, are of great value
- Multi-agency support for carers is not a hugely complicated and disruptive thing to arrange. What is needed is a flexible approach to roles and sometimes some additional training. It is often particularly difficult to engage GPs, and some sites needed to invest extra effort in this
- Of particular importance is the role played by voluntary sector organizations and this needs to be managed carefully so as not to use the best of everyone's capabilities and capacities without adding to people's workloads or ignoring work already being done
- Mutli-agency work is particularly important for identifying and engaging carers. Good practice means involving carers from the start of a project, being aware of the challenges in involving carers, ensuring they have adequate support and training and finding a diverse group of carers
- Most of the carers who had been involved with the Demonstrator Sites felt they had benefited from it. The sites were particularly good at using approaches which targeted well some of the neediest carers. Breaks support, especially when flexible and personalised was shown to have the potential to really sustain carers and prevent burnout.
- Cost savings could clearly be made through carer support and it was clear that the minimal costs of carer support makes financial sense as it creates a long-term financially sustainable system.

## **JOURNAL ARTICLES**

**Can we move beyond burden and burnout to support the health and wellbeing of family caregivers to persons with dementia?** (2012) Meredith Lilly, Carole Robinson, Susan Holtzman and Jaon L. Bottorff, Health and Social Care in the Community, Volume 20, No 1, 103-112

This article reports on research from British Columbia. The context is that Canada has seen more than a decade of policy and service support provided with the intention of supporting people to stay at home as they get older. It is recognised now that this has had negative consequences on

family members who act as carers. This study used focus groups to investigate the health, wellness and support needs of family caregivers to persons with dementia.

The study found two main themes in the data. Firstly, these carers feel forgotten and abandoned, and do not feel that they receive adequate services to support their care-giving; secondly the respondents reported the burden of being expected to look after themselves. Respondents reported that being told that it is important that carers look after themselves in order to be able to keep in caring, feels like rhetoric and adds pressure to carers. The authors contend that while there has been recognition of the issue of caregiver burnout, recent policies in Canada have not responded in a way that provides carers' preferred support. The evidence suggests that caregivers are only offered services when they are at immediate risk of becoming patients themselves, or when they make an explicit demand for help often being forced to admit that they cannot cope any longer. The implications are relevant to Canadian policy and international practice, the authors suggest what is needed is preventive support which built into social care policy.

**The impact of dementia on care transitions during the last two years of life** (2012) Mari Aaltonen, Pekka Rissanen, Leena Forma, Jani Raitanen and Marja Jylha, *Age and Ageing*, Volume 41, 52–57

This article reports a Finnish study about care transitions. In the last years of life, older people tend to be moved between different care facilities, posing particular challenges for people with dementia by increasing confusion, which in turn increases risk, and difficulties in ensuring continuity of care necessary for the wellbeing of people with dementia. This study examined the records of everyone over the age of 70 who died in Finland between 2002-2003, to compare the number of care transitions in the last two years of life of those with dementia and those without.

The study found that dementia increased the number of care transitions by 32% for older people living at home two years before death. This percentage decreased to 20% for those living in care homes two years before death. The number of transitions increased as death got closer, and people with dementia were more likely to die in primary care rather than specialist care hospitals.

The problem with this high number of transitions is that it is inconsistent with good quality care for people with dementia, which stresses familiar environments and good continuity of care. What should be happening is that the progressive nature of the disease should lead to planning which includes consideration of the changing care needs which are then factored into arrangements made.

**Constructing Moral Responses to Risk: A framework for hopeful social work practice** (2011) Sonya Stanford, *British Journal of Social Work*, Vol 41, 1514–1531

This article reports an Australian study about the place of social work in a risk-averse society. The author starts from the premise that risk is a regulatory system that is repressive and undermining to social work. There have been a number of critiques of the social services sector that find that risk has overtaken need as the focus of social and economic policies, and as such regulation has overtaken practices of social care. Within this environment, social workers report feeling increasingly despondent about their work, restricted as they are by the discourse of risk which restricts action and makes them feel powerless to do the work they want to do and work within the values they feel are important.

The author states that it is imperative that if real care or support is to be given to service users, then social workers need to keep connecting to their sense of moral agency which ensures that they get the best outcomes for their clients, even in the presence of risk. It should be remembered that social workers have moral agency, the ability to act against and within the system they work to make the best moral outcomes. The author sites studies that emphasise the resilience, hopefulness and optimism of social workers that allows them to overcome the hurdles

they face, and she then draws together a framework that can help social workers in their day-to-day practice.

This small scale study involved interviews with social workers, where they were asked to discuss an intervention that had challenged or troubled them in some way. They started by discussing risk, and respondents talked about service users in two ways, *at risk* was most closely linked to the concept of vulnerability, whilst the language of *a risk* was used when they were considered to pose a danger or problem to the social workers. With those who were *a risk*, the social workers saw themselves as then being *at risk* and this influenced their moral stance towards that client, with compassion and empathy being less strongly expressed in those situations.

Overall the study found that the majority of the social workers would consider the position of the client before the position of themselves when faced with risk situations. These practitioners did not see themselves as constrained or useless in the face of the risk regulations, rather they saw themselves as being in a situation where they could make a difference and work around and through those regulations. Respondents conceptualised risk as a personal moral issue, rather than a regulatory one, and they personalised their response to risk in an individual level according to each particular client and their situation with that client.

Those social workers who maintained a focus on their clients rather than their own risk:

- thought about personal and professional morals, ethics and values
- thought through the reality and degree of risk to clients and to themselves
- believed in the possibility of change for their clients, and
- considered practice and theoretical frameworks.

Those who focused more heavily on their own risk, were more likely to practice a controlling stance, were more likely to:

- not consider the reality and degree of risk
- not consider change a possibility
- not consider practice frameworks, and
- emphasise their organisational and personal contexts.

These findings have clear implications for social work education and supervision. From an organisational perspective, there is a clear need to provide supportive working environments and within that to develop supervision practices that support workers to engage in good practice and that lessen the fear of reprisal. Supervision could become a useful place to explore ethical and moral dilemmas around risk, but it need to be focused on exploring emotions, facilitating critical inquiry and supporting social workers' self confidence in making the decisions they do. Critically reflective processes will help social workers to understand more about the decisions they made and how that creates or influences the concept of risk.

Belief in the possibility of change is key to social workers being able to see beyond risk in people's lives. Strengths-based approaches in training and education are key to facilitating this. An understanding of theoretical frameworks and injustice was also found to impact on how practitioners respond to risk. There is a need for teaching to cover how contextualising risk (rather than avoiding it) is a fundamental basis for engaging with practice.

**The Definition of Social Work in the United Kingdom 2000–2010** (2012) Jonathan Dickens, International Journal of Social Welfare, Vol 21, 34-43

Definitions of social work have been debated for a long time, but have recently seen a revival in light of the advent of personalisation and devolution, which has provided all four countries in the UK the opportunity to re-define, re-organise and regulate social work. This article identifies and discusses what the author sees as four key tensions inherent in social work.

The first tension lies in whether to define social work either in terms of its core values and principles or in terms of roles and tasks. The values-based approaches to definitions tend to be broad and vague, and are used to attract support from a wide range of other professionals and organisations, with the intention being to put across a general concept of social work. The difficulty with this is that these concepts do not always translate into roles and tasks. A definition by role and tasks, on the other hand, tends to be straight-forward descriptions of what already happens rather than inspirational accounts of what could be. The other challenge here is that trying to include all the roles and tasks as defined by all stakeholders is very difficult and results in overlong and complicated definitions and documents.

The second tension lies in the social-individual debate. This is whether social work is about the individual (as is very much the case in personalisation) or tackling inequality and social injustice. One suggestion is that it is not either or, but tackling inequality through working with individuals.

The third tension is between care and control. This has often been understood as social workers having control over service users, and their challenge being to care within that control. More recently, this debate is about giving as much control as possible to the service user, through personalisation, whilst being aware of the safety issues in giving that control.

The fourth tension is the public-professional dimension and the question of who has a say in defining social work. There are many potential different stakeholders and interest groups who could contribute to a definition of social work. There are alliances and conflict between these groups, but there is increasing signs of definitions which are built with political and managerial control in mind. The author suggests that the voices of practitioners and academics tend not to be heard, and although service user views are taken, there is evidence that this can be adopted to serve the interests of managers and politicians.

What all this shows is that social work is a profession in a fragile position, held in different tensions, in particular between the multiple different groups and bodies that claim a say over the roles and tasks of social workers. As policy shifts, social work is at the centre of ongoing debates and power struggles, and so social workers need to be aware of staying open to the new ideas that emerge, but assertive about the responsibilities and difficulties of the job.

**Goal setting as a feature of homecare services for older people: does it make a difference? (2012)** John Parson, Paul Rouse, Elizabeth Robindon, Nicolette Sheridan and Martin Connolly, *Age and Ageing*, Volume 41, 24-29

Traditional homecare services often focus on treating a person's illness or long term condition, and *taking care* of them, rather than using models of reablement which focus on helping individuals return to independence. The philosophy of reablement is to provide care which helps self-esteem, improves quality of life and maximises independence. Central to this philosophy is the use of personalised goals. This study looked at the impact of using a goal facilitation tool (TARGET) on quality of life among a sample of older people referred for homecare.

The study found that the quality of life of those who used the goal facilitation tool greatly improved over time, in comparison with those who received standard homecare. This group saw a much higher rate of activities which were structured around the individual's needs rather than generic tasks. This group also had a higher degree of individually tailored support plans, although the number of reviews of these plans was lower than expected. Training was an important part of making this work, with the new approach needing a big cultural shift. Shared understanding of the core principles behind the approach were also critical to success.

**Carers' responses to challenging behaviour: A comparison of responses to named and unnamed vignettes** (2012) Dave Dagnan, *Journal of Applied Research in Intellectual Disabilities*, Vol 25, 88–94

Research into the role of beliefs and emotions in influencing the response of carers to behaviours they find challenging in people with learning disabilities has suggested that it is important to understand the emotional processes involved in these responses, to feed into carer training and intervention. One of the most referenced models in this field of work is that of Weiner (1995) which states that attributions of the amount of control someone has over their behaviour will influence people's emotional response, in terms of regulating anger and sympathy. The evidence about the applicability of this model is mixed, and one reason offered for this is that most of the studies done do not use actual instances of behaviour from real people as stimuli. The authors of this study wanted to see if it made a difference whether or not carers knew the person responsible for the behaviour or not.

In this study, 62 paid carers reported their emotional responses to vignettes of real behaviour. Some of these vignettes were behaviour carried out by a person known to them, and some were vignettes of an unnamed person. The study found that carers were less positive in their responses to the named and known people, than to unnamed people. The consequence of this is significant for the use of Weiner's model or any work with carers that addresses behaviour they find challenging. As such, any work done with carers around this issue needs to be carried out using real life examples so as to replicate their real emotional responses.

**Living the High Life? Residential, social and psychosocial outcomes for high-rise occupants in a deprived context** (2011) Ade Kearns, Elise Whitley, Phil Mason and Lyndal Bond, *Housing Studies*, Volume 27, No 1, 97-126

This article reports the findings from a study to re-examines outcomes for high-rise residents in deprived social housing areas in Glasgow. The researchers asked questions relating to residential outcomes of high-rise occupants in comparison to non high-rise dwellers. They looked at sense of community and social relations, psychosocial benefits, differences between household types, and whether or not it is possible to see any difference in effects depending on building type and height. The findings showed that dissatisfaction was higher in high-rise than in other flats in houses, although neighbourhood outcomes (e.g. quality of environment and local services and amenities) were reported as poor across all dwelling types in the deprived areas in question. Anti-social behaviour was worse in high-rise than in houses. Interestingly, living higher up in the high-rise was linked to feeling more satisfied about the area. The higher up you are, the more insulated you are from the area within which you live.

Social outcomes are worse for occupants of flats than houses, and markedly worse in high-rise flats than non high-rise flats or houses. Occupants of high-rise flats were twice as likely to report poor cohesion in the local community and poor social contact or social support. However, whilst adult and family household report greater likelihood of infrequent contact with family and friends than in other dwelling types, the older households in high-rises were no more likely to report this than older households in other dwelling types. Also, whilst adult households in high rises are more likely to report feeling unsafe, this is not the same for older residents. Again, those at the lower floors were more likely to report negative impacts than those higher up.

Psychosocial outcomes were worse for occupants of flats than houses and some were worse for occupants of high-rise flats. In particular security-related outcomes were at least twice as likely to be poor in high-rise compared with houses. Empowerment-related outcomes were also twice as likely to be poor for high-rise occupants. The effect of high-rise on poor outcomes was weakest for family household respondents and strongest in older person households.

What this research shows is that as high-rise housing is not going to be replaced in the foreseeable future, if at all, then residents are likely to benefit from some interventions. Management of the blocks needs to be improved to reduce anti-social behaviour and foster community engagement. Overall, there is the need for social and community level interventions, not just regeneration schemes from outside that are intended to impact positively on communities. The lack of social cohesion and social support demonstrates a need for community-based schemes. Living in high-rises reflects very badly on the perception of self-worth amongst residents, and so there is need for shift in status of high-rises. Whether high-rises work or not, ultimately depends on the context of the wider society within which it is located, and it is important to examine more what the aspects of context are that really matter.

**What does vulnerability mean? (2012)** Fiona Parley, British Journal of Learning Disabilities, Vol 39, 266-276

This article reports on a study in which care staff were asked about their perceptions of vulnerability and abuse. There are many different variations in definitions of vulnerability that lead to confusion and to policies and guidance with different understandings of vulnerability

Many of the participants (twenty care staff) struggled with defining vulnerability and related it to something else such as risk or particular care groups, and also described it in terms of a lack of understanding, or the inability to make big decisions. They talked of vulnerability in terms of degrees, with the recognition that some people are very vulnerable, but others may only be vulnerable in relation to certain areas of life, for example relationships. For some participants vulnerability and risk were synonymous, whilst for others there was a clear distinction to be made between people who were at risk and those who were vulnerable.

Overall, there is confusion as to what vulnerability means, whether it is simply a label put on by other people, or something experienced by the person themselves, and whether it is directly related to risk or has other consequences for the type of care being provided. Policies do not help, as definitions of vulnerability are few and far between and differ between documents. Clearer definitions would enable better implementation of policy in practice. A better understanding of what vulnerable means, and how it is experienced, would also enable staff to better support people who may be vulnerable to develop coping strategies which would increase resilience. If there is no common understanding of what vulnerability means, or how it is experienced and linked to other aspects of the individual's life, then taking a personalised approach to decreasing vulnerability is very difficult.

**The characteristics of residents in extra care housing and care homes in England (2012)** Robin Darton, Theresia Baumker, Lisa Callaghan, Jacquetta Holder, Ann Netten and Ann-Marie Towers, Health and Social Care in the Community, Volume 20, No 1, 87-96

This paper presents the findings of a study comparing the characteristics of the residents of nineteen extra care housing schemes and care homes. In extra care housing schemes older people have their own independent living arrangements but with care and support where needed. Whilst these schemes have been researched before, there has been no comparison of the characteristics across sites or comparison between extra care homes and care homes.

The study found that overall, residents in extra care homes were younger and less physically and cognitively impaired than those who moved into care homes. However, there were clear similarities between the two groups in terms of prevalence of medical conditions, and some residents in extra care homes had high levels of dependence. However, in terms of cognitive impairment, these were much lower in extra care housing schemes than in care homes, even in those designed for people with dementia. What the study shows is that extra care housing is for people making a planned move rather than reacting to a crisis, and so these schemes prefer people to move in before any development of severe cognitive impairment.