

RESEARCH AND POLICY UPDATE

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Welcome to the fifty-fifth 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.

ABSTRACT

This month's focus on recent journal articles covers a range of different topics, but first there is a summary of the key points relating to social care in the Government's new White Paper on the NHS, **Equity and Excellence: Liberating the NHS**. Then moving on to journal articles, the first two cover issues of disability and independence, with one looking at the use of **advanced technology by people with disabilities in the UK** and the second a report of a study which looks at the **challenges of balancing independence and safety in care for people with dementia and sight loss**. Following this is a report on **balancing risk and the innovations agenda in social care** and this is then followed by a longitudinal study which has investigated whether **the higher risk of disability onset among older people who live alone be alleviated by strong social relations**. Then two pieces about organisational practices are reported, the first is a **literature review on integrated team working**, and the second a summary of a study looking at **the lifespan and life-cycle of self-help groups**. Two studies relating to people with learning disabilities are also included, one on **mainstream in-patient mental health care for people with intellectual disabilities: service user, carer and provider experiences**, and the other looking at **skills for support: personal assistants and people with learning disabilities**. Finally, a piece on a topic about which there appears to be little research published, **Housed Gypsy Travellers, Social Segregation and the Reconstruction of Communities**.

GOVERNMENT ACTIVITY

[Equity and excellence: Liberating the NHS – White Paper](#)

The government has issued its white paper on the NHS which outlines the changes in approach for the coming parliament. Many of the changes require primary legislation and a consultation period is currently running. The main areas that impact on social care are as follows:

Putting patients first

- The system will focus on personalised care that reflects individuals' health and care needs, supports carers and encourages strong joint arrangements and local partnerships.
- Shared decision-making will become the norm.

- Patients will have access to all the information they want to, and more control over their care records.
- The idea of 'choice' will be extended to include choice of treatment and provider in some mental health services from April 2011; this will be extended wherever practicable.
- The collective voice of patients and the public will be strengthened through a powerful new consumer champion, HealthWatch England, located in the Care Quality Commission.
- Local Involvement Networks (LINKs) will become the local HealthWatch, and the Government will enhance the role of local authorities in promoting choice and complaints advocacy, through the HealthWatch arrangements they commission.
- The Department of Health will encourage further personal budget pilots to come forward and will explore the potential for introducing a right to a personal health budget in discrete areas such as NHS continuing care. The Government will use the results of the evaluation in 2012 to inform a wider, more general roll-out.
- The government will implement the ban on age discrimination in NHS services and social care to take effect from 2012.

Primary Care Trusts

- The Government will devolve power and responsibility for commissioning services to GPs and their practice teams working in consortia.
- GP consortia will have a duty to promote equalities and to work in partnership with local authorities, for instance in relation to health and adult social care, early years services, public health, safeguarding, and the wellbeing of local populations.
- PCT responsibilities for local health improvement will transfer to local authorities, who will employ the Director of Public Health jointly appointed with the Public Health Service.
- The Government expects that PCTs will cease to exist from 2013, in light of the successful establishment of GP consortia.

NHS Commissioning Board

- The Government will establish an independent and accountable NHS Commissioning Board. The Board will lead on the achievement of health outcomes, allocate and account for NHS resources, lead on quality improvement and promoting patient involvement and choice. The Board will have an explicit duty to promote equality and tackle inequalities in access to healthcare. The Government will limit the powers of Ministers over day-to-day NHS decisions.
- Strategic Health Authorities will be abolished as statutory bodies during 2012/13. From 2012 the Board will perform those national functions relevant to its new role that are currently carried out by the Department of Health.

Partnership working

- To strengthen democratic legitimacy at local level, local authorities will promote the joining up of local NHS services, social care and health improvement.
- Building on the power of the local authority to promote local wellbeing, the Government will establish new statutory arrangements within local authorities – which will be established as "health and wellbeing boards" or within existing strategic partnerships – to take on the function of joining up the commissioning of local NHS services, social care and health improvement.
- The Government will simplify and extend the use of powers that enable joint working between the NHS and local authorities. It will be easier for commissioners and providers to adopt partnership arrangements, and adapt them to local circumstances.

Quality and standards

- The Government will strengthen the role of the Care Quality Commission as an effective quality inspectorate across both health and social care.
- NICE will rapidly expand its existing work programme to create a comprehensive library of standards for all the main pathways of care. The standards will cover areas that span

health and social care. The Health Bill will put NICE on a firmer statutory footing, securing its independence and core functions and extending its remit to social care.

- Monitor will be turned into the economic regulator for the health and social care sectors, with three key functions: promoting competition, price regulation, supporting continuity of services. Monitor's powers to regulate prices and license providers will only cover publicly-funded health services. However, its powers to apply competition law will extend to both publicly and privately funded healthcare, and to social care.

The White Paper also states the Government's planned timeframe for adult social care:

- Later this year, the Government will set out its vision for adult social care, to enable people to have greater control over their care and support so they can enjoy maximum independence and responsibility for their own lives.
- The Department of Health will establish a commission on the funding of long-term care and support, to report within a year. The Commission will consider a range of ideas, including both a voluntary insurance scheme and a partnership scheme.
- The Government will reform and consolidate the law underpinning adult social care, working with the Law Commission.
- The Government will bring together the conclusions of the Law Commission and the Commission on funding of long-term care, along with its vision, into a White Paper in 2011, with a view to introducing legislation in the second session of this Parliament to establish a sustainable legal and financial framework for adult social care.

JOURNAL ARTICLES

The use, role and application of advanced technology in the lives of disabled people in the UK (2010) Jennifer Harris, *Disability & Society* Volume 25, No 4, 427–439

This report examines how advanced technology is used by disabled people in the UK, and in particular, the problems experienced when using it. It also seeks to examine why so many devices are abandoned after a short space of time. The paper seeks to end the silence from disabled people in relation to advance technologies and the situation this silence leads to, in which designers and engineers continue to develop new appliances with little idea of the views of disabled people. In this paper, advanced technologies refer to electronic devices both mainstream and specialist that assist disabled people at home.

The study used in-depth interviews, focus groups and literature reviews to build up a picture of how people use advanced technologies. The study found that disabled people had lots of ideas about new devices or adaptations to existing devices which could make positive changes to people's lives and could be adopted by designers. The study found a range of learning challenges as a result of using technology including:

- Lack of, or poor quality, training
- Difficult to use instructions
- Need to rely on family to make it work.

However, they also found lots of positive learning experiences including access to different types of training, both formal and informal, good on-line instructions, and the value of learning with the family. The study went further to break down the learning issues into pragmatic, manipulation and psychological issues. There were a lot more barriers than enablers here, which shows quite what an obstacle there is to be overcome in adopting new technologies.

Pragmatic barriers included:

- Time
- Patience
- Cost

- Remembering functions
- Linking old devices to new
- Lack of ongoing support.

Manipulation barriers included issues relating to navigating through menus and the different types of controls on appliances.

Psychological issues were substantial and more difficult to overcome and included:

- Fearing own inadequacy
- Embarrassment at computer ignorance
- Fear of damaging device
- Frustration at complexity of the device
- Negative attitudes to technology.

The study went on to look at choice and options, and found that when the device was publically funded then generally the decisions were made by professionals, and the service user had no choice in type of design of the device. This tended to make it more difficult for them to work with the device in question. For those who were buying privately and had greater choice, they were particularly concerned with how to make the right choice amongst many different options and in these cases advice was wanted. In particular, people want their devices to be flexible, that is to be used away from home, or in different places or situations around the home. Generally, those devices that were abandoned were not flexible enough, not user-friendly enough, not adaptable to changing need, or simply superseded by new technology.

Balancing independence and safety: the challenge of supporting older people with dementia and sight loss (2010) Vanessa Lawrence and Joanna Murray, *Age and Ageing*, Volume 39, 476–480

Dementia and sight loss are common in older adults, with both conditions producing a high risk of disability. When combined, care is more complicated, and care professionals have highlighted a lack of evidence on how best to support adults with both conditions. This paper reports on part one of a study that used interviews with people with visual impairment and dementia, their family members and care professionals.

Key points:

- Care professionals are very aware of the lack of guidance on dealing with this issue.
- They are also concerned about the conflict of maintaining safety and minimising risk. This population are potentially at high risk and there are challenges around ensuring independence and good quality of life.
- There was recognition of the need to discuss risk. To find out what the preferences of the individual concerned were and then discuss how that could happen, taking into consideration and discussing risk clearly with the individual and family members.
- Many felt that they might be being over-cautious and that this may be due to being insufficiently skilled to address the complexities of the problem.
- There were different approaches depending on the background of the team, but little overlap between teams. For example, mental health teams did not work with sight impairment teams and there was recognition that this would be beneficial in providing all parties with increased understanding of the individual and their capacities.
- Closer inter-disciplinary working may in turn produce a support system that would maximise the independence of clients and improved joint working would benefit both professionals and service users.

Balancing risk and innovation to improve social work practice (2010) Louise Brown, British Journal of Social Work, Volume 40, 1211–1228

This paper examines innovation within social work practice, what it means, how it works and in particular how to balance innovative practice with the risks involved. The researcher outlines that the UK government is particularly keen on public sector innovation as a way to ensure future services are efficient and effective. There is very little literature, however, on innovations in social work, and few links made between innovations and risk taking.

As innovation involves the adoption and development of new approaches, then risk is inherent in the implementation process. The Audit Commission recognises this and states that it is therefore those departments with a culture of risk taking which are most likely to be the best innovators. In relation to social work, however, this is complicated by the vulnerability of the client group, the lack of incentives to innovate, the regulatory frameworks and the scarce resources. None of these factors create a risk-taking culture and therefore work against innovation. That is not to say that there have not been innovations in social work, and the study outlines four cases of innovative approaches which have got over the risk-taking hurdle, but not without problems.

The study concludes that in order for innovation to continue and to flourish further in social work, the government needs to act to create risk management strategies that address the four complicating factors outlined (vulnerability, lack of incentives, regulatory framework, scarce resources). There is also the need to publish guidance on risk and innovation within social work. There is a strong need to manage risk through a move away from a tick-box culture to one that fosters analytic and intelligent deliberation. Finally, there is a key need to invest in innovation which needs time and financial resources to be developed.

Can the higher risk of disability onset among older people who live alone be alleviated by strong social relations? A longitudinal study of non-disabled men and women (2010) Rikke Lund, Charlotte Juul Nilson and Kirsten Avlund, Age and Ageing, Volume 39, 319–326

This study examines whether the increased risk of disability onset among older people who live alone could possibly be moderated by either higher social participation or by being satisfied with social relations. This hypothesis is based on the evidence that social relations are an important factor in maintaining independence. For example, being married has been shown to be related to be protective against disability onset in both genders, and there is evidence of an association between greater disability and low levels of social participation.

The study is based on secondary analysis of data from a randomised intervention study on preventative home visits. In order to keep the analysis clear from complicating factors, they limited the sample to those with good functional ability. The study was carried out with a baseline and a three year follow-up.

Findings showed the following:

- Men who lived alone, had low levels of social participation or were unhappy with the levels of social participation had a significantly increased odds ratio of disability onset.
- For women, not being satisfied with social participation was significantly associated with disability onset.
- Men who cohabited did not have their disability onset influenced by social participation levels.
- For women, not being satisfied with social participation status was associated with higher disability onset in co-habiting women.
- Generally, men seem to benefit more from spousal support, and women from the support of others.

Integrated Team Working: a literature review (2010) Sian Maslin-Prothero and Amy Bennion, International Journal of Integrated Care, Volume 10

This paper presents the findings of a literature review carried out to inform a research project evaluating two integrated health and social care teams in England. The following main themes and points emerged.

Models of integrated working

It was clear that there are no standard definitions of integrated working, and there are multiple models used. There are two different approaches: stand alone organisations, which provide the integration of health and social services in a new service, and cross-agency integration.

Policy drivers that were key to the success of integrated team working included:

- the need for clear governance arrangements
- successful management of the different cultures and structures in the different agencies
- a shared understanding of the purpose of the joint venture as well as commitment to the venture
- removal of structural constraints through the Health Act (1999)
- effective shared knowledge systems such as shared IT systems
- establishment of new roles to support integrated working.

The prioritisation of these drivers was dependent on staff role, with managers more likely to stress the importance of policy level support, whilst front-line staff looked at the practicalities.

A number of barriers to successful integrated team working were identified:

- Division between health and social care professions
- Organisational pressures
- Unrealistic expectations
- Lack of clarity of purpose
- Failure to reach shared objectives
- Lack of understanding and clarity of others' roles
- Unclear career pathways
- Lack of clarity of management roles and responsibilities.

However, a number of benefits were also identified:

- Increased job satisfaction
- Greater team working and development of a shared culture
- Greater speed of referral
- Better communication and understanding between teams speeds up service delivery and problem solving
- More responsive services (this was backed up by research into service user opinions of integrated services).

A number of factors relating to staff development were also highlighted:

- Some view working in an integrated team as risky in terms of staff development, however this is easily overcome if roles and responsibilities are clearly agreed.
- Staff are often very wary of working in another's culture. Time needs to be spent in fostering a shared culture.
- Managers need to learn how to manage multi-disciplinary teams.
- Specific skills needed to work successfully in integrated teams need to be formally recognised and linked to career progression.

The lifespan and life-cycle of self help groups: a retrospective of groups in Nottingham, UK (2010) Sarah Chaudhary, Mark Avis and Carol Munn-Giddings, Health and Social Care in the Community, Volume 18, Number 4, 346–354

This report is based on the analysis of a practice database held by Self Help Nottingham, an organisation that supports self help groups. The aim of the study was to provide qualitative and descriptive information about the life-cycle of these groups, the problems they face and the issues that are liable to cause closure.

Findings:

- 55% of the groups closed whilst still in development, and the main reason given for these closures was the withdrawal of the key or founding member. The other main reason was 'dwindling numbers'. Other reasons included problems with connecting to external organisations and practical problems, such as finding a venue to meet.
- For established groups, the main reasons for closure were key member withdrawal and declining numbers. Also, in these more established groups, closure could be forced by the unwillingness of other members to take responsibility for the organisation of the group. Established groups also faced problems when links with the external agencies changed.
- Groups lasted between one and 27 years.
- Those least likely to work included those for ex-prisoners, domestic violence, rape and sexual abuse. This may point towards a link between social stigma and non-working self-help groups.
- Physical health groups were most likely to become established than groups addressing social issues or mental health.
- The aims and ways of working differ widely between self-help groups. Many prefer to stay private and limit their membership instead of publicizing widely. In this way, they can retain a commitment to the group's philosophy and ensure those who join are also willing to sign up to their philosophy and approach.
- Literature shows that self-help groups are more widely used by people with higher levels of education and socio-economic status.

Mainstream in-patient mental health care for people with intellectual disabilities: service user, carer and provider experiences (2010) Ben Donner, Robin Mutter and Katrina Scior, Journal of Applied Research in Intellectual Disabilities, Volume 23, 214–225

Government guidelines indicate the use of mainstream mental health services for people with learning disabilities as far as possible, but little is known about the experiences of this group when undergoing in-patient care. This study used interviews with service users, carers and community nurses, to examine experiences, presenting and discussing the results with focus groups.

The first set of findings relate to the use of inpatient care as respite. Service users and carers reported receiving 'good basic care', with service users appreciating the close proximity of support staff. Carers strongly felt benefit to themselves as a result of the respite stay, but were unable to identify any benefit to the service user.

In terms of the inpatient experience, all but one of the service users experienced it as disempowering. There were numerous instances of enforced compliance, with many being unsure as to why they were there in the first place. There was a strong emphasis on compliance to medication regimes, with little explanation, many rigid rules and threats of punishment. Communication and relationships between staff and service users were restricted and constrained in a way that many were not comfortable with.

Almost half the service users felt that the ward was an unsafe place, with multiple threats of violence being experienced, alongside use of illicit drugs and personal theft. They also expressed

how treatment was limited to medication, with little access to talking therapies, and very little to do. Approximately half of the participants felt that they were well informed by staff, and the same number felt that they had been heard. This is not a high proportion, and to most participants was a symptom of their learning difficulty. The participants expressed clearly how their learning difficulties impacted negatively on their experience as staff were not sufficiently trained or experienced with working with people with learning difficulties. This had serious repercussions when service users were insufficiently cared for as they felt that they could not make themselves understood, or they did not receive a proper assessment. There was a widespread assumption that presenting problems were associated with the learning difficulty and not mental health.

Service provider groups recognised that better joint working is needed, yet currently the systems are not in place for this to happen. Existing stressful working practices with limited time, resources and staff mean that insufficient time is available to be given to people with additional or 'complicating' factors such as learning disabilities. One positive point that has emerged from this study, however, is the inclusion of carers in care and the provision of information.

Skills for support: personal assistants and people with learning disabilities (2010) Val Williams, Lisa Ponting, Kerrie Ford and Philippa Rudge, *British Journal of Learning Disabilities*, Volume 38, 59–67

This paper reports on a research project undertaken to study the communication skills of personal assistants (PAs) working with people with learning disabilities. The research project grew out of a first phase of study, a survey, which highlighted that PAs often received no training in how to work with people with learning disabilities. There then followed a set of focus groups to find out what people thought good and bad support looked like. From this emerged the methodology used for this part of the study, wherein fourteen different people were filmed working with their PA. The video was analysed using conversation analysis.

Five main themes emerged: respect, choices, friendliness, giving advice, and support to speak up. These were in effect the outcomes most associated with good support and the analysis then went on to show the main mechanisms used by PAs to make these work. These techniques included:

- Stepping back – physically, as in stepping away so that the person can get on with taking control of something such as making a cup of tea or non-verbally. Not adding something or taking control of the conversation. Being aware of letting the person with the learning disability have their own say.
- Listening and observing – often the PA has to observe when the person they are working with should be making a choice. They need to be aware of what is going on and prompt when needed.
- Body language is very important. Good PAs used a lot of mutual laughter and smiling and were very in tune with the body language of the person they were working with – often following it.
- Time – waiting and giving the person time to respond, think and act is very important.
- Team work – ensuring the person with the learning disability has the information at hand to be able to make team decisions, such as, how to spend a budget.
- Personal relationship. Building up a real relationship meant that conversations could flow normally about everyday things.

Housed Gypsy Travellers, Social Segregation and the Reconstruction of Communities (2010) Margaret Greenfields and David Martin Smith, *Housing Studies*, Volume 25, No 3, 397–412

This paper explores the *accommodation careers* and social adaptations of Gypsies and Travellers living in bricks and mortar accommodation. It has been estimated that there are 300,000 Gypsies

and Travellers living in the UK, with the percentage living in housing being as much as two thirds. Some families have lived in conventional accommodation for several generations. Whilst some have been willing to make the move, for many the move has been forced by lack of suitable sites or suitable alternative accommodation. For many, it is a difficult adjustment to make with the loss of community and the complexities of dealing with living in standard accommodation. Little research has been done into examining these difficulties and this study looked at these experiences through interviews with Travellers and Gypsies.

Cultural identity and the importance of maintaining traditional networks were repeatedly mentioned by participants in the study. Many reported experiencing hostility from new neighbours, and this, mixed with the emphasis on maintaining networks and cultural identity resulted in dependence on traditional kin-based networks and adaptive strategies is reinforced when the move to bricks and mortar accommodation takes place. The strong history of maintaining autonomy and resisting assimilation, coupled with the reinforcement of traditional networks means that attempts to bridge and integrate people from different backgrounds is hindered. Declines in traditional income opportunities and discrimination in the workplace mean that many end up increasingly dependent on welfare support. There is also a link to this lack of work and increase in ill-health for populations traditionally active and outdoors based.

The study goes on to identify traits of cultural discontinuity, that is the description given to the experiences of individuals and communities which have had to abandon their former ways of life. This often manifests itself in low educational attainment, depression, alcoholism, drug abuse and family breakdown. This is more common amongst groups who also suffer racism and discrimination such as that experienced by Traveller and Gypsy communities. The study concludes with the observation that in the absence of real political will to tackle the multiple and deep-rooted discrimination they face, these communities will continue to look to each other for social support, which ultimately helps perpetuate their long-term exclusion from society and negates any interventions to build integrated communities.

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