

RESEARCH AND POLICY UPDATE

ISSUE 63 April 2011

Welcome to the sixty-third 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 sees a focus on journal articles. These are listed below:

- **Making choices about support services: disabled adults' and older people's use of information**
- **Knowledge of mental capacity issues in community teams for adults with learning disabilities**
- **Neighbourhood deprivation, health inequalities and service access by adults with intellectual disabilities: a cross-sectional study**
- **Should we refer for a dementia assessment? A checklist to help know when to be concerned about dementia in Adults with Down Syndrome and other intellectual disabilities**
- **It's all changed: carers' experiences of caring for adults who have Down's syndrome and dementia**
- **Supported employment for persons with mental illness: systematic review of the effectiveness of individual placement and support in the UK**
- **Quality of life: a survey of parents of children/adults with an intellectual disability who are availing of respite care**
- **Personalisation: Perceptions of the Role of Social Work in a World of Brokers and Budgets**
- **Demystifying the process? A multi disciplinary approach to assessing capacity for adults with a learning disability**
- **How long are we able to go on? Issues faced by older family caregivers of adults with disabilities**

Making choices about support services: disabled adults' and older people's use of information (2011) Kate Baxter and Caroline Glendinning, Health and Social Care in the Community, Volume 19 (3) 272-279

Recent government policies aim to increase the amount of choice people have over their health and social care. The intention is that people should have increased ability to input into decisions surrounding their care, however for this to happen requires people to have access to information which best suits their decision-making processes. This qualitative study recruited 50 disabled working age and older adults to explore choice-making. Those recruited were selected due to the fluctuating nature of their care and support needs. Participants were interviewed three times between 2007 and 2009, asked in the first interview to discuss choices recently made and the information needed to make their choices and then to reflect on those choices in the following two interviews.

The interviews were analysed thematically. Findings were presented according to the following themes:

Sources of information: Participants usually used more than one source of information, and there was no evidence that they stuck to particular sources. They liked to cross check information and felt that they could never have too much information.

Older people were less likely to use the internet, but it was a common source for disabled people. Leaflets and pamphlets were a valued source for both groups, but particularly older people. Experiential information from other people or their own experiences were also particularly valued. Verbal information was thought to be difficult to remember.

Discovering the options: A particularly significant finding was that people only found information about services they knew existed. This was especially the case with social care, with many not knowing what services they could use. People either had some idea of service availability due to previous experience, work or contact with others who had used social care, or had no idea at all and only came across social care options by chance.

Weighing up the options: This relates to people's use of information in making decisions. Three key issues emerged: trust, ease of access and timeliness.

Trust: Most respondents spoke about trusted sources of information, especially healthcare professionals with whom they had built up a longstanding relationship, such as the GP. Social care and housing professionals were less trusted, partly because the relationship was not established, but in particular because participants felt that they were not as knowledgeable as information tended to vary between sources. Consistent information was key to trusting the person and the information. Trusted sources were also those who were seen to have no interest in the outcome and to have the best interest of the participant at heart.

Ease of access: this was important to everyone, and particularly problematic for those with fluctuating needs. Those with sudden onset needs had information readily provided, but people with fluctuating needs had to be more active in seeking information. People found information through their personal contacts, and for older people family were particularly instrumental in finding information. The internet was used, but concerns raised about the fact that there was too much information and how to judge the quality of the information.

Timeliness of information: Getting the right information at the right time was particularly important for people with fluctuating support needs. Specialist nurses were particularly important sources of the right information at the right time. Timeliness of information from GPs and hospital services was less satisfactory, with people feeling unable to ask for the information when they needed. Many people also felt they did not want to pester people and so would not ask for information when it was needed.

The research raises three important issues for health and social care practice. Firstly, people with no knowledge of services will have difficulties in finding the right information to make informed choices. If they do not know about services then they cannot find the information; services should consider how they provide information to new and previously unidentified customers. Secondly, trusted relationships are key to ensuring people have the information they need to make choices and these take time to establish. Thirdly, it is difficult for people to get high quality information at the time at which they need it. Accessing the right information at the right moment is a very difficult thing to do. The paper concludes by questioning the appropriateness of placing such an emphasis on choice, when the infrastructure for provision of information is not in place.

Knowledge of mental capacity issues in community teams for adults with learning

disabilities (2011) Paul Willner, Rosemary Jenkins, Paul Rees, Vanessa Griffiths and Elinor John, Journal of Applied Research in Intellectual Disabilities, Volume 24, 159–171

A recent study by the Mental Health Foundation, carried out before the Mental Capacity Act was implemented, found widespread confusion amongst staff about the Act and its implementation, they all felt they needed more training. That study recommended a skills and knowledge audit be carried out, and this report is a first attempt to evaluate the state of knowledge of mental capacity issues among health and social care professionals working with adults with learning disabilities.

This study used structured interviews to discuss three scenarios based on real situations concerning a financial issue, a health issue and a relationships issue. Forty professionals were interviewed from 10 different multidisciplinary community teams for people with learning disabilities.

The study found the following areas in which the knowledge of the professionals in relation to mental capacity issues was lacking:

Identification of capacity issues In the scenarios, the participants were too quick to accept that decisions had been made, and to focus on capacity issues in the outcomes of those decisions. They failed to recognise that the identification of capacity had to be made before the decisions had been made.

Whose responsibility? 15% of participants felt capacity was to be assessed by specialists, rather than it being the responsibility of the professional to make a judgment about their client's capacity.

Reluctance to decide A high number of participants were unable or unwilling to make judgments about the capacity of those in the scenarios presented to them, preferring to ask for specialist input or defer the decision in other ways.

Weighing up severity of disability against complexity of decision Amongst the small proportion of participants who did make a judgment only 17% provided the correct justification. There was a lack of understanding about whether the disability itself is a reason for incapacity.

Assessment of capacity Of those who did not make a judgment fewer than 20% identified the information they would need to make an assessment.

Decision or outcome The participants endorsed the idea that the outcome of the decision needs to be considered, when in fact the MCA stresses the fact that it is the capacity to make the decision that should be considered and not the outcome.

Identification that a best-interests decision is needed There was evidence that participants had problems with accepting best-interest decisions made by the team as a whole. Participants were less likely to accept when a single decision-maker needed to be identified, preferring to stick to team decision-making. Participants were not very good at identifying the most suitable groups to make best-interest decisions in the scenarios given.

The authors conclude by saying that the study raises real concerns about the knowledge of MCA and its use by professionals working with people with learning disabilities. They also note that the two people in the study who had received no MCA training did as well as those who had received training, which points towards the quality and applicability of the training received.

Neighbourhood deprivation, health inequalities and service access by adults with intellectual disabilities: a cross-sectional study (2011) SA Cooper, A McConnachie, LM Allan, C Melville, E Smiley and J Morrison, *Journal of Intellectual Disability Research*, Volume 55, Number 3, 313–323

Studies have shown that adults with intellectual disabilities experience health inequalities and are more likely to live in deprived areas, and this study takes that information further to ask whether the extent of deprivation of the area a person lives in affects their access to services, thus increasing their health inequality.

The study recruited 1,023 participants. They collected information on each individual relating to their use of primary and secondary health services, and through information, information was collected about their family and social supports. The level of deprivation for the area in which each participant lived was assessed using Carstairs scores which relate to information from the Scottish census.

The findings demonstrated that the participants were more likely to live in deprived areas than the general population, and that whilst there was little difference in their use of primary care services, they were significantly less likely to use secondary services. People with learning disabilities living in deprived areas were more likely to be living with family carers, whilst those living in less deprived areas were more likely to be living with paid carer support or in care settings. Overall, however, there was little difference in health inequalities between those people living in areas of deprivation and those who were not.

The study showed that the factors that influence service utilisation by adults with learning disabilities are the response of the carer and the response of the health services. Considering the complex health needs of adults with learning disabilities, it is surprising that the population were not using primary care services more than the general population, and the authors relate this to the reliance on a response from a carer to recognise the health need. This is unlikely to be different depending on levels of deprivation, which may account for the lack of difference. The authors state that there is an added complexity in this study in that it is unsure if adults with learning disabilities are as affected by the deprivation of the area within which they live as the general population. This may be because they are protected from the hardships by other family members, or that they have moved to an area of deprivation from a wealthier area and continue to be supported by family members elsewhere. There is little research done on this, but this study points towards a need to better understand the impacts of area deprivation on adults with learning disabilities.

Should we refer for a dementia assessment? A checklist to help know when to be concerned about dementia in Adults with Down Syndrome and other intellectual disabilities (2011) Sarah Whitwham and Judith McBrien, *British Journal of Learning Disabilities*, Volume 39, 17–21

Recent government policy has pointed towards the need for appropriate dementia services for people with learning disabilities, and good practice guidance has been issued. However, the issue of recognising deterioration in people with learning disabilities is complex, and there is little guidance to address it. This paper reports on a study which aimed to develop and test a checklist that could serve as a prompt to carers and professionals to consider the possibility of dementia in a person with learning disabilities.

To develop the list, the researchers analysed recent reasons given for referrals to dementia services and found the three key themes being mood, memory and behaviour. These three domains were then incorporated into questions asking about any negative change over the last 12 months, with examples given underneath to show what is meant by negative change. Each question has an 0-3 scoring system, with 0 indicating no change and 3, extensive change. There was also space to note any other negative changes.

The first stage in validating the system was to ascertain whether higher scores correlated to diagnosis of dementia. The system was tested with 159 individuals with learning disabilities, 146 of whom had Down Syndrome. After 12 months of collecting the data, 39 people out of the 159 recruited had a diagnosis of dementia, and higher scores on the checklist significantly correlated with the subsequent diagnosis.

Work was then done to establish a cut-off point of scores at which people should be referred for dementia assessment. This cut-off was set at 3, but further investigation found that some people had scored lower than that and still subsequently been diagnosed with dementia. The majority of this group had Down's Syndrome and tended to score on the behaviour question but not the memory or mood one. As a result, the researchers added two questions to the checklist: Are the points gained due to behaviour change? Does the person have Down's Syndrome? If the answer to either question was yes, then the person should be referred. The study then reassessed the data and found that if these two questions had been asked, then the testing would only have missed one diagnosis out of the 39 found.

The authors conclude by saying they feel positive about the applicability of this simple tool which has been thoroughly tested for validity and reliability. They suggest it could be used both as part of a check when professionals have concerns, but also as part of an annual review, thus picking up more quickly on signs of dementia.

It's all changed: carers' experiences of caring for adults who have Down's syndrome and dementia (2011) Katrina McLaughlin and Aled Jones, British Journal of Learning Disabilities, Volume 39, 57-63

Whilst there is quite extensive literature about Down's syndrome and dementia, there is a lack of information about the needs of those who care for people who have Down's syndrome and dementia. The paper reports on an in-depth qualitative study which was undertaken with individuals caring for adults with Down's syndrome at differing stages of dementia. The findings point towards the changing information needs of carers in the pre and post diagnosis stages and the need for specialist health and social care professionals to understand these varying needs. There is also a clear need for health and social care professionals to inform carers about the possibility of dementia for people with Down's syndrome and the signs to look out for. This is particularly important given that many people may not be in regular contact with health or social care professionals when the start to notice changes.

All of the carers in this study were unaware that adults with Down's syndrome could be affected by dementia. They were also unaware of the symptoms of many of the other treatable conditions that can mimic the symptoms of dementia. As many people who have Down's syndrome have

limited communication abilities, they are dependent on the carer to notice when skills have deteriorated and this will not happen if the carer is un-informed as to what may be happening.

Carers frequently mentioned the value of knowing other people who were caring for someone with dementia, but those who were lone carers were less likely to feel that this was possible. The researchers therefore suggest that telephone support groups should be considered by service providers. There was little sense that provision of support to carers was meeting sufficiently the needs of the carers.

Supported employment for persons with mental illness: systematic review of the effectiveness of individual placement and support in the UK (2011) John Heffernan and Paul Pilkington, *Journal of Mental Health*, 1-13

People with mental illness are much more likely to be unemployed than those who do not, with 41% of incapacity benefit claims in 2006 being made to people with a mental illness. This is an important social disability, but is also important because research has shown that access to and maintaining employment is an important component in recovery from mental illness.

In North America, the Individual Placement Support model has been widely used as a vocational support service for people with mental illness, and there is a strong evidence base which is increasing interest in the approach amongst practitioners in the UK. The main principles of IPS include accessing competitive rather than sheltered employment, eligibility for employment based not only on functioning but on choice, support in rapid job search, the integration of vocational services with mental health services, ensuring that client preference is closely considered in the job search, and creating individualised approaches to job support. The mental health teams have vocational specialists working closely with them to help these goals be achieved, and there is ongoing support provided after rapid job search and placement. There is also a fidelity scale to assess how closely the model is being adhered to.

This paper reports on a systematic review carried out to answer the question *What is the evidence of effectiveness of the IPS model of supported employment within the United Kingdom?* The study found that there is currently a small evidence base on the effectiveness of IPS in the UK, however what evidence there is, points towards IPS being more effective than conventional training and vocational rehabilitation in placing people into competitive employment.

There is evidence that IPS can be effective in getting people into non-competitive employment, education and training. This will depend on there being members of community mental health teams who are dedicated to working to the IPS model. The paper concludes by outlining that there is currently limited evidence on what could be an effective way of helping people with mental illness back into employment, and that more evidence is needed.

Quality of life: a survey of parents of children/adults with an intellectual disability who are availing of respite care (2011) Maria Caples and John Sweeney, *British Journal of Learning Disabilities*, 39, 64-72

This study aimed to describe the Quality of Life of parents of children or adults with learning disabilities who are availing of respite care. The purpose of the study was to inform the development of respite care services to examine parental need and preferences for respite care and its impact on Quality of life. The study was based on the Irish experience, but is relevant to the UK, with both countries experiencing a shortfall in respite care when compared to demand.

The study used a questionnaire which was sent to 150 families. The findings point towards families who support each other but receive very little support from external family or friends,

have reduced social lives with parents usually socialising separately. Although the majority of families reported being satisfied with the support they received from disability services, they also identified that they would like more respite, flexibility and on a regular basis. Families reported financial constraints due to one parent (usually the mother) giving up work to be a full-time carer, and there were also social isolation consequences of this. Overall, however, the families felt largely that they had a good quality of life and that respite care was important in maintaining this.

Personalisation: Perceptions of the Role of Social Work in a World of Brokers and Budgets (2011) Janet Leece and David Leece, *British Journal of Social Work*, Volume 41, 204–223

In a world in which personalised support is increasingly the way forward, it has been argued by many that this new approach requires a new type of workforce. This paper reports on the perceptions of 66 disabled people, carers and elders of the role social workers should perform in this *new world*.

The study used a grounded theory approach, opening discussions by posting threads on eighteen online forums. The thread was designed to generate discussion about the future role of social work in a personalised system. In total 153 responses were received from 66 different individuals.

The main themes emerging from the discussion related to power and autonomy, with over half of all respondents questioning the relevance and usefulness of social services and social workers, and a range of comments relating to why social workers are needed when people can *do it for themselves*. In particular, people were overwhelmingly positive about the role of brokers as opposed to social workers in helping them to get the services they need, as brokers are independent of services. Discussions took place around the concerns people had about the professional power of social workers to make decisions, and there was a sense of greater flexibility and personal autonomy with independent brokers. They also expressed how social workers were split between their duties to the service user and their need to safeguard budgets. Social workers being accountable to people other than the service users also seemed problematic to many. Going further, a number of respondents felt that for brokerage to be really effective, it should come from user-led organisations who would be accountable to service users.

The authors conclude by stating that the study points towards the idea that service users may not want a social care workforce with greater levels of professional control, as outlined in the Social Work Task Force document *Building a safe and confident future*. Rather they prefer autonomy and power over support to be in the hands of service users and carers.

Demystifying the process? A multi disciplinary approach to assessing capacity for adults with a learning disability (2011) Rachel Skinner, Chris Joiner and Liz Chesters, *British Journal of Learning Disabilities*, Volume 39, 92–97

Following on from the article earlier in this RPU which outlined the problems faced by professionals in assessing the capacity of adults with learning disabilities, this paper reports on the development of a system that can be used to assess capacity of people with learning disability who were referred for ophthalmic intervention.

The team put together a screening process which would enable them to assess capacity before providing the information leaflet about the ophthalmic intervention, rather than giving the person the leaflet and then assessing their understanding of it afterwards.

Research has shown that the simplifying of information and style of questioning has a significant impact on the outcomes of capacity assessment, and this initial screening was a way of ensuring

that the information provided would facilitate the process. By doing the screening first, the team were then in a position where they could adopt the right approach to discussion with the person in question.

This first screening process included:

- Consideration of the individual's communication capabilities
- Their mental health status
- Their understanding that there is a decision to be made.

This screening enables a lot of information to be gathered about information processing, memory, suggestibility and communication of basic information. Carrying it out is an alternative to either assuming incapacity because of diagnosis or carrying out a lengthy detailed assessment specific to eyes which may be beyond the individual's comprehension.

In the pilot of this system, the majority of people did not get to the second phase, which would involve information provision and explanation. It meant that information could instead be provided that was best suited to the communication and capacity abilities of the individual. The authors conclude by saying that this approach is easily adaptable to other assessment situations.

How long are we able to go on? Issues faced by older family caregivers of adults with disabilities (2011) Karola Dillenberger and Lyn McKerr, British Journal of Learning Disabilities Volume 39, 29-38

This paper reports on a study into the experiences of older parents caring for an adult son or daughter with disabilities in Northern Ireland. Improvements in health and social care mean that increasing numbers of people are carers in their old age, consequently there is a need to understand the particular needs of older care givers. This mixed methods study asked 29 caregivers about their experiences of care giving using semi-structured interviews, the schedules for which were modeled on the Carers' Assessment of Difficulties Index and Carers' Assessment of Managing Index.

Key findings:

- The majority of the participants reported their own health as good or fair, even though many were suffering from various health problems.
- Family support played an important role in caring for their son or daughter for many participants, although some had no other family support. A very small minority would ask friends or neighbours for help.
- Day care and respite appeared to be the biggest help for most participants, but there were challenging in using these services including lapses in general supervision and medical care.
- The vast majority had made no long term plans for the future care of their son or daughter.
- Many worried about future care and about their own health and well-being.
- Most had not discussed the issue with social services, although those that had had found it useful.

The implications for practice from this study is that policy makers and practitioners need to consider the needs of older care givers when making future plans for adults with disabilities, especially with regards to future planning.