

ODI MONTHLY RESEARCH SUMMARY – September 2007

The aim of this monthly summary is to disseminate briefing on newly published disability research according to key ODI themes such as; Young People, Human Rights, Employment, Independent Living and Older People. This summary may not cover all disability related research reports of interest published in the last month. If you feel there is an important report I have missed please forward to me and I will include in the next summary. Previous summaries can be found on the ODI website: <http://www.officefordisability.gov.uk/publications/research/monthly-research.asp>

[**Note** - The views expressed in these reports are not necessarily those held by the ODI or any other Government Department].

Independent Living

Research project on advocacy and autism

Townson, L, Macauley, S, Harkness, E, Docherty, A, Dias, J, Eardley, M and Chapman, R.

Disability and Society, Vol.22, Issue 5, pages 523-536

<http://www.informaworld.com/smpp/content~content=a780900543~db=all~order=pag>
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This article presents the findings of a qualitative research project about the difficulties in accessing advocacy faced by adults labelled as having autism and Asperger's Syndrome in the Northwest of England. It is also an example of partnership working between three organisations. The article examines both the process of team-led (emancipatory) research and the project findings.

Seven main themes emerged throughout the research: late diagnosis and lack of service support; bad experiences with systems of care; feelings of 'not belonging' (identity issues); barriers around communication and sensitivity towards individuals; lack of awareness and access to advocacy and rights; difficulties of 'fitting into' what is already available; and interest in developing knowledge around advocacy. Examination of the main themes pointed to a disturbing link between poor service response, episodes of crisis and mental ill health. The Carlisle People First Research Team is made up of 6 researchers who are labelled as having 'learning difficulties' who work in partnership with one other researcher.

Our lives, our communities: promoting independence and inclusion for people with learning difficulties

Joseph Rowntree Foundation

<http://www.jrf.org.uk/knowledge/findings/socialcare/2124.asp>

This study examines the issue of independence and inclusion for people with learning difficulties. Rather than being led by university researchers, people with learning difficulties research the lives of other people with learning difficulties.

Key findings include:

- Research by people with learning difficulties was often seen as not serious or reliable.
- The more choices were available to people with learning difficulties, the more likely they were to be included in their local communities.
- Some people interviewed did not receive enough support to manage their lives and were left to struggle by themselves.
- Parents were usually the most important people in the lives of those with learning difficulties, but they did not always allow them freedom to make their own decisions.

People who lived in community-based homes had the most choice and freedom but there were still difficulties, such as only going out when staff and transport were available.

People who lived in residential homes and those who lived with their parents found it harder to be independent and to make decisions in their lives.

Most people with learning difficulties who were interviewed did not have full control of their money, but they also thought it important that there was support for people. There were conflicting views about what sort of support this should be.

The impact of the Supporting People programme on adults with learning disabilities

Joseph Rowntree Foundation

<http://www.jrf.org.uk/knowledge/findings/socialcare/2106.asp>

This study explores how the Government's *Supporting People* programme is affecting housing and support for people with learning disabilities in England.

According to the report:

- The Government has only loosely defined 'housing-related support' and this has resulted in significant variation in the type and amount of support available in different areas.
- The introduction of Supporting People appears to have increased the availability of supported living services for people with learning disabilities.

- However, this has often come at the expense of abandoning the principles of supported living so that, in some cases, it is indistinguishable from residential care.
- Interviews with people with learning disabilities showed they were largely in control of choices about their everyday activities, such as what to wear, what to eat or how to spend their time.
- However, the more fundamental choices which framed individual lives – including where to live, who to live with and who to receive support from – were still typically made by service managers or commissioners.
- The analysis of five-year *Supporting People* strategies suggests that administering authorities intend to focus in future on the development of services which offer individual tenancies and low-level floating support to people with learning disabilities.

Employment and Benefits

Mental Health and Employment

The Sainsbury Centre for Medical Health, briefing 33

[http://www.scmh.org.uk/80256FBD004F3555/vWeb/fIKHAL776J7D/\\$file/briefing+33_mental_health_and_employment.pdf](http://www.scmh.org.uk/80256FBD004F3555/vWeb/fIKHAL776J7D/$file/briefing+33_mental_health_and_employment.pdf)

This briefing paper looks at the barriers to employment for people with common and severe mental health problems and at the positive initiatives that are being undertaken by the public, voluntary and commercial sectors to help them find and sustain work. It highlights the importance of employment as part of the recovery from and prevention of mental health problems.

Maintaining standards: promoting equality. Professional regulation within nursing, teaching and social work and disabled people's access to these professions.

Disability Rights Commission

http://www.maintainingstandards.org/files/Summary%20report_final.pdf

The Disability Rights Commission launched a Formal Investigation (FI) in May 2006 looking at the barriers people with impairments and long-term health conditions face in trying to pursue careers in teaching, nursing and social work across Great Britain.

The report into the investigation, *Maintaining Standards: Promoting Equality*, published in September 2007, concluded that they often face barriers to entry and progression throughout large parts of the public sector. It also found that the mass of regulations and guidance which govern health do nothing to protect the public, whilst often deterring people from applying or remaining in these professions.

Outcomes for disabled children

<http://www.york.ac.uk/inst/spru/pubs/rworks/aug2007-02.pdf>

Sloper, P, Rabiee, P and Beresford, B

Social Policy Research Unit (SPRU)

Using the framework of the 'Every Child Matters' five outcomes for children, the research explored which outcomes disabled children and their parents wish to achieve from service provision. The findings from this research were split into two, one summary for the outcomes the disabled children desired and the other the parents' desired outcomes.

The report found that although disabled children aspired to the same sort of outcomes as non-disabled children, the level of achievement expected, the way there were prioritised and what the outcomes meant, differed significantly. Some outcomes, e.g. physical and emotional well-being, communication and safety, were seen as fundamental and needed to be addressed before the others. Sometimes the goal was not progress but maintenance of an existing situation. The conclusion of the research was that there is a need to widen definitions of key concepts within the ECM framework to take into account the views and capabilities of disabled children.

Outcomes for parents with disabled children

Sloper, P, Rabiee, P and Beresford, B

Social Policy Research Unit (SPRU)

<http://www.york.ac.uk/inst/spru/pubs/rworks/aug2007-03.pdf>

The key findings from the parents' report were:

The desired outcomes of parents focused on maintaining or enhancing their personal identity, their physical and emotional well-being and their skill and knowledge base. There is a need for a better balance between their caring and parenting roles. Family level outcomes were also desired: including maintaining family life and ensuring the positive adjustment of siblings. Parents also wanted to feel confident about the services they were using and to know that professionals were working in partnership with them.

Comparing transition expectations of young people with moderate learning disabilities with other vulnerable youth and with their non-disabled counterparts

Caton, S and Kagan C

Disability and Society, Vol. 22, Issue 5, pages 473-488

<http://www.informaworld.com/smpp/content~content=a780900439~db=all~order=pag e>

This article uses data obtained from a study that examined transition experiences of young people with moderate learning disabilities. A comparison is made between those experiences and the experiences of both other vulnerable young people and non-disabled youth. It was found that non-disabled youth experience extended transitions with events that signify adult status taking place well into young people's 20s. On the other hand, vulnerable youth transitions are often (out of necessity) rushed, with young people having to take on responsibility beyond their years. The results of the study claim that for young people with moderate learning disabilities the experiences of transition more closely mirror those of other vulnerable youth than they do the non-disabled population.

Older people

Improving services and support for older people with mental health problems

Age Concern

http://www.ageconcern.org.uk/AgeConcern/Documents/full_report.pdf

The report concludes that the levels of unmet mental health needs amongst older people are extremely high. The facts about mental health problems in later life should generate a sense of urgency and of anger about the lack of attention paid to them.

According to the report one in four people aged 65 and over have symptoms of depression, much of which could be prevented. This demands the development of a public health approach to depression in later life. The majority of older people with mental health problems did not receive services. The report identifies a need to shift attention to them, to ensure that they are supported by loved ones and enabled to care for themselves - by design, not by accident or neglect.

The report calls for action on the mental health problems for which there is strong evidence of what works (such as depression, anxiety, delirium, dementia) and identifies a need to pay more attention to problems that have been invisible to date

but which will become more pressing in the future, such as older people with alcohol and drug misuse problems and people growing older with severe and enduring mental health problems.

Thanks for reading,

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