

NHS Evidence – learning disabilities Evidence Bulletin 035 February 2010



The Learning Disabilities Specialist Collection (LDSC) makes available best current evidence for decision makers supporting people with learning disabilities.

Our New Evidence Bulletin combines the monthly Bulletin and Quarterly Update.

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Welcome to the latest evidence update

Welcome to our new Evidence Bulletin, which combines the monthly Bulletin and Quarterly Update. It includes extended summaries of three articles and a links to published articles by heading. Each Bulletin will be available in pdf format to download and print, as many people have told us that they like this facility.

We have created extended summaries of three recent papers for this month's bulletin, looking at:

- How much did people with learning disabilities participate in research in Canada?
- What are the views of key stakeholders about depression in people with mild intellectual disabilities?
- Chronic pain: Under recognised and undertreated?

Advocacy & Empowerment

How much did people with learning disabilities participate in research in Canada?



This review looked at the issue of participation in research by people with learning disabilities in Canada from 1987 to 2006. The researchers looked at over 500 studies, but found only 21 representative of studies in the population of interest. Nine studies met all inclusion/exclusion criteria and were able to provide sufficient data upon which to make a calculation of participation. Participation varied between 41.8% and 100%. The authors found that participation was higher where investigators direct contacted participants, the data collection was non-invasive and consent was required from substitute decision-makers only. There was no clear trend of increasing or decreasing participation over time.

The authors suggest that poor participation to research jeopardises validity of findings by introducing selection bias or reducing statistical power to answer a question, and that therefore the consideration of participation in research design is essential to ensure issues important to people with learning disabilities are addressed.

Participation in intellectual disability research: a review of 20 years of studies, Cleaver S et al., in Journal of Intellectual Disability Research, 54, 3, 187-193.

Read the LDSC Extended Summary: <http://tinyurl.com/advN0302LDSC>

We also found one single study:

1. **Living 'a life like ours': support workers' accounts of substitute decision-making in residential care homes for adults with intellectual disabilities**, Dunn M et al, in Journal of Intellectual Disability Research 54, 2, 144 – 160.

Link to article: <http://tinyurl.com/advN0301>

- Qualitative, grounded theory analysis of 21 interviews with support workers working in residential care home\ for adults with ID, and observations of care practices.
- Authors argue support workers interpret substitute decision-making within a broad moral account of their care role, orientating their support towards helping residents to live 'a life like ours'. They draw on their own values and life experiences to shape substitute decisions.
- Clear discrepancies are revealed between legal regulation of substitute decision-making and support workers sense of their work.



NHS

Evidence

Mental Health

What are the views of key stakeholders about depression in people with mild intellectual disabilities?



This focus group study in Australia aimed to bring together the perspectives of 64 key stakeholders (people with intellectual disability, healthcare professionals, family/caregivers & support workers) regarding the risk factors and characteristics of depression and to explore the support and service needs of those with intellectual disability/depression and staff or family members who support them.

A range of emotional, social, and behavioural themes were identified across groups regarding signs of depression, although different groups emphasised different aspects of each issue. In addition, common themes emerged across groups including environmental factors and personal features prompting development of depression or indicating an increased likelihood of developing depression.

Personal and social support needs were emphasised by all groups. People with ID also expressed strong feelings regarding importance of '*time off for yourself*' and '*staying home when you want to*'. All groups stated that there were insufficient counselling and mental health services, and where they existed, providers were inadequately trained to work with people with ID. Supporters all emphasised the need for education about and information regarding depression, services and referral options.

The authors stress the need to consider disruptive life events as potential risk factors, and also the need to consider that challenging behaviours may provide an additional indication of depression in people with mild ID. They point out the lack of perceived availability of trained personnel for screening and assessment of depression and for support and interventions and suggest the need for further research into the presentation of depression in and the risk factors in this population, to help develop clearer screening and referral protocols.

Detecting and treating depression in people with mild intellectual disability: the views of key stakeholders, McGillivray J & McCabe P, in British Journal of Learning Disabilities Pages 38, 1, 68 – 76.

Link to LDSC Extended Summary <http://tinyurl.com/mhN0303LDSC>

We also found two single studies:

1. **Service use and cost of mental disorder in older adults with intellectual disability**
Strydom A et al, in The British Journal of Psychiatry 196: 133-138.

Link to article: <http://tinyurl.com/mhN0301>

- Data collected on receipt and costs of accommodation, health and personal care, physical as well as mental illness, dementia, sensory impairment and disability in a representative sample of adults with intellectual disability aged 60 years and older ($n = 212$).
- Average weekly cost (GBP) per older person was £790 (£41 080 per year).
- Accommodation accounted for 74%.
Overall costs highest for those living in congregate settings.
- Gender, ID severity, hearing impairment, physical disorder and mental illness had significant independent relationships with costs.
- Mental illness was associated with an additional weekly cost of £202.
- Older adults with ID comprise 0.15–0.25% of population of England but consume up to 5% of total personal care budget.
- Interventions to meet needs and might prove to be cost-effective should be sought.

2. **The development of a sex offender assessment and treatment service within a community learning disability team (the SHEALD project): mapping and assessing risk**, McBrien J et al, in Tizard Learning Disability Review, 15, 1, 31-43.

Link to article: <http://tinyurl.com/mhN0302>

- Managing risk of sex offending and sexually harmful behaviour presented by some men with ID is enhanced if community services map number in their catchment area, apply appropriate risk assessment and management methods, and implement evidence-based treatment.
- Methods and progress of one community ID service in mapping and assessing the risks is described.

Health

Chronic pain: Under recognised and under treated?



This postal questionnaire survey of 250 carers of people learning disabilities supported by a single organisation set out to look at the nature, prevalence and impact of chronic pain. For the purpose of this study, the authors defined chronic pain as pain experienced most days for a minimum of 6 months. 157 responses were received, which is a response rate of 63%

Carers reported chronic pain in 13% of the sample ($n = 21$). 6.3% had pain in two sites and 2% had pain in three or more sites. For 19 of those with pain, carers reported this as mild chronic pain, while severe pain was reported for two service users.

Pain was more prevalent in those with a mild learning disability than in those with more severe disability. The authors suggest this might be a reflection of the ability of those with mild disabilities to communicate their discomfort. Many people were receiving no treatment at all for their pain. Where treatment was in evidence it tended to be non-prescription painkillers such as paracetamol and brufen. The authors also point to the notable absence of involvement of specialist pain services.

The authors conclude that despite the small sample size, their findings suggest that pain in the learning disability population may be under-recognised and under-treated, and that this might be especially true in the case of those with more severe disabilities who may have impaired capacity to communicate about their pain.

Chronic pain in people with an intellectual disability: under-recognised and under-treated? McGuire B et al, in Journal of Intellectual Disability Research, 54, 3, 240-245.

Read the LDSC Extended Summary: <http://tinyurl.com/hlthN0302LDSC>

We also found one review this month:

1. **Dysphagia: the challenge of managing eating and drinking difficulties in children and adults who have learning disabilities**, Harding C & Wright J, in Tizard Learning Disability Review, 15, 1, 4-13.

Link to article: <http://tinyurl.com/hlthN0301>

- Review of literature identifying key issues relevant to children and adults who have dysphagia, or eating, drinking and swallowing difficulties and a learning disability.
- Methods for attempting to identify this area of difficulty effectively are explored and other issues that affecting management are discussed, e.g. carer support and training and use of appropriate



communication strategies to support and enable participation from the client with learning disability.

Communication

We found one single study this month

1. **Social perception in children with intellectual disabilities: the interpretation of benign and hostile intentions**, Leffert J et al., in Journal of Intellectual Disability Research, 54, 2, 168-180.

Link to article: <http://tinyurl.com/commN0301>

- 58 children with ID and 189 children without ID viewed 13 vignettes where social cues accompanied a negative event to provide information about intentions of the character causing the event. Questions designed to assess aspects of social perception were then asked.
- Three situations were portrayed representing types of situations posing conflicting information:
 - (1) conflict between negative event and social cues, which conveyed benign intentions;
 - (2) presence of conflicting social cues that conveyed insincere benign intentions;
 - (3) additional items examining effect of salience of negative event and cues on accurate interpretation of benign intentions
- Children with ID had lower interpretation accuracy than children without ID for all three social situations. Children with ID had difficulty interpreting benign intentions when negative event was made salient.
- Authors conclude that presence of conflicting information poses cognitive processing challenges in a variety of social situations, making it difficult for children with ID to arrive at accurate interpretations and that children with ID were less likely than children without ID to interpret intentions accurately.

Vulnerable Adults & Abuse

We found one study this month:

1. **Targeted violence, harassment and abuse against people with learning disabilities in Great Britain**, Chih Hoong Sin et al, in Tizard Learning Disability Review, 15, 1, 17-27.

Link to article: <http://tinyurl.com/vabN0301>

- Fear and experience of violence, harassment and abuse of those with learning disabilities are significant barriers to full social inclusion.
- Findings from extensive review of literature looking into disabled people's experiences of targeted violence, harassment and abuse are presented.
- Findings suggests people with learning disabilities and/or mental health conditions are at higher risk, and experience greater levels, of violence, harassment and abuse, not only than non-disabled people but also than other disabled people.
- Situational vulnerabilities mean probability and experience of violence, harassment and abuse are not due any inherent characteristics of those with learning disabilities.
- Under-reporting and lack of appropriate response and support from criminal justice agencies compromise access to justice.
- People with learning disabilities are found to have propensity to report to third parties instead of to criminal justice agencies.
- Lack of joined-up working in various agencies hampers efforts at redress.
- There are particular concerns over a vacuum of responsibility as a result of confusion about the [No Secrets guidance](#).

Invitation to User Group Meeting



We would like to invite you to the first meeting of the NHS Evidence learning disabilities user group, which will take place in Oxford during the afternoon of 28th May 2010. We will be presenting information about the aims and objectives of the collection, but more importantly taking the opportunity to get your input on your information needs, and views about the future of the site, so that we can improve the service we provide and make it more relevant to your needs.

If you would like to attend, get in touch with sally.jordan@minervation.com.

In order to help our venue planning, we need to hear from you by Wednesday 31st March.

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