



NHS Evidence – learning disabilities Evidence Bulletin 041 August 2010



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Welcome to the latest evidence update

Welcome to the Evidence Bulletin. This month our extended summaries focus on support to people with visual impairment and understanding and responding to pain. We also highlight published studies from almost 40 journals under the collection's headings for you to browse and explore further at source if you wish.

Health



What was the impact of a special visual assessment service for people with learning disabilities?

This study reflected the work of the Special Visual Assessment Clinic (SVAC), an optometry led multi professional service delivered in a Resource Centre in Belfast, Northern Ireland. The study looked at the impact of corrective eye treatment for people referred to the service. The service carried out visual assessments and in addition attempted to design a questionnaire that could be used to look at the impact of improved vision on the quality of life of those assessed and treated.

The study findings suggest that prior to the SVAC taking place there was limited awareness of vision related problems amongst all these groups. Following the assessment of the team and corrective treatment (mainly the provision of glasses), there was a heightened awareness of visual needs and of the benefits of eye examinations which included some tentative links to quality of life.

The authors suggest however that perhaps a shorter and more accessible checklist or aide memoire would facilitate people with a learning disability, carers and staff in identifying triggers that might suggest a problem of a visual nature.

Making a difference. Visual health needs of people with a learning disability, McGlade A et al., in British Journal of Learning Disabilities 38, 3, 187–193,

Extended Summary: <http://tinyurl.com/es4101>



How do staff in residential services recognise and manage pain in people with learning disabilities?

This audit looks at responses to pain in people with learning disabilities living in residential or supported living services in Surrey. The authors investigated staff beliefs around pain thresholds and what strategies they adopted to recognise and manage pain. 56 staff were interviewed using a structured schedule looking at beliefs, some of which were tested against reality of practice.

The results show that pain is not being effectively recognised or managed by staff, and highlighted the need for training, as well as the need for appropriate pain recognition tools and communication aids to be used.

The audit looked at nine standards relating to the identification and management of pain, identified from the literature were reached. The audit found that 6 standards were not met at all, three were met in part, but none were fully met. The authors suggest their findings highlight the poor responses to pain in residential



services in the area. People rarely got offered pain medication or any other strategy and even when pain was recognised, medication was rarely given more than once.

Pain in people with learning disabilities in residential settings – the need for change, Beacroft M & Dodd K, in British Journal of Learning Disabilities 38, 3, 201–209

Extended Summary: <http://tinyurl.com/es4102>

- 3. Nursing Perspectives on Cancer Screening in Adults With Intellectual and Other Developmental Disabilities**, Tyler C et al., in Intellectual and Developmental Disabilities 48,. 4, 271-277.

Link to article: <http://tinyurl.com/hlth4101>

- Developmental disabilities nurses were surveyed to better understand and improve healthcare disparities documented in cancer screenings of adults with intellectual and other developmental disabilities.
- Two thirds of respondents believed that adults with intellectual and developmental disabilities received fewer cancer screenings compared with general population.
- Most frequently cited barriers to cancer screenings were:
 - patient need for sedation,
 - unsuccessful attempts at screening,
 - failure of primary care clinician to order cancer screening tests.
- Nurses observed health care providers frequently did not tailor cancer screening recommendations to individuals' family histories, life expectancies, or their disability-specific cancer risks.
- Authors suggest interventions to improve cancer screening centered around education and training, accessibility, financing–insurance, modification of procedures, and patient tracking.

Autism

Single Studies

- 1. Prevalence of autism in an urban population of adults with severe intellectual disabilities – a preliminary study**. Saemundsen, E. et al., in Journal of Intellectual Disability Research, 54, 8, 727–735

Link to article: <http://tinyurl.com/aut4101>

- Participants ($n = 256$) recruited through Regional Office for the Affairs of the Handicapped in Reykjavik using a screening tool for autism, the Childhood Autism Rating Scale and the Autism Diagnostic Interview-Revised (ADI-R).
- Point prevalence of severe ID was 3.7/1000, male–female ratio of 1.2:1.
- Participation rate in study was 46.5%.
- Participants were younger than non-participants and more often residents of group homes.
- Prevalence of autism was 21%, male–female ratio of 1.8:1.
- Of individuals with autism, 40% were verbal and 72% had active epilepsy and/or other neurological conditions and handicaps.
- Study identified twice the number of autism cases than previously recognised within Icelandic service system. Authors suggest estimated prevalence of autism found should be considered minimal.



- 2. Long-Term Safety and Adverse Events of Risperidone in Children, Adolescents, and Adults With Pervasive Developmental Disorders**, Hellings J et al., in Journal of Mental Health Research in Intellectual Disabilities, 3, 3, 132-144

Link to article: <http://tinyurl.com/aut4102>

- Long-term adverse events of risperidone were examined in 19 children, adolescents, and adults with Pervasive Developmental Disorders and intellectual disability, continuing risperidone for a mean of 186.5 weeks, following a 46-week risperidone study.
- 19 individuals continued long-term follow-up after risperidone placebo-crossover acute study (22 weeks) and 24-week maintenance phase on 40 participants.
- Long-term ratings included Dyskinesia Identification Systems Condensed User Scale and Neuroleptic Side Effects Checklist. Weight and prolactin levels also measured.
- Range of significant neurological side effects occurred:
 - akathisia in 10%,
 - 2 individuals developed tardive dyskinesia,
 - 1 developed oculogyric crisis;
 - withdrawal dyskinesia occurred in 2 of 9 individuals discontinuing risperidone.
- All 10 children and adolescents continued > 7% weight gain. Adults gained less weight, but 2 developed Type 2 diabetes.
- Prolactin (PRL) elevation continued in all 7 patients with PRL measures but normalized in 2 individuals after aripiprazole addition.
- Movement side effects were significant.
- Children and adolescents continued > 7% weight gain; PRL elevation continued.

Challenging Behaviour

Single Studies

- 1. Effects of Symptoms of Comorbid Psychopathology on Challenging Behaviors Among Atypically Developing Infants and Toddlers as Assessed With the Baby and Infant Screening for Children With Autism Traits (BISCUIT)**, Matson J et al., in Journal of Mental Health Research in Intellectual Disabilities, 3, 3, 164-176

Link to article: <http://tinyurl.com/cb04101>

- Individuals from 17 to 36 months of age with varying diagnoses (intellectual disability, developmental delay, and Down syndrome) were evaluated.
- Greater levels of symptoms of co-morbid psychopathology were related to higher rates of challenging behaviours.
- Inattention/Impulsivity, Avoidant Behaviour, Anxiety/Repetitive Behaviours, and Tantrum/Conduct Problems were significantly related to high rates of Aggressive and Destructive Behaviours, Stereotypies, and Self-Injurious Behaviour.
- Those displaying greater levels of Eating/Sleep Problems engaged in more Aggressive and Destructive Behaviours and Stereotypies but not Self-Injurious Behaviour.
- Authors conclude that even at young ages, children with atypical development without an autism spectrum disorder diagnosis are at high risk for a variety of problem behaviours and disorders that may be related to one another.



2. **The evaluation of periodic service review (PSR) as a practice leadership tool in services for people with intellectual disabilities and challenging behaviour**, Lowe K et al., in Tizard Learning Disability Review, 15, 3, 17-28

Link to article: <http://tinyurl.com/cb04102>

- A system of evidence-based periodic service review (PSR) was implemented in specialist health services for people with challenging behaviour, to support the adoption of a positive behavioural approach.
- Extent and accuracy of PSR implementation, its impact on staff knowledge and attitudes, and its value as a practice leadership tool were assessed.
- Results indicated PSR was implemented regularly, and scoring was based accurately on tangible evidence, and increased scores over time indicated service improvement in line with PSR principles.
- Staff generally welcomed PSR as a quality monitoring tool, and greater knowledge of rationale and process for PSR was associated with more positive attitudes.
- Managers regarded PSR as a valuable aid to practice leadership and had used innovative implementation methods to maximise its acceptance by staff teams.

Communication

Single Studies

1. **Describing dialogue between persons with profound intellectual and multiple disabilities and direct support staff using the scale for dialogical meaning making**. Hostyn, I. Et al., in Journal of Intellectual Disability Research, 54, 8, 679–690.

Link to article: <http://tinyurl.com/comm4101>

- Eighteen videotaped observations of persons with profound intellectual and multiple disabilities and their support staff were coded using the S-DMM and a consensus-rating procedure.
- Quantitative scores and qualitative arguments the ratings, demonstrate how the S-DMM aids to significantly describe staff–client dialogue.
- Authors conclude that using the S-DMM to describe dialogue with persons with profound intellectual and multiple disabilities appears to be promising. They discuss the value of the S-DMM with regard to implications for research and practice.

2. **Social reasoning skills in adults with Down syndrome: the role of language, executive functions and socio-emotional behaviour**, Hippolyte, L. et al., in Journal of Intellectual Disability Research, 54, 8, 714–726

Link to article: <http://tinyurl.com/comm4102>

- Investigation of the ability to understand appropriateness of others' social behaviour in 34 adults with DS, using the Social Resolution Task (SRT). Results compared with those of 34 typically developing (TD) children matched for gender and receptive vocabulary.
- Relationships among SRT experimental task, cognitive competences (receptive and productive vocabulary, non-verbal reasoning, inhibition, selective attention) and caregiver-rated measure of socio-emotional behaviour were examined in the DS group.
- DS participants' global SRT scores did not differ from those of the controls.
- Analyses of SRT sub-scores revealed DS group identified significantly fewer inappropriate situations than control group. When they correctly identified behaviour as inappropriate, they were able to explain the rules underlying their responses as well as the controls
- Regression analyses showed receptive vocabulary and selective attention and specific dimension of socio-emotional profile (social relating skills) constituted best predictors of DS adults' performance on the SRT.
- Authors conclude that DS participants demonstrate relatively good social reasoning skills in comparison with TD children matched for verbal age.



Mental Health

Single Studies

1. **Profiles of Patients With Intellectual Disability and Mental Illness in Specialized and Generic Units in an Ontario Psychiatric Hospital**, White S et al., in, Journal of Mental Health Research in Intellectual Disabilities, 3, 3, 117-131

Link to article: <http://tinyurl.com/mh04101>

- Study compared the profile of patients with ID served in a specialized unit ($n = 40$) to those in generic units ($n = 141$) within one psychiatric teaching hospital in Ontario.
- Hypothesis was that specialized patients would differ in terms of psychiatric diagnoses, service needs, overall level of functioning, and length of stay when compared with their counterparts in generic units.
- Retrospective review of select data from Resident Assessment Instrument-Mental Health (RAI-MH) and Global Assessment of Functioning (GAF) was conducted for patients with ID discharged from all units of hospital from 2006 to mid-2009.
- Though patients were demographically similar, those in specialized unit stayed in hospital longer than generic patients.
- Differences in psychiatric diagnoses, reasons for referral, overall functioning, and medication use were also found.

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