



NHS Evidence – learning disabilities Evidence Bulletin 039 June 2010



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Welcome to the latest evidence update

Welcome to the Evidence Bulletin. This month in our extended summaries we report on a meta-analysis of interventions in challenging behaviour and an RCT in health interventions in community settings. 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.

Challenging Behaviour



What are the effects of biological, psychotherapeutic and contextual interventions used to treat challenging behaviour in people with learning disabilities?

The authors of this meta-analysis set out to explore the effects of treatments described in the published literature between 2000 and 2008. A search of *ERIC*, *PsycINFO*, *Web of Science* and *Medline* identified eighty potential articles, from which 30 contained sufficient data to enable statistical meta-analysis. Eighteen of the studies described biological interventions, 13 psychotherapeutic and nine

contextual interventions. These interventions were either applied alone (unimodal) or combined with others (multimodal).

The meta analysis found an overall standardised mean difference of 0.671 which following a sensitivity analysis, the effect size was to be robust. They also carried out a funnel plot-, a fail-safe N-, and Duval's and Tweedie's trim and fill-analysis, and concluded from this that the meta-analysis did not suffer from publication bias effects.

They conclude that there are therefore several biological, psychotherapeutic and contextual interventions which effectively reduce challenging behaviours among persons with learning disabilities and suggest further research should focus on working mechanisms of successful interventions.

A meta-analysis of intervention effects on challenging behaviour among persons with intellectual disabilities, Heyvaert M et al., in *Journal of Intellectual Disability Research* 54, 7, 634 – 649

Link to extended summary: <http://tinyurl.com/cb39es1>

Single studies

1. **Facing the commissioning challenge: responding effectively to people whose behaviour is challenging**, Bering S, in *Advances in Mental Health and Intellectual Disabilities*, 4, 2, 4-12

Link to full text: <http://tinyurl.com/cb39001>

- Description of commissioning for better health and care outcomes for people by ensuring needs and wishes are well understood, the market managed, and a range of local supports and provision available at a reasonable price.
- The author aims to demystify the 'commissioning' role, and highlights the case for change in current practice, exploring some of the key barriers that must be addressed and suggesting ways to achieve better outcomes.



- 2. Outcome measurement for people with intellectual disability who present challenging behaviour**, Baker, P & Daynes S, in Advances in Mental Health and Intellectual Disabilities, 4, 2 13-19

Link to article: <http://tinyurl.com/cb39002>

- Health service interventions for people with challenging behaviour should be routinely monitored and evaluated in order to be maximally effective.
- In addition to monitoring frequency, duration and severity of behaviour attention should be given to monitoring impacts on quality of life of the individual and those with whom they share their environments.
- The authors conclude the need for a battery of measures to identify valid acceptable outcomes.

- 3. Implementing interventions for an individual with complex needs through a co-ordinated approach**, Parris A, in Advances in Mental Health and Intellectual Disabilities, 4, 2, 33-37

Link to article: <http://tinyurl.com/cb39003>

- Case study of a young man with severe intellectual disability and autism engaged in high-frequency self-injurious behaviour.
- Review of input from local Learning Disabilities Team, particularly from behaviour support service.
- Input concentrated on co-ordination of care, as part of care programme approach (CPA).

Mental Health

Reviews

- 1. Dementia in Older Adults With Intellectual Disabilities—Epidemiology, Presentation, and Diagnosis**, Strydom A et al., in Journal of Policy and Practice in Intellectual Disabilities, 7, 2, 96-110

Link to article: <http://tinyurl.com/mh39001>

- Comprehensive review of published literature from 1997–2008 with a specific focus on
 - (1) epidemiology of dementia in ID in general as well as in specific genetic syndromes
 - (2) presentation
 - (3) diagnostic criteria for dementia
- Varied methodologies and inherent challenges in diagnosis yield a wide range of reported prevalence rates of dementia.
- Rates of dementia in population with ID (not Down syndrome) are comparable with or higher than general population.
- Alzheimer's disease onset in Down Syndrome appears earlier and prevalence increases from under 10% in the 40s to more than 30% in the 50s, with varying prevalence reported for those 60 and older.
- Incidence rates increase with age.
- Few studies of dementia in other genetic syndromes were identified.
- Presentation differs in ID population compared with general population
- Authors recommend large-scale collaborative studies of high quality research to further knowledge on epidemiology and clinical presentation of dementia in this population.



Single studies

1. **The association between self-report and informant reports of emotional problems in a high secure intellectual disability sample**, Lewis C & Morrissey C, in Advances in Mental Health and Intellectual Disabilities, 4, 2, 44-49

Link to article: <http://tinyurl.com/mh39002>

- Study exploring relationship between self and informant reports of emotional problems in a forensic ID sample.
- Emotional Problems Scales (EPS) and informant Behaviour Rating Scale (EPS-BRS) routinely administered to 30 individuals with ID in a secure forensic setting.
- There were no significant relationships between corresponding scales of EPS-SRI and EPS-BRS, apart from EPS-SRI and EPS-BRS scales measuring anxiety.
- Results continued to be non-significant, even when positive impression management was controlled.
- Authors conclude findings suggest little relationship between self and informant ratings in a forensic ID sample, and support the need to gather information from multiple sources when assessing such individuals.

2. **Staying in the here-and-now: A pilot study on the use of dialectical behaviour therapy group skills training for forensic clients with intellectual disability**, Sakdalan J et al., in Journal of Intellectual Disability Research, 54, 6, 568-572

Link to article: <http://tinyurl.com/mh39003>

- Pilot study to evaluate effectiveness of DBT group skills training programme adapted for offenders with ID.
- Six participants completed 13-week adapted DBT group skills training programme.
- All participants exhibited challenging behaviours and have history of prior charges or convictions for violent crimes.
- Study conducted pre- and post-tests using instruments measuring dynamic risks, relative strengths, coping skills and global functioning.
- Results showed improvement across all measures. A decrease in the level of risks, increase in relative strengths and general improvement in overall functioning were found to be significant.
- Authors conclude that results were promising for a stand-alone adapted DBT group skills training programme for this client group.

3. **Staff Perceptions of Essential Prerequisites Underpinning End-of-Life Care for Persons With Intellectual Disability and Advanced Dementia**, McCarron M et al., in Journal of Policy and Practice in Intellectual Disabilities, 7, 2, 143-152

Link to article: <http://tinyurl.com/mh39004>

- Work undertaken to understand perspectives of agency staff in ID services and specialist palliative care fields.
- Qualitative descriptive design composed of 13 focus group interviews involving 50 participants drawn from six ID service providers and seven participants from one specialist palliative care service.
- Thematic analysis identified two core themes: building upon services' history and personal caring—offering quality and sensitive care, and supporting comfort and optimal death in persons with ID and advanced dementia.
- Challenges raised for service systems in areas of aging in place, person-centred care and inter-service collaboration.
- Authors recommend more practice relationship-based and collaborative approaches to care and stronger evidence-based research program on timing and the efficacy of palliative care for persons with ID and dementia.



Person Centred Services

Reviews

1. **Supported Accommodation for People With Intellectual Disabilities and Quality of Life: An Overview**, Noonan Walsh P et al., in Journal of Policy and Practice in Intellectual Disabilities, 7, 2, 137-142

Link to article: <http://tinyurl.com/pcs39001>

- Review of evidence from research published between 1995 and 2005 in English-language peer-reviewed academic journals related to quality of life in models of supported accommodation for adults with intellectual disabilities identified in English-speaking nation deinstitutionalization and post-deinstitutionalization studies.
- Areas examined:
 - To review outcome of deinstitutionalization and post-institutionalization studies
 - To examine instruments used to measure outcomes for individuals
 - To compare costs and benefits associated with different models of supported accommodation
- In deinstitutionalization studies, consistent evidence found of greater choice and self-determination, participation in social networks or relationships and community-based activities, and personal satisfaction in community-based settings.
- Post-deinstitutionalization studies provided consistent evidence for greater choice, self-determination, and participation in community-based activities in smaller settings, but no evidence for greater physical health or material well-being, and little evidence for a relationship between type of setting and employment.
- Authors conclude future research needed to meet methodological challenges, to investigate apparent failure of smaller residences to improve residents' well-being and to study systematically factors not directly addressed in studies under review: e.g. poverty and income, organizational culture, and geographical variation.

Health



Which health assessment tools improved healthcare in people with learning disabilities living in community settings?

Many studies have shown that people with learning disabilities in community settings are much more likely to have poor health and healthcare support. This is for a variety of reasons, but includes poor communication, recall difficulties and incomplete patient health information. This cluster randomized-controlled trial was conducted with adults with learning disability to investigate two interventions used to enhance interactions among adults with learning disability, their care providers and general practitioners (GPs). The two interventions described in the

study are the Comprehensive Health Assessment Program (CHAP), and the Ask health diary, designed for ongoing use. The study team followed up participants 12 months post-intervention. Evidence of health promotion, disease prevention and case-finding activities were extracted from GPs clinical records.

The study found increased health promotion, disease prevention and case-finding activity were in the intervention groups using the CHAP. This health review tool had a positive impact on *Pneumococcus* vaccination, hearing testing, Hepatitis A vaccinations, vision testing, and weight measurement.

However, the study found no significant strong changes in the measured outcomes in the group who used the Ask health diary alone.



The authors conclude that the use of the CHAP instrument can increase health promotion, disease prevention and case-finding activity in adults with learning disability living in community settings. They suggest their findings confirm previously demonstrated benefits of the CHAP tool, and that its use could be extended to less formal residential settings.

Cluster Randomized-Controlled Trial of Interventions to Improve Health for Adults with Intellectual Disability Who Live in Private Dwellings, Lennox N et al, in Journal of Applied Research in Intellectual Disabilities, 23, 4, 303-311

Link to extended summary: <http://tinyurl.com/hlth39es1>

Single studies

1. Loss of response to melatonin treatment is associated with slow melatonin metabolism

Braam W et al, in Journal of Intellectual Disability Research, 54, 6, 547-555

Link to article: <http://tinyurl.com/hlth39001>

- Determination of Melatonin clearance in two female (aged 61 and 6 years) and one male (aged 3 years) patients with chronic insomnia, late melatonin onset and mild ID.
- Sleep quality for all participants worsened few weeks after initial good response to melatonin treatment, suggesting melatonin tolerance.
- Following 3-week washout period, patients received melatonin 1.0, 0.5 or 0.1 mg, respectively.
- Salivary melatonin level measured before melatonin administration, and 2 and 4 h thereafter.
- After melatonin clearance test, treatment was resumed with considerably lower dose.
- For all patients melatonin concentrations remained >50 pg/mL at 2 and 4 h after melatonin administration.
- After melatonin treatment sleep problems disappeared.
- Same procedure followed in three patients who did not show loss of response to melatonin after 6 months of treatment.
- In all patients in control group melatonin concentrations decreased between 2 and 4 h after melatonin administration with a mean of 83%.
- Authors hypothesise loss of response to melatonin treatment can be caused by slow metabolisation of exogenous melatonin.
- In patients with loss of response to melatonin, melatonin clearance test should be considered and considerable dose reduction is advised.

2. Evaluation of Community-Based Health Promotion Programs for Special Olympics Athletes,

Marks B et al, in Journal of Policy and Practice in Intellectual Disabilities, 7, 2, 119-129

Link to article: <http://tinyurl.com/hlth39002>

- Health screenings conducted during Special Olympics competitions and games have consistently shown that a significant number of athletes with intellectual disabilities (IDs) were overweight or obese, and surveys have indicated that athletes need more fitness training than they receive from their sport practices.
- In 2002, Special Olympics initiated five community-based health promotion pilot projects for athletes aimed at improving physical fitness and lifestyle behaviours.
- Evaluation of the program and predictors of program success carried out with 56 athletes with ID participating in five programs.
- Data drawn from interviews with participants; 54 coaches, residential staff and parents at baseline and after the program completion. Five program directors were interviewed after program completion.
- Positive psychosocial and health benefits included
 - improved perceived health
 - reduced body weight
 - increased fibre intake,
 - improved self-confidence
 - more positive attitudes toward exercise



- decreased barriers to exercising
- Themes emerging related to implementing health promotion programs and carers ensuring ongoing support.
- Authors conclude that results support need to broaden health promotion programs to more community-based settings.

Supporting Family Carers

Single studies

1. **Early childhood predictors of mothers' and fathers' relationships with adolescents with developmental disabilities**, Mitchell D & Hauser-Cram P, in Journal of Intellectual Disability Research 54, 6, 487 – 500

Link to article: <http://tinyurl.com/sfc39001>

- Study focused on relationships of 72 mothers and 53 fathers with their 15-year-old teens with developmental disabilities and their predictors from early childhood years.
- Data collected from parents through interviews and self-administered questionnaires and from their children with disabilities through structured assessment at age 3 and 15.
- Mother–teen and father–teen relationships were predicted by earlier parenting stress.
- Father–teen relationship also predicted by early behaviour problems (mediated by parenting stress).
- Socio-economic status, type of disability and child's level of functioning not predictive of later relationships between parents and teens.
- Authors conclude that findings suggest two points of potential intervention during early intervention years - parenting assistance and support to reduce stress during early childhood years can benefit both mothers and fathers and helping families and children cope with and diminish problem behaviours could yield multiple advantages for parents and children and deserves emphasis in early intervention and pre-school programmes.

2. **Maternal responses to child frustration and requests for help in dyads with fragile X syndrome**, Wheeler A et al., in Journal of Intellectual Disability Research, 54, 6, 501 - 515

Link to article: <http://tinyurl.com/sfc39002>

- 46 mother–child dyads, in which child had full-mutation FXS, were observed in their homes during a task designed to elicit frustration in the child.
- Each child given a wrong set of keys and asked to open a box to retrieve a desired toy.
- Mothers provided with correct set of keys and instructed to intervene when they perceived their child was getting too frustrated.
- Almost all mothers intervened to help their children and most used encouraging/directing behaviours.
- Few used comforting or negative control.
- Child age and child behaviours during frustrating event were significant predictors of encouraging/directing behaviours in mothers.
- Children whose mothers reported higher depressive symptomology used fewer requests for help, and mothers of children with more autistic behaviours used more negative control.
- Authors conclude results suggest child age and immediate behaviours are more strongly related to maternal responsiveness than maternal traits such as depression and stress.



Autism

Single studies

1. **A parent training model for toilet training children with autism**, Kroeger K & Sorensen R in Journal of Intellectual Disability Research, 54, 6, 556-567

Link to article: <http://tinyurl.com/aut39001>

- Multiple baseline across subjects study.
- Two boys diagnosed with autism were toilet trained using modified Azrin & Foxx intensive teaching protocol.
- First subject, - 4-year-old boy, no history of attempted toilet training.
- Second subject - 6-year-old boy, history of failed toilet training in home and school.
- Training conducted in home setting where novel parent-training approach was implemented.
- Participant 1 was continent at end of second day of training, and completely toilet trained by day 10 of intervention.
- Participant 2 was continent after day 1 and completely toilet trained by day 5 of the intervention.

Day Services & Employment

Single studies

1. **A Comparative Study of the Situation of Supported Employment in Europe**, Beyer S et al, in Journal of Policy and Practice in Intellectual Disabilities, 7, 2, 130-136

Link to article: <http://tinyurl.com/dsemp39001>

- Agencies offering supported employment (SE) in European Union (EU) surveyed using Web-based questionnaire.
- 184 organizations responded (Finland, Spain, and UK).
- Majority of respondents offered wide range of services - 83% offered SE.
- Data showed organizations offering services in addition to SE (e.g., vocational training or sheltered work provision).
- Significant variation found in provision of key elements of SE, particularly workplace support.
- Funding varied across areas - 22% overall reliant on short-term European funding.
- Authors conclude that funding for SE is fragile and variations in model used may disadvantage people with more severe ID.
- Fewer hours worked in UK than elsewhere suggest lack of harmonization of welfare benefit legislation across EU.

Learning Disability Policy

Single studies

1. **Placement, relocation and end of life issues in aging adults with and without Down's syndrome: a retrospective study**, Patti P et al., in Journal of Intellectual Disability Research, 54, 6, 538-546

Link to article: <http://tinyurl.com/ldp39001>

- Retrospective study of adults with ID born prior to 1946 conducted to analyse number of relocations experienced over a 5- and 10-year period.
- Cohort consisted of 140 individuals (61 with DS between aged 50–71, and 79 without DS aged ages 57–89) who had been referred to a diagnostic and research clinic.



- Analyses revealed number of relocations over a 5 and 10 year period were significantly greater in the DS group.
- Placement in nursing home for end of life care was significantly higher in DS group.
- Majority (90%) in non-DS group remained in group home setting.
- Mortality was significantly earlier in DS group with mean age at death 61.4 years compared with 73.2 years in non-DS group.
- Authors suggest that aging adults with DS encounter more relocation's and are more likely to have their final placement for end of life care in a nursing home.

Centre for Health Service Research in Intellectual Disabilities

University College London are launching a new Centre for Health Service Research in Intellectual Disabilities on Tuesday 13th July 2010 at UCL.

The centre will provide a more prominent focus for intellectual disability research at UCL, a basis for obtaining grant funding across NHS services and academia, and opportunity to engage with people with learning disabilities and carers in joint research projects that will bring genuine benefits for people with intellectual disabilities.

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