



NHS Evidence – learning disabilities Evidence Bulletin 038 May 2010



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Welcome to the latest evidence update

Welcome to the Evidence Bulletin. This month we focus our extended summaries on mental health services, community residential placements for adults with learning disabilities and also forensic issues, including offenders with learning disabilities. We also highlight the published studies from the 40 journals that we scan.

In this month's edition we did not find any reviews, but several single studies which we hope you will find useful.

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HEALTH

Extended summaries



Who is involved in end of life decisions for people with learning disabilities in a residential care setting?

This retrospective study of medical files set out to explore the nature of end of life decision making for people with intellectual disabilities who were living in a Dutch residential care service.

The authors created a checklist against which to review the medical files of people who died at the centre from 2002 to 2007.

47 residents died during the period and end of life decisions were taken for 27 of those 47 cases. The files revealed that more residents died in their fifties than in any other decade of life and that the age of death in the study population lower than in the general Dutch population. The family was involved in decision making in half of the cases and nurses supporting the residents were involved in all cases.

The authors found no mention in the files about the views of residents themselves, nor about their capacity to take an end-of-life decision, suggesting that this had not been explored in any of the cases reviewed.

The authors suggest that this small scale study demonstrates that medical end-of-life decisions played a part in significant numbers of people with IDs who died within the residential centre, but that the process was not clear from medical files. They call for further research to establish the extent to which people with IDs and their representatives are involved in such decision making. They suggest the development of guidelines to support policy makers and practitioners in end of life decision making.

End-of-life decisions: an important theme in the care for people with intellectual disabilities

Wagemans A et al in Journal of Intellectual Disability Research, 54, 6, 516–524

Link to LDSC extended summary: <http://tinyurl.com/hlth06LDSC>



How Extensive should health checks for people with learning disabilities in primary care be?

This study looked at the impact of specific health checks for people with learning disabilities in GP practices already incentivised through the Quality and Outcomes Framework (QOF). The authors point out that little is known about data being routinely recorded in such health checks in relation to people with learning disabilities, and they set out to explore the additional value of a health check for people with learning disabilities compared with the standard care

provided through the QOF structure.

They identified representative practices from four Primary care trusts, with 27 practices eventually taking part. The practices were asked to carry out health checks over a 6-month period, and the resulting data were analysed.

651 patients with learning disabilities were identified in the 27 participating practices. 9 practices undertook health checks on 92 patients. Significant differences were found in the recorded information, between those who underwent a health check and those who did not. Recorded information for the group who had a health check was higher for the 'QOF targets' domain, compared with the 'ID-specific' domain.

The authors suggest there may be potential confusion between the requirements of the recently introduced Directly Enhanced Service (DES) incentives to general practitioners and those of the Quality and Outcomes framework as to who should be offered a health check and they recommend that future research should focus on the impact on patients' and carers' views as well as health professionals' experience of delivering such health checks.

Health checks in primary care for adults with intellectual disabilities: how extensive should they be?
Chauhan U et al., *Journal of Intellectual Disability Research*, 54, 6, 479–486

Link to LDSC extended summary: <http://tinyurl.com/hlth061LDSC>

Single Study

1. **Sexual risk assessment for people with intellectual disabilities**, Embregts P et al., in *Research in Developmental Disabilities*, 31, 3, 760-767
 - Authors developed a risk assessment questionnaire that included environmental risk variables.
 - Psychologists and staff members completed this for 56 intellectually disabled clients with sexually offensive behaviour problems.
 - Factor analyses revealed three subscales: quality of supervision, offending behaviour and emotional and social stability.
 - Reliability analyses showed sufficient to good reliability for both total scale and identified subscales
 - Implications for treatment of sexually offensive behaviour of clients with intellectual disabilities are discussed.

Link to article: <http://tinyurl.com/hlth0601>

MENTAL HEALTH

Single Studies

1. **The mental health of young children with intellectual disabilities or borderline intellectual functioning**, Emerson E et al., in *Social Psychiatry and Psychiatric Epidemiology*, 45, 5, 579-587
 - Study to determine within a nationally representative sample of young Australian children: (1) the Secondary analysis of population-based child cohort of 4,337 children, aged 4/5 years, followed up at age 6/7 years. Main outcome measure was scoring within 'abnormal' range at age 6/7 years on the parent-completed Strengths and Difficulties Questionnaire.



- Compared to typically developing children, children identified at age 4/5 years as having intellectual disability or borderline intellectual functioning:
 - showed significantly higher rates of possible mental health problems for total difficulties and on all five SDQ subscales at age 6/7 years)
 - were significantly more likely to be exposed to socio-economic disadvantage at age 4/5 and 6/7 years.
- Authors conclude that children with limited intellectual functioning make a disproportionate contribution to overall child psychiatric morbidity.

Link to article: <http://tinyurl.com/mhlth0601>

2. **Pathways Through Services for Offenders With Intellectual Disability: A One- and Two-Year Follow-Up Study**, Lindsay W et al., in [American Journal on Intellectual and Developmental Disabilities](#), 115, 3, 250–262

- Pathways through services for offenders with ID were reviewed. 197 offenders with ID accepted into three types of community and three types of secure forensic ID services took part.
- Comparisons made with 280 participants referred but not accepted into services.
- 2 years follow up carried out to review pathways.
- Those accepted into services had higher charge rate than did those who were referred (46% and 25%, respectively).
- Greatest diversity in pathway seen in participants in community forensic ID and inpatient services. Individuals in secure settings showed least diversity over time.
- Relatively high percentage of those accepted into generic community services remained in these services.

Link to article: <http://tinyurl.com/mhlth0602>

3. **The First Confirmed Case of Down Syndrome with Dementia with Lewy Bodies**, Prasher V, et al., in [Journal of Applied Research in Intellectual Disabilities](#), 23, 3, 296-300

- Case study reporting first case fulfilling operational criteria for Dementia with Lewy bodies found to have Lewy bodies on neuropathological examination
- Very few studies have showed an association between dementia with Lewy bodies and Down syndrome.
- The occurrence of DLB in persons with DS is widely unrecognized.

Link to article: <http://tinyurl.com/mhlth0603>

4. **Psychopathology: Differences among adults with intellectually disabled, comorbid autism spectrum disorders and epilepsy**, Smith K & Matson J, in [Research in Developmental Disabilities](#), 31, 3, 743-749

- Systematic examination of group differences among adults with ID, comorbid autism spectrum disorders (ASD), and epilepsy through detailed exploration of characteristics disorders present in area of psychopathology.
- Assessment of psychopathology made with ASD-comorbidity-adult version (ASD-CA).
- One hundred participants, with ID held constant, matched and compared across four equal groups comprising
 - 25 participants with ID,
 - 25 participants with epilepsy,
 - 25 participants with ASD,
 - 25 participants with combined ASD and epilepsy.
- When controlling for age, gender, race, level of ID, and hearing and visual impairments, results revealed significant differences among groups,
- Trend analysis demonstrated individuals with ID expressing combined comorbid ASD and epilepsy were significantly more impaired than the control group or groups containing only single comorbid factor with ID

Link to article: <http://tinyurl.com/mhlth0604>



PROFOUND & MULTIPLE LEARNING DISABILITIES

Single Study

1. **Cognitive Functioning of Children with Severe Intellectual Disabilities and Children with Deafblindness: A Study of the Perceptions of Teachers and Parents in the USA and India**, Narayan J et al., in [Journal of Applied Research in Intellectual Disabilities](#), 23, 3, 263-278
 - Questionnaire focusing on perceptions of teachers and parents of children with severe intellectual disability and children with deafblindness was administered to 125 teachers and parents from India.
 - Many perceptions of participants were similar in both countries.
 - Examples cited were similar across both countries.
 - Teachers in study tended to credit performance more readily than parents and teachers were more likely to report emerging skills and teaching strategies.
 - Authors conclude that the study implies it may be possible to develop assessment tools that can be used across countries for educational planning.

Link to article: <http://tinyurl.com/pmld0601>

DAY SERVICES & EMPLOYMENT

Single Study

1. **A Comparison of Quality of Life Outcomes for People with Intellectual Disabilities in Supported Employment, Day Services and Employment Enterprises**, Beyer S et al., in [Journal of Applied Research in Intellectual Disabilities](#), 23, 3, 290-295
 - Comprehensive Quality of Life Scale, and Work Environment Scale collected for people with intellectual disabilities: 17 supported employees; 10 employment enterprise workers; 10 day service attendees; and 17 non-disabled work colleagues of supported employees.
 - Supported employees reported higher objective quality of life than employment enterprise workers and day service attendees.
 - Non-disabled co-workers reported higher objective quality of life and autonomy at work than people with intellectual disabilities.
 - Supported employees reported higher subjective quality of life than non-disabled co-workers.
 - Authors conclude there is support for utility of supported employment as means to provide constructive occupation and enhanced quality of life to people with intellectual disabilities.

Link to article: <http://tinyurl.com/dsemp0601>

LEARNING DISABILITY POLICY

Single Studies

1. **Predictors of Job Satisfaction among Staff in Residential Settings for Persons with Intellectual Disabilities: A Comparison between Three Residential Models**, Yueh-Ching Chou et al., in [Journal of Applied Research in Intellectual Disabilities](#), 23, 3, 279-289
 - Cross-sectional study to assess whether differences in staff job satisfaction between three residential models for adults with intellectual disabilities
 - Standardized self-administered questionnaire distributed with demographic questions with 1301 staff completing the questionnaire.
 - Staff working at small homes had significantly higher level of job satisfaction than staff from other two models.



- Characteristics of organizations at which they were employed rather than staff's individual characteristics were strongly associated with job satisfaction.

Link to article: <http://tinyurl.com/ldpol0601>

AUTISM

Single Study

1. The relationship between carers' report of autistic traits and clinical diagnoses of autism spectrum disorders in adults with intellectual disability, Bhaumik S et al., in Research in Developmental Disabilities, 31, 3, 705 - 712

- Study of the relationship between carer-reported autistic traits and independent diagnoses of autism spectrum disorders (ASD).
- Data were collected on carers' subjective report of autistic traits and clinical diagnoses of ASD.
- Findings suggest that in the absence of other measures, the presence of autistic traits can serve as a useful proxy measure for ASD in research (and/or clinical settings).
- Information on autistic traits may help healthcare practitioners to identify people with possible ASD.

Link to article: <http://tinyurl.com/aut0601>

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