



# NHS Evidence – learning disabilities Evidence Bulletin 043 October 2010



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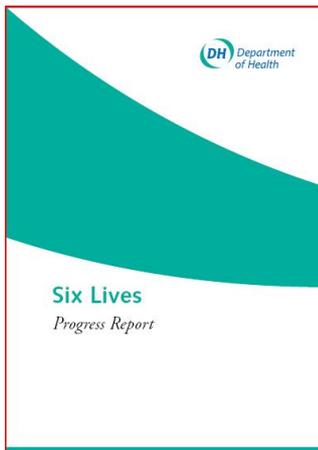
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## Welcome to the latest evidence update

Welcome to the Evidence Bulletin. This month we provide an extended summary on a study looking at daytime sleepiness and its effect on behaviour as well as our usual digest of published studies from almost 40 journals under the collection's headings for you to browse and explore further at source if you wish.

### Six Lives Progress Report



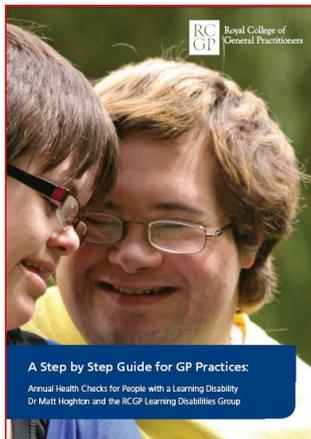
The Department of Health has published a report today on progress to improve healthcare for people with learning disabilities in line with the recommendation of the Parliamentary and Health Service Ombudsman and Local Government Ombudsman in their March 2009 investigation 'Six Lives'.

'Six Lives' investigated the deaths of six people with learning disabilities first highlighted by Mencap in their 2007 report 'Death by Indifference'. It looked not only in detail at what happened to those six people, but also the lessons that could be drawn for services as a whole to improve care for people with learning disabilities. 'Death by Indifference' also prompted an independent inquiry into access to healthcare chaired by Sir Jonathan Michael.

The recommendations from this inquiry informed the actions set out for health in the 'Valuing People Now' strategy.

View full text here: <http://tinyurl.com/sixlives>

### A Step by Step Guide for GP Practices: Annual Health Checks for people with a learning disability



This guide is produced to help GPs, practice nurses and primary administration team organise and perform quality annual health checks on adults with a learning disability. It focuses on the Cardiff Health check for People with a Learning Disability developed by Professor M. Kerr, Welsh Centre for Learning Disabilities.

The introduction for annual health checks with people with learning disabilities is important:

1. To improve health outcomes for people with learning disabilities.
2. To help identify and treat medical conditions early.
3. To screen for health issues particular to people with LD and specific conditions.
4. To improve access to generic health promotion in people with LD.
5. To develop relationships with GPs, practice nurses and primary care staff particularly after the comprehensive paediatric care finishes at the age of 18.

View full text here: <http://tinyurl.com/LDhealthcheck>



## Health



### **Do Adults with learning disabilities experience more falls and injuries than adults in the general population?**

The World Health Organisation has identified falls in the over 65s as a major health issue and considerable investment has been made in specialist interventions and teams. This study set out to find out more about the pattern of injuries and falls in adults with learning disabilities and compare this pattern to that found from information in a national health survey for the general population. The authors recruited adults with learning disabilities from the Greater Glasgow health Board area, gathering data at two time points 12 months apart, using a number of instruments. 511 adults

took part at both time points from an initial cohort of 899. The authors carried out face-to-face interviews with participants 2 years after they had first been recruited into a longitudinal study then gathered information about falls and injuries within the preceding twelve month period.

The study found incidence of at least one injury in the 12-month period was 20.5% (105), of which 12.1% (62) was because of falls. The found incident injury was predicted by having epilepsy and not having autism. Incident fall injury was predicted by urinary incontinence and they found Down syndrome reduced the risk. The Authors concluded that adults with learning disabilities experience a higher rate of injuries and falls when compared with the general population, experiencing more fractures, burns, poisoning, cuts; more injuries caused by falls, trips and slips; burns from using kitchen equipment and causes not relevant for the general population.

They suggest that some differences relate to differing life-styles experienced by adults with ID, for example, being unlikely to drive and using fewer tools but using kitchen equipment and therefore that it will be important to consider the role and contribution of carers when considering interventions to prevent injuries.

Whilst the large size of the cohort is a strength of the study the authors also point out that accident data were reliant on recall and this could be a significant limitation. They suggest a need for further study on fractures/osteoporosis; development and piloting of balance, safety, and staff training interventions.

**Injuries, falls and accidents among adults with intellectual disabilities. Prospective cohort study,** Finlayson, J. Et al., in Journal of Intellectual Disability Research, 54: 966–980

**Read Extended Summary:** <http://tinyurl.com/hlthsum1>

### Reviews

1. **Health checks for people with learning disabilities: a systematic review of the evidence,** Robertson J et al., Improving health and lives: public health observatory

**View full text here:** <http://tinyurl.com/hlth43001>

- People with learning disabilities have poorer physical and mental health than other people.
- These are health inequalities that can, to a significant extent, be avoided.
- One reason for the poorer health of people with learning disabilities is that they often have difficulty in recognising illness, communicating their needs and using primary health care services.
- Primary health services have a legal responsibility to take account of the special needs of people with learning disabilities and reduce the health inequalities they face. One practical step GP practices in England can take to better support people with learning disabilities is to offer them annual health checks. Since 2009, GPs have received extra money for providing these health checks.



## Single Studies

2. **Survival with Rett syndrome: comparing Rett's original sample with data from the Australian Rett Syndrome Database**, Freilinger M et al., in Developmental Medicine & Child Neurology, 52, 10, 962-965

**Link to article:** <http://tinyurl.com/hlth43002>

- Comparison of survival of all Austrian female participants from Rett's historical cohort (1966) with affected females registered in Australian Rett Syndrome Database.
- Of females in original Austrian group, three are still alive. Median age at death: 13 years 4.8 months. Probability of survival up to age of 25 years was 21%, compared with 71% in Australian cohort
- No practical or statistically significant differences in survival between various birth year groups within Australian cohort found.
- Authors suggest data indicate that survival of females with Rett syndrome has improved since late 1960s but no change in survival over the last 30 years.

## Mental Health



### **How effective is Group Cognitive-Behavioural Treatment for Men with Intellectual Disabilities at Risk of Sexual Offending?**

This multi-site collaborative study set out to explore the effectiveness of group cognitive-behaviour therapy for men with learning disabilities who have committed sexual offences. Such treatment is rarely offered for sexual behaviour issues in men with learning disabilities and there is little research data on effectiveness at present.

In this study, nine collaborating sites ran thirteen, one year long cognitive-behavioural treatment groups for men with learning disabilities and sexually abusive behaviour. The men in the groups were recruited from community services and secure provision. They were assessed by the teams for their sexual knowledge, victim empathy and cognitive distortions before and after the group treatment. All the treatment facilitators were trained and followed a treatment manual developed by the collaboration.

Forty-six men took part in the research. 83% had engaged in more than one incident of sexually abusive behaviour. 57% of those who came for treatment were required by law to attend. 92% of those who began treatment completed it one year later, which the authors suggest indicates considerable motivation amongst the men to get treatment for their difficulties.

The men showed statistically significant increases in sexual knowledge and victim empathy, as well as reductions in cognitive distortions over the period of the treatment. Changes found in the treatment period were maintained at the six month follow-up.

Few of the men showed further sexually abusive behaviour during the treatment period or during the 6-month follow-up period.

The study attempted to identify those characteristics that might be related to re-offending, but found only 'presence of autistic spectrum disorders' as one such factor.

The authors point to a number of strengths of the current study, e.g. the vast majority of men who started the treatment stayed until the end, the large multi site nature of the study enabled data to be collected from 46 participants, and facilitators to be trained to work with a common treatment manual across all sites. However,



they also stress that this created problems in maintaining treatment fidelity with datasets not always complete for each man.

They suggest however that the current study provides further evidence that cognitive-behavioural treatment for men with mild or borderline learning disabilities and sexually abusive behaviour shows promise and deserves further multi-site research, and suggest this form of treatment should be on offer to more men with learning disabilities and sexually abusive behaviour.

**Effectiveness of Group Cognitive-Behavioural Treatment for Men with Intellectual Disabilities at Risk of Sexual Offending**, Sex Offender Treatment Services Collaborative – Intellectual Disabilities (SOTSEC-ID), in Journal of Applied Research in Intellectual Disabilities, 23, 6, 537-551

**Read Extended Summary:** <http://tinyurl.com/mhsum01>

## Reviews

1. **Psychotherapy for people with learning disabilities: creating possibilities and opportunities. A review of the literature**, Taylor J., in Journal of Learning Disabilities and Offending Behaviour 1,3, 15-25

**Link to article:** <http://tinyurl.com/mhrev43001>

- Offenders with learning disabilities, particularly in prison settings, have largely been unable to access treatment strategies provided for offenders who do not have such disabilities.
- This paper provides brief exploration of reasons and evidence for exclusion of people with ID from psychological therapies. Paper presents evidence that people with ID can successfully engage in psychotherapy.
- Author concludes there is no evidence to support exclusion of people with disabilities from treatment options.

## Single studies

2. **Trauma and post-traumatic stress disorder (PTSD) in a high secure forensic learning disability population: future directions for practice**, Brackenridge I & Morrissey C in Advances in Mental Health and Intellectual Disabilities 4, 3, 49-56

**Link to article:** <http://tinyurl.com/mh43001>

- National Centre for High Secure Learning Disability Services at Rampton Hospital service evaluation on aspects of trauma experience and post-trauma symptoms in current population.
- Most individuals had experienced a great deal of lifetime trauma, typically multiple types of abuse.
- High rate of potentially trauma-related symptoms noted in files.
- File records of potentially traumatic events often lacking in detail.
- Limited information available in files about events themselves, with no information to suggest any trauma-specific assessments had been used to measure trauma exposure or symptoms.
- PTSD as diagnosis was rarely considered with little consideration of trauma-specific interventions.
- Service under study plans to address needs of patients who have experienced trauma and abuse by conducting routine structured assessments, offering adapted evidence-based psychological interventions and providing trauma-specific education for staff.

3. **People with learning disabilities placed out of area: the South London experience**, Chaplin E et al., in Journal of Learning Disabilities and Offending Behaviour, 1, 3, 5-14

**View full text here:** <http://tinyurl.com/mh43002>

- Long-stay NHS hospital closures has seen placement of people with ID who offend placed 'out of area' many miles from local services.
- Local services development and quality of care monitoring has been made difficult as a result of this.
- Paper describes exercise to develop local care pathways for this group and those receiving treatment locally.



- No significant differences found between two groups regarding rates of psychiatric disorder, quality of life or levels of unmet need.
  - Main difference found was out of area group was largely characterised by range of aggressive and challenging behaviour, necessitating additional structure and securities provided by out of area placements.
4. **Experiences of implementing an Adapted Sex Offender Treatment Programme for people with learning disabilities in a secure setting**, McNair L et al., [Journal of Learning Disabilities and Offending Behaviour](#), 1,3, 26-32

**Link to article:** <http://tinyurl.com/mh43004>

- Brooklands' Adapted Sex Offender Treatment Programme (ASOTP) adopted by Calderstones Partnership NHS Foundation Trust in 2006.
- Two groups of men (n = 10) have completed programme and one group (n = 6) is in progress.
- Treatment model uses cognitive behavioural framework and is nurse-led initiative, utilising trained ward staff.
- Paper discusses experiences of initiating and delivering the ASOTP programme.
- Issues encountered include staff retention, clients discontinuing group, length of group, length of wait for clients to commence treatment and high levels of administration.
- Changes have been made before commencement of second wave in 2008.
- Paper discusses how ASOTP were able to overcome some, but not all, of initial difficulties and highlights potential pitfalls for future groups.

## Challenging Behaviour



### **What are the characteristics of assessment and treatment, low and medium secure units for people with challenging behaviour or mental health problems and how do they compare to each other?**

Specialist Healthcare provision for people with learning disabilities and challenging behaviour or mental health problems has developed over several years, particularly as the long stay hospitals have closed and been replaced by community based services. The NHS and the independent private and voluntary sector all play a role in the provision of assessment and treatment, low and medium secure units. This study set out to discover something of the nature of these services and to compare them along a number of characteristics.

The authors surveyed all National Health Service (NHS) and independent sector (IH) health settings providing specialist inpatient services for people with learning disabilities, collecting data on setting and patient characteristics, staffing and management and care processes and outcomes.

201 of a possible 217 services returned the survey questionnaires, a very high return rate. The authors found that services were unevenly distributed across England. They also found many differences between NHS and independent sector settings. Independent assessment and treatment units for example tended to be bigger with higher occupancy and lower staff ratios. In assessment and treatment, low and medium secure units, independent sector units had fewer visits to patients, used more seclusion, more physical restraint and had more locked areas.

Independent sector units also had more complaints from users. There were also more complaints from relatives in assessment and treatment units and low secure units in the independent sector. Independent sector providers however used fewer agency staff in assessment and treatment units (although they used



more in medium secure units). They also carried out more appraisals of staff and more consultations with GPs and dentists.

The authors point out a concern in that they found a quarter of people in NHS assessment and treatment units who had completed treatment had no plan for discharge within the following month, which may create significant difficulties for the individuals concerned as well as blocking assessment and treatment services for those that may need them.

They also point out that the uneven distribution of services is likely to have an impact on local joint planning and may contribute to 'bed-blocking' and re-admission. They also raise the concern that the large numbers of people currently in such units raises the question of whether they may be recreating the large long stay institutions that Government policy has sought to close and replace.

**Health Service Inpatient Units for People with Intellectual Disabilities and Challenging Behaviour or Mental Health Problems**, Mansell J et al., in *Journal of Applied Research in Intellectual Disabilities*, 23, 6, 552-559

**Read extended summary:** <http://tinyurl.com/cbsum01>

#### Single studies:

1. **The use of medication to manage behaviour problems in adults with an intellectual disability: a national guideline**, Unwin G & Deb S, in [Advances in Mental Health and Intellectual Disabilities](#), 4, 3, 4-11

**View full text here:** <http://tinyurl.com/cb43001>

- Development of a national guideline project for the use of medication in the management of problem behaviours in adults with an intellectual disability. The article highlights important issues in clinical practice in the field, and addresses current evidence base on effectiveness of psychotropic medications in management of problem behaviours.
  - Authors state that there is a lack of good research evidence to support use of medication for problem behaviours. Medication used for this purpose should be used with a clear rationale, following a thorough assessment of the individual, and carefully monitored: withdrawal should always be considered.
2. **The use of psychotropic medication for the management of problem behaviours in adults with intellectual disabilities living in Canada**, Bradley E & Cheetham T, in [Advances in Mental Health and Intellectual Disabilities](#), 4, 3, 12-26,

**Link to article:** <http://tinyurl.com/cb43002>

- Canadian perspective on use of psychotropic medication in management of problem behaviours in adults with intellectual disabilities.
- Psychotropic medication and intellectual disabilities explored in context of Canadian health and social services, clinical practices, medical training.
- Survey of use of psychotropic medication for problem behaviours across Canada carried out.
- Geographic, political, cultural and other influences on development of health and social services and training requirements for physicians are described.
- In Canada there are no national, provincial or territorial policies or guidelines on use of psychotropic medication for the management of such behaviours with no requirements for prescribing physicians to have training in the care of people with intellectual disabilities.

3. **Prescribing psychotropic medication for problem behaviours in adults with intellectual disabilities in a specialist psychiatric unit in Hong Kong**, Kwok H et al., in [Advances in Mental Health and Intellectual Disabilities](#), 4, 3, 27-33

**Link to article:** <http://tinyurl.com/cb43003>



- Study to examine pattern of prescription of psychotropic medications to manage problem behaviours for adults with intellectual disabilities in a specialist psychiatric unit in Hong Kong.
  - Individuals aged 18 or above with problem behaviours and receiving psychotropic medication for treatment in hospital, outpatient and community settings were studied.
  - 236 patients met inclusion criteria.
  - 46% had moderate intellectual disability
  - Autism spectrum disorder commonest psychiatric diagnosis (35%)
  - Aggression commonest problem behaviour (52%).
  - Antipsychotics, mood stabilisers and antidepressants were prescribed to 96%, 20% and 13% of subjects respectively.
  - Authors state that profile of problem behaviour in Chinese population with ID is consistent with findings reported in world literature.
4. **A case series on the use of risperidone for the management of aggression in adults with intellectual disabilities**, Deb S & Ajit G in [Advances in Mental Health and Intellectual Disabilities](#), 4,3, 39-44

**Link to article:** <http://tinyurl.com/cb43004>

- Case series showing antipsychotics could be effective, but often used with non-drug measures and sometimes cause side-effects.
- Clinicians did not always carry out thorough assessment followed by formulation before prescribing
- Clinicians did not carry out tests to detect side-effects of risperidone such as metabolic syndrome.
- Authors recommend clinicians should use psychotropic medication for minimum period of time and at lowest possible dose, also considering non-drug management of aggression at outset and at regular interval.

## **Autism**

### **Single studies**

1. **Distinguishing features of autism in boys with fragile X syndrome**, Brock M & Hatton D., in [Journal of Intellectual Disability Research](#), 54, 10, 894-905

**Link to article:** <http://tinyurl.com/aut43001>

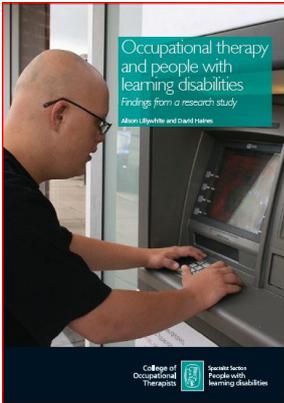
- Backward regression was used to identify the combination of parent-report questionnaire items that best predicted autism symptoms in a sample of 60 males with FXS, ages 4–18 years old on a specialised autism screening tool for young males with FXS.
- Social and repetitive behaviours distinguished males with FXS/autism, with repetitive behaviours playing a more prominent role than previously documented in the literature.
- The authors conclude that healthcare workers could interview parents about a few key behaviours to determine if young child with FXS should be formally evaluated for autism.



## Learning Disability Policy

### Single studies

#### 1. Occupational Therapy and people with learning disabilities: Findings from a research study



Commissioned by the College of Occupational Therapists and its Specialist Section - People with Learning Disabilities, this book explores the nature of occupational therapy practice for people with learning disabilities across the United Kingdom (UK), from the perspectives of occupational therapists and support workers.

This publication provides a comprehensive overview of the nature of occupational therapy practice for people with learning disabilities to inform, guide and support occupational therapy practice across the UK. The recommendations made within this publication will be of use to carers, their families and others who work in the field of learning disabilities as well as driving forward best practice and raising the profile of occupational therapy practice for the profession.

View full text here: <http://tinyurl.com/ldp43001>

## Person Centred Services

### Single studies

#### 1. Status and Trends in the Direct Support Workforce in Self-Directed Supports. Intellectual and Developmental Disabilities, Bogenschutz M et al., 48, 5, 345-360.

Link to article: <http://tinyurl.com/pcs43001>

- Challenges in recruitment, retention and training of direct support workers in field have grown acute.
- Authors investigate status of direct support workforce for people using self-directed supports in 1 Midwestern state, based on the results of a statewide survey of service users.
- Results of study suggest people who use self-directed funding options are satisfied with their ability to direct staffing, though challenges remain.
- Presence of higher than expected wages but lower than expected benefits provision compared with traditional services may have serious policy and staff retention ramifications.
- Staff training remains a challenge, with service users in this sample reporting low rates of training beyond a general skill set.



## Supporting Family Carers

### Single studies

1. **Employment impact and financial burden for families of children with fragile X syndrome: findings from the National Fragile X Survey**, Ouyang L et al., in Journal of Intellectual Disability Research, 54, 10 918–928

**Link to article:** <http://tinyurl.com/sfc43001>

- Using national fragile X family survey, data on 1019 families was analysed.
- Out-of-pocket expenditures related to fragile X were reported.
- Almost half of families affected by FXS experienced increased financial burden and nearly 60% had to change work hours or stop work because of FXS.
- Families with health insurance were significantly less likely to report an excess financial burden.
- Authors conclude that families affected by FXS experienced significant employment impact and financial burden.

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