



NHS Evidence – learning disabilities Evidence Bulletin 045 December 2010



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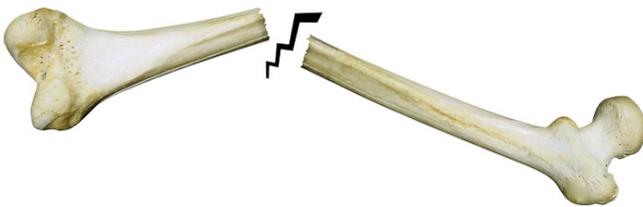
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Welcome to the latest evidence update

Welcome to the Evidence Bulletin. This month our extended summaries are looking at osteoporosis in people with learning disabilities and the outcomes for a people with severe challenging behaviour who were resettled from hospital to an NHS provided community service, 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.

Health



Is there an increased risk from osteoporosis in people with learning disabilities?

This literature review looks at the issue of bone health in people with learning disabilities. A search of databases revealed a number of studies, identifying a number of additional risk factors present in people with learning disabilities, for example: reduced physical activity, hypogonadism, low testosterone, early menopause in women, presence of Down syndrome and other syndromes causing hypotonicity and higher prevalence of endocrine disorders.

The majority of studies found also identified an increased prevalence of osteoporosis and osteopenia with associated low bone mineral density (BMD).

In addition, the authors carried out a further survey of The authors' analysis of 149 case notes from outpatients and found thirty (20%) with a history of falls, 15 (11%) with a history of fractures and 11 who had suffered low impact fracture. 54% of those in the survey fulfilled the criteria for further screening and of those, 55% who went on to have the screening were found to have osteoporosis and 33% osteopenia.

The authors conclude that screening for risk factors associated with low BMD in adults with ID should be routine, and if the risk factors are present, then further investigations should be done. Early stage treatment should be offered in those found to have osteoporosis and osteopenia to prevent morbidity and improve quality of life.

Osteoporosis in people with intellectual disabilities: a review and a brief study of risk factors for osteoporosis in a community sample of people with intellectual disabilities, Srikanth R et al., in Journal of Intellectual Disability Research,

Read extended summary: <http://tinyurl.com/hes01>

Exercising choice and control – women with learning disabilities and contraception, McCarthy M in British Journal of learning disabilities, 38,4, 293-302

Link to article: <http://tinyurl.com/hlth45001>

- Semi-structured in-depth interviews with women with learning disabilities to ask about experiences of being prescribed contraception. Postal survey investigated General Practitioners' prescribing practices. A service user group was involved at different stages of the project.
- Most of the women reported other people made key decisions about starting to use contraception and which method to use.
- The women and doctors said they liked having a third party (staff member or relative) present for consultations.
- Many doctors were unclear about responding to issues of capacity to consent to treatment.



Life and Death of a Child with Down Syndrome and a Congenital Heart Condition: Experiences of Six Couples, Reilly D et al., in *Intellectual and Developmental Disabilities*, 48,. 6, 403-416.

Link to article: <http://tinyurl.com/hlth45002>

- Semi-structured interviews explored the experiences of 6 couples whose child with Down syndrome and a congenital heart condition had died.
- Four themes emerged: dilemmas associated with dual diagnosis; treatment decisions during life and the death of their child; ways couples coped when bereaved and 'ripples' from child's life.
- Authors suggest the practical implications of the results include importance of considering the specific needs of couples, individuals, and fathers within partnerships.

Vitamin D status and optimal supplementation in institutionalized adults with intellectual disability, Kilpinen-Loisa, P et al., in *Journal of Intellectual Disability Research*, 53, 1014–1023.

Link to article: <http://tinyurl.com/hlth45003>

- 138 adults (95 males and 43 females) with ID living in nursing homes of Pääjärvi Inter-Municipal Association took part.
- Clinical data on the aetiology and severity of ID, other illnesses, medications, anthropometry and fractures during 5 years were collected from medical records.
- Participants were allocated to receive vitamin D3 either per orally 800 IU daily for 6 months (PO group, $n = 72$) or as a single intramuscular injection of 150 000 IU (IM group, $n = 66$).
- Blood samples obtained at baseline and 6 months for parameters of calcium homeostasis, including serum concentrations of 25-hydroxyvitamin D (S-25-OHD) and parathyroid hormone (P-PTH).
- Vitamin D insufficiency was found to be common.
Oral and intramuscular administrations of vitamin D3 improved vitamin D status without adverse effects.
- Treatment response at 6 months was better in PO group.
- Authors conclude that high-dose intramuscular vitamin D3 injections can be convenient way to maintain sufficient vitamin D status in adults with ID.
- They recommend vitamin D supplementation with per oral 800 IU/day for all adults with ID living in nursing homes.

Challenging Behaviour



What were the outcomes for 19 people with severe challenging behaviour who moved into NHS provided community based accommodation?

This study looked at quality of life consequences for adults with learning disabilities with challenging behaviour moving from a long stay hospital to community settings. The adults concerned were assessed as having challenging behaviour of a severity that was deemed to require continuing healthcare. The service that was developed to replace the hospital was

provided by a specialist NHS trust through special project arrangements, providing 'homelike' accommodation in community settings. The intention of the trust was also to develop staff training in Positive Behavioural Support (PBS) and Active Support (AS).

19 people took part in the study, with baseline data collected on adaptive and challenging behaviour and psychiatric status. Data on quality of care and lifestyle indicators were collected whilst everybody involved was still in hospital (T1); when one group had moved into their new homes but most still remained in the hospital (T2); when most had moved to the community but a minority remained in hospital (T3) and at follow-up (T4), when all lived in the community.



The authors found no significant deterioration in quality of care or lifestyle outcomes, and that community provision was more homelike and associated with improvements in working methods and staff contact. There was increased family contact, greater participant involvement in household and constructive activity. There was a reduction found in staff-reported challenging behaviour.

The authors conclude that quality of care and lifestyle outcomes in the new NHS provided services were generally equivalent or superior to hospital levels. The authors suggest a need for a longer-term follow-up study to identify whether improvements in the early stages of the move are maintained or enhanced. They point out however that they were not able to evaluate on one of the main goals of the resettlement which was to establish new working methods through training in positive behavioural support and active support and suggest therefore the need for further study to establish whether implementation of such approaches would bring about sustained behaviour change.

Resettlement Outcomes for People with Severe Challenging Behaviour Moving from Institutional to Community Living, Perry J et al., in Journal of Applied Research in Intellectual Disabilities, 24, 1–17

Read extended summary: <http://tinyurl.com/cbes001>

The use of multi-element behaviour support planning with a man with severe learning disabilities and challenging behaviour, MacDonald A et al., in British Journal of Learning Disabilities 38, 4, 280–285

Link to article: <http://tinyurl.com/cb45001>

- Data collected through length of personal behavioural support showed decreases in challenging behaviour while participation in activities increased.
- Over 15 month period, client's participation increased and remained high – with clear link between consistent implementation of the Behaviour Support Plan and increased participation in activity.
- Authors conclude multi-element model can be used to provide behaviour support in everyday settings with consequent decreases in challenging behaviour and increases in participation in activity.
- They suggest key requirements for ensuring success as: establishing functionality of behaviour to ensure behaviour support plans address reasons behind behaviour; a multi-element approach to address those factors maintaining behaviour; direct input from specialist behaviour support staff.
- Effectiveness was linked to quality of implementation and Periodic Service Review.

Mental Health

Screening for mental health problems in adults with learning disabilities using the Mini PAS-ADD Interview, Devine M et al., in British Journal of learning disabilities, 38, 4, 252-258

Link to article: <http://tinyurl.com/mh45001>

- Variation in prevalence of mental health of people with learning disabilities is a consequence of assessment methods used and different populations studied. This study screened for mental health problems in adults with mild-to-moderate learning disabilities in region of the UK providing community-based services.
- Mini PAS-ADD Interview schedule was used and a number of specifically trained interviewers interviewed staff who supported adults with learning disabilities in work/day care settings
- A 33.3% prevalence rate of mental health problems in this community sample was found.
- Sample was found to score higher on sub-scales of depression and psychosis compared with other prevalence studies.
- Results of the study fall between previous community prevalence studies (range 14% to 50%)



Prevalence of Psychiatric Diagnoses and Challenging Behaviors in a Community-Based Population of Adults With Intellectual Disability, Grey I et al., in [Journal of Mental Health Research in Intellectual Disabilities](#), 3,4, 210-222

Link to article: <http://tinyurl.com/mh45002>

- Community-based sample of 159 adults primarily with mild and moderate ID surveyed for presence of psychiatric disorders and challenging behaviours using the Behavior Problem Inventory and the Psychiatric Assessment Schedule (PAS-ADD).
- Individuals meeting threshold on PAS-ADD were subsequently evaluated using Mini PAS-ADD Interview.
- Screening using PAS-ADD indicated prevalence rate of 10% with a large discrepancy between overall rate of challenging behaviours (45%) and rate of psychiatric disorders identified by Mini PAS-ADD Interview (6%).
- Rate of more severe behaviour problems (8%) was closer to rate of psychiatric disorders (6%).
- 31% of people with severe challenging behaviours were rated as having psychiatric disorders and individuals with severe challenging behaviours were found to be substantially more likely to present with a psychiatric disorder.
- Relationship between different topographies of challenging behaviours and discrete diagnostic categories of psychiatric disorders was unclear.
- Study reports low prevalence of psychiatric disorders in a community-based population.
- Presence of severe challenging behaviours appeared to have association with psychiatric disorders but not specific to discrete diagnostic categories.

Secure inpatient services for people with intellectual disability: lessons from developing a new service, Hall, I et al., in [Advances in Mental Health and Learning Disabilities](#), 4, 4, 15-24

Link to article: <http://tinyurl.com/mh45003>

- Description of needs assessment enabling development of new secure service for men with intellectual disability with substantial additional mental health needs.
- Essential part of process was consultation with stakeholders with service user and family perspectives particularly helpful.
- Special arguments needed for some aspects of treatment programme.
- Foundation trusts able to develop services at financial risk, before contracts are signed, enabled development to take place at a faster pace.
- Good relationships with community teams were essential along with integration with mainstream forensic services.
- Service development has led to many people with intellectual disability with very high needs being supported much nearer to home.

Low security: patient characteristics which lead to an offer of admission and staff perceptions in a unit for people with intellectual disability Yacoub, E in [Advances in Mental Health and Learning Disabilities](#), 4, 4, 25-34

Link to article: <http://tinyurl.com/mh45004>

- Characteristics of patients referred to a low secure intellectual disability unit were studied, along with views of staff working on the unit on the concept of low security
- Case-controlled study for 33 patients referred to the unit over 42 months.
- Characteristics of 18 patients offered an admission were compared with those of 15 patients not offered an admission.
- 5 staff working on unit were interviewed about concept of low security.
- Patients offered an admission were more able than those not offered an admission, they posed more risks and were more complex diagnostically.
- Staff working on unit felt patients were appropriately placed overall.
- Complexity of need of patients on unit required sophisticated care planning and management strategies.



Improving mental health services for people with intellectual disabilities: service users' views, O'Brien A & Rose J, in [Advances in Mental Health and Learning Disabilities](#) 4, 4, 40-47

Link to article: <http://tinyurl.com/mh45005>

- Study of opinions of people with an intellectual disability with additional mental health needs about services they receive.
- Semi-structured focus group methodology used
- Participants valued staff who listened to them and actively tried to help with their difficulties.
- Participants also wanted choice and control over their lives, particularly with regard to meaningful day activities.

Person Centred Services

Person-Centered Planning: Analysis of Research and Effectiveness. Intellectual and Developmental Disabilities, Claes G et al in [Intellectual and Developmental Disabilities](#) 48, 6, 432-453.

Link to article: <http://tinyurl.com/pcsr4500>

- Purpose of study to review current status of effectiveness research; describe its effectiveness in terms of outcomes or results; and discuss effectiveness of PCP in relation to evidence-based practices.
- Review found overall that PCP has positive, but moderate, impact on personal outcomes
- Evidence provided is weak with regard to criteria for evidence-based research.

How adults with learning disabilities view living independently, Bond R & Hurst J., in [British Journal of Learning Disabilities](#) 38, 4, 286–292

Link to article: <http://tinyurl.com/pcs45001>

- Qualitative study exploring experiences of 9 adults with mild learning disabilities living alone with minimal support.
- Seven themes emerged: feelings on living alone, practical issues, support issues, choice and control, vulnerability, health issues and impact of having a learning disability.
- Issues raised reflected need to increase social inclusion and provide right level of support.
- Participants talked about service providers needing to be aware of their vulnerability and wanted respect for right to make their own choices.

Social aspects of eating events among people with intellectual disability in community living, Adolfson P et al., in [Journal of Intellectual and Disability Research](#), 35, 4, 259-267

Link to article: <http://tinyurl.com/pcs45002>

- Participant observations used to study meals as social events for 32 participants, 9 in supported living and 23 in group homes.
- Breakfast and dinner often eaten alone - lunch at daily activity centre and food eaten between meals (snacks) mostly shared.
- Meals for participants in supported living seldom social, and meals for participants in group homes often hierarchical.
- Participants often limited in choosing company at meal - typically other people with ID and staff.



Day Services & Employment

A Preliminary Investigation of Factors Affecting Employment Motivation in People With Intellectual Disabilities, Andrews, A & Rose, J. L. in Journal of Policy and Practice in Intellectual Disabilities, 7, 239–244

Link to article: <http://tinyurl.com/dsemp45001>

- Preliminary study into what factors motivate people with learning disabilities to work.
- 10 young work-age adults attending supported learning courses at FE college were asked about their feelings in a focus group.
- Participants were asked what factors motivated them to work and what factors deterred them from working.
- Three major themes were monetary gain, social aspects, and perceived competence.

Choice-Making in Vocational Activities Planning: Recommendations from Job Coaches, Cobigo, V et al., in Journal of Policy and Practice in Intellectual Disabilities, 7, 245–249

Link to article: <http://tinyurl.com/dsemp45002>

- Providing opportunities to express choices and interests in planning vocational activities is a factor in achieving employment outcomes.
- Service providers encounter important barriers to understanding vocational interests of persons with intellectual disabilities who have difficulty expressing choices verbally.
- A method of recording choices expressed through nonverbal means was designed and field-tested.
- Interviews were conducted with participating job coaches to assess the practical value of this method and provide recommendations regarding implementation and dissemination.
- Results demonstrate the need for training to enable support staff to embed choice-making opportunities in the daily life of persons with intellectual disabilities.

Microenterprise Options for People With Intellectual and Developmental Disabilities: An Outcome Evaluation, Conroy J et al, in Journal of Policy and Practice in Intellectual Disabilities, 7, 269–277

Link to article: <http://tinyurl.com/dsemp45003>

- 27 people with intellectual and developmental disability from Kent County, Michigan, USA, chose to engage in microenterprise. Changes in qualities and quantities of work life were measured. Participants reported enhanced quality of work life in most of 17 areas. Overall “scale score” significantly increased by 26 points on a 100-point scale.
- Support workers’ data revealed significantly enhanced quality of work life in 5 of 14 areas and overall scale increase of 6 points.
- Authors suggest microenterprise offers an alternative to traditional sheltered workshops or day centres that promises to be satisfying, meaningful, enjoyable, and may cost significantly less.

Activity, Aging, and Retirement: The Views of a Group of Scottish People With Intellectual Disabilities, Judge J et al., in Journal of Policy and Practice in Intellectual Disabilities, 7, 295–301

Link to article: <http://tinyurl.com/dsemp45004>

- Study to understand perceptions of people with ID with respect to retirement: mandatory transition from attending day centres in two Scottish localities.
- Semi-structured interviews conducted with 16 older adults.
- Five themes emerged from analysis: the importance of activity, day centre as social hub, confusion concerning retirement, desire for continuity, and value of independence.
- The older adults placed great value on participation in daytime activity and on attendance at local authority-run day centres, wishing to remain active well into old age and to contribute to local communities.
- Participants highlighted difficulties understanding “retirement” and felt that they had a disconnected role in process.
- Authors suggest closer scrutiny of daytime activity for older people as retirees and of the process of preparation for lifestyle change.



Supporting Family Carers

Poverty transitions among families supporting a child with intellectual disability, Emerson E et al., in Journal of Intellectual and Developmental Disability 35, 4, 224-234

Link to Full text: <http://tinyurl.com/pwd45002>

- Analysis of data collected over 12-month period for families supporting a child with intellectual disability ($n = 370$); supporting a child with other disability ($n = 1,418$) and supporting a child with no disability ($n = 7,215$).
- When compared to families not supporting a child with disability, families supporting a child with ID were more likely to be poor, more likely to become poor and less likely to escape from being poor.
- Authors conclude there were few differences between families supporting or not supporting a child with disability with regard to levels of exposure to potential trigger events or to strength of association between exposure and poverty transitions.

Parenting stress in mothers of adults with an intellectual disability: parental cognitions in relation to child characteristics and family support, Hill, C.& Rose, J., in Journal of Intellectual Disability Research, 53, 969–980.

Link to article: <http://tinyurl.com/pwd45003>

- Face-to face interviews administered with 44 mothers of adults with ID. Vineland Adaptive and Maladaptive Behaviour Scale, Family Support Scale, Parenting Sense of Competence Scale, a shortened version of the Parental Locus of Control Scale and Parenting Stress Index were also completed.
- Correlations observed between parenting stress and other study variables. Parental cognitive variables predicted 61% of variance in parenting stress.
- Parenting satisfaction, mediated relationships between adaptive behaviour and parenting stress and between family support and parenting stress.
- Authors suggest results indicate importance of cognitive variables in stress of mothers of adults with ID.

Learning Disability Policy

Support workers within learning/intellectual disability services perception of their role, training and support needs, Windley, D. & Chapman, M, in British Journal of Learning Disabilities, 38, 4, 310–318

Link to article: <http://tinyurl.com/ldp45001>

- Data collected by focus group ($n = 3$) and semi-structured interviews ($n = 5$).
- Participants saw key role as maximising quality of life, identified '*Trial and error*' as main mode of skill development for new staff and experienced stress as a result of conflict between their beliefs and demands of the service.
- Preference for more on site supervision to provide leadership was indicated.
- Training by community learning disability team was highly regarded.
- Authors suggest development of personal skills and relating training to human rights and person-centred planning perspectives would best enable staff to carry out their roles.



Parents with Disabilities

Supporting parents: development of a tool to measure self-efficacy of parents with learning disabilities, Bloomfield, L et al., in British Journal of Learning Disabilities, 38, 4, 303–309.

Link to article: <http://tinyurl.com/pwd45001>

- The last 20 years has seen a steady rise in number of parents with learning disabilities referred to social workers and community health practitioners.
- A common experience for parents with learning disabilities is to have their child removed from home and placed permanently in care
- Often judged as inadequate parents, research suggests they can be good enough parents when provided with parenting support.
- Study reports development of a tool to measure self-efficacy of parents with learning disabilities, to evaluate parenting initiatives specifically aimed at this parent group.
- A tool to measure parenting self-efficacy (TOPSE) has been adapted to be accessible to parents with learning disabilities.
- 18 parents took part in study to complete and comment on the tool with help of a researcher from the community learning disabilities team.
- Tool consists of 45 self-efficacy statements and requires further testing with larger sample of parents with learning disabilities.

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