



NHS Evidence – learning disabilities Evidence Bulletin 044 November 2010



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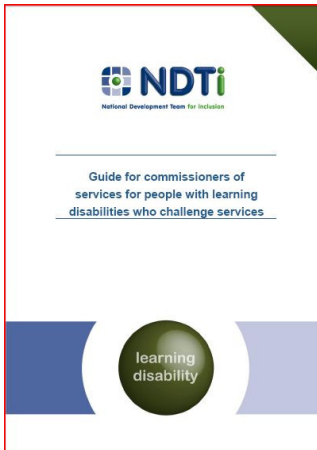
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Welcome to the latest evidence update

Welcome to the Evidence Bulletin. This month our extended summaries are looking at behavioural interventions in self injurious behaviour and an evaluation of an assertive outreach team, 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.



Guide for commissioners of services for people with learning disabilities who challenge services, National Development Team for Inclusion

A guide by the National Development team for Inclusion (NDTi) to help commissioners to implement Government policy on how to commission cost and outcome effective services for people with learning disabilities described as 'challenging services'.

People with learning disabilities labelled as 'challenging' services continue to get poor quality services and outcomes. Costs of these services are often very high. Government policy on changing this is described in the '[Mansell report](#)'.

NDTi has studied areas that have made progress with implementing guidance in the Mansell report and this guide summarises evidence from this work.

Seven areas are described where practice needs to change

- I. Vision and values
- II. Leadership
- III. Relationships
- IV. The service model
- V. Provider and staff skills
- VI. Having an evidence base
- VII. Specific commissioner actions

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

Challenging Behaviour



What evidence is there for the effectiveness of behavioural interventions in self injurious behaviour?

Self injurious behaviour (SIB) affects a significant number of people with severe learning disabilities, with some estimates suggesting this may be as many as 25%. SIB of course poses risks to the person's health and impacts on their quality of life. This review of literature from 1998 to 2008 updates a previous review and attempts to identify what contribution is made by behavioural approaches to supporting people who engage in SIB. The author systematically reviews articles found in peer reviewed journals, professional guidelines and from 'grey' literature. 34 documents were identified as relevant although the

majority of these were single case studies.

There were significant methodological problems with many of the papers, and the reports often left out key information such as ethical considerations and consent issues, long term efficacy and impacts on outcomes other than changes in frequency of SIB during the intervention. Because of the fact that many were single case studies, whilst they were illuminating, it is difficult to generalise on the basis of the findings.



The review found that reductions in SIB, the main outcome measure reported, were highly variable, and were often produced in controlled experimental environments rather than in natural clinical environments. Additionally, reductions were also often achieved with the use of aversive interventions, with punishment being used in some studies, which clearly raises significant ethical concerns.

The author concludes that research into behavioural interventions for SIB has yielded mixed results in the last ten years with a dearth of research considering how techniques can be applied in clinical or 'real life' settings. He calls for more research to be published by practising clinicians in order to develop more effective interventions.

Behavioural interventions for self injurious behaviour: a review of recent evidence (1998–2008), Prangnell, S, in *British Journal of Learning Disabilities*, 38, 259–270.

Read extended summary: <http://tinyurl.com/es4401>



What did stakeholders in an 'Assertive Outreach Team' think about the service it provided?

This small scale evaluation of an assertive outreach team (AOT) for people with learning disabilities and challenging behaviour set out to evaluate the service on the basis of Maxwell's Multi-dimensional Quality Evaluation Model. The study examined the differing indices of quality that different stakeholders in the service were likely to focus on which include effectiveness, efficiency, economy, equity, access to services, appropriateness and social acceptability. Participants were AOT staff and service managers (6), members of Community Learning Disability Team (CLDT 11) and staff from support services who had received input from the team (7). 47 questionnaires were distributed, and 24 were returned,

giving a response rate of 51%.

The authors found the service to be effective at significantly reducing or eliminating challenging behaviour with those referring to the AOT rating it as 'quite useful' and reporting a reduction in challenging behaviour in 71% of clients. The team was developed following the closure of an inpatient unit at a long stay hospital and was consequently staffed solely by nurses. Joint working did take place however and was seen overall as useful overall. AOT staff rated contact more highly than other respondents.

Referrers were satisfied with the AOT overall, with nearly half referring to expertise and approach. The most common area of dissatisfaction referred to lack of clarity about role and remit of the AOT, the relationship with the wider LD service and communication issues.

The authors point out a number of limitations of the study, including the lack of direct input from people with learning disabilities and unpaid carers. All respondents were paid support staff, rather than family members.

The effectiveness of the service was evaluated only in terms of a reduction in challenging behaviour, not taking into account other areas such as increases in meaningful activities or quality of life measures. The numbers involved were also small, which suggests caution in generalising results.

This small scale evaluation however did show the AOT provided a locally based service rated as effective, efficient, accessible, equitable and appropriate. The evaluation found a need for greater clarity about role and remit and improved communication with the wider LD service. The authors also suggest that the AOT needs to move towards multi-disciplinary membership in line with [Guidance from the Royal Colleges](#).

Evaluating an assertive outreach team for supporting clients who present behaviour that challenges, McKenzie, K & Paterson, M., in *British Journal of Learning Disabilities* 38, 319–327.

Read extended summary: <http://tinyurl.com/es4402>



Review:

The use of clozapine among individuals with intellectual disability: A review, Singh A et al., in [Research in Developmental Disabilities](#) 31, 6, 1135-1141

Link to article: <http://tinyurl.com/cb44001>

- Clozapine is currently being prescribed in the USA for adults with learning disabilities for reasons other than refractory or treatment resistant schizophrenia, increasingly being used to treat behavioural problems. Authors review and summarize available studies regarding use of clozapine for behavioural purposes among individuals with ID.
- Findings suggest effectiveness of clozapine in targeting challenging behaviours among people with ID is inconclusive at present.

Single studies:

Self-Injurious Behavior and Fragile X Syndrome: Findings From the National Fragile X Survey, Symons F, in [American Journal on Intellectual and Developmental Disabilities](#), 115, 6, 473-481.

Link to article: <http://tinyurl.com/cb44002>

- National Fragile X Survey data used to examine reported self-injurious behavior (SIB) to generate lifetime and point prevalence estimates; document detailed features of (frequency, types, location, severity) in relation to gender and to compare co-morbid conditions between matched pairs of individuals with SIB and those without.
- Results suggest significant gender differences in frequency, topography, and location of SIB as well as sleep difficulties, co-morbid conditions, pain sensitivity, and seizures.
- Comparisons of matched pairs revealed differences for males in sensory and attention problems, hyperactivity, aggression, autism, and anxiety and for females, in autism, attention, and anxiety.

Frequency and severity of challenging behaviour in people with profound intellectual and multiple disabilities, Poppes P in [Research in Developmental Disabilities](#), 31, 6, 1269-1275

Link to article: <http://tinyurl.com/cb44003>

- 181 people with profound intellectual and multiple disabilities (PIMD) (mean age:35; 56% male) took part in study.
- Prevalence, frequency and severity of self-injurious (SIB), stereotypical and aggressive/destructive behaviour was determined using Behaviour Problem Inventory. An additional questionnaire determined presence of sensory impairments and health problems.
- Prevalence of 82% for SIB and stereotypical behaviour found in sample. Aggressive/destructive behaviour was seen in 45%.
- SIB occurred on a daily or weekly basis. Stereotypical behaviour was seen on a daily basis and aggressive/destructive behaviour usually once a week.
- Severity of challenging behaviour usually rated by staff as of minor consequence for the person.
- Relationship found between having visual, tactile or psychiatric problems and occurrence of challenging behaviour.
- Participants with visual impairments, tactile impairments or psychiatric problems showed significantly higher mean scores regarding challenging behaviour.
- Authors found challenging behaviour in target group to be very common.
- Prevalence figures are high, but direct support professionals did not rate such behaviour as of serious consequence.



Health

Single Studies:

Seizures in Fragile X Syndrome: Characteristics and Comorbid Diagnoses, Berry-Kravis E et al in American Journal on Intellectual and Developmental Disabilities 115, 6, 461-472.

Link to article: <http://tinyurl.com/hlth4401>

- Data from national survey of caregivers of individuals with fragile X syndrome found of 1,394 individuals (1,090 males and 304 females) with full mutation, 14% of males and 6% of females reported seizures.
- Seizures more often partial, began between ages 4 and 10 were infrequent and easily treated.
- Autism found to be significantly associated with seizures as co-occurring condition.

Participation in Sports by People with Intellectual Disabilities in England: A Brief Report., Robertson, J. & Emerson, E in Journal of Applied Research in Intellectual Disabilities, 23: 616–622.

Link to article: <http://tinyurl.com/hlth4402>

- Using sample of 2784 people with intellectual disabilities in England, participation in sports and measures of personal characteristics, living situation, social participation, and socioeconomic status associated with participation were analysed.
- 41% of participants had taken part in sports in the past month. 34% of those who did not take part said they would like to.
- Authors conclude that targeting interventions to increase participation in sports by people with intellectual disabilities may make a significant contribution to improving their health and well-being.

Obesity, Food Selectivity, and Physical Activity in Individuals With Fragile X Syndrome Raspa M et al in American Journal on Intellectual and Developmental Disabilities 115,. 6, 482-495.

Link to article: <http://tinyurl.com/hlth4403>

- National survey data from 884 families indicate rate of obesity in adults with fragile X syndrome is similar to general population (~30%).
- Male children with fragile X syndrome had higher rates of obesity (31%) when compared with typically developing same-aged peers (18%).
- Physical activity levels for children were higher than for adults
- Several cognitive and behavioural characteristics, food selectivity, and physical activity were related to overall health and body mass index.

Motor performance of children with mild intellectual disability and borderline intellectual functioning, Vuijk, P. et al in Journal of Intellectual Disability Research, 54: 955–965

Link to article: <http://tinyurl.com/hlth4404>

- 170 children between 7 and 12 years old with mild intellectual disabilities or borderline intellectual functioning were tested using the Movement Assessment Battery for Children (MABC).
- 81.8% with mild ID and 60% with borderline functioning performed below the 16th percentile.
- Both groups demonstrated relative weakness in manual dexterity.
- Authors conclude that children with ID had more motor problems than the normative sample, supporting the notion that the level of motor and cognitive functioning are related in children with ID.



Mental Health

Hurting No-One Else's Body but Your Own: People with Intellectual Disability Who Self Injure in a Forensic Service, Duperouzel, H & Fish, R in Journal of Applied Research in Intellectual Disabilities, 23: 606–615

Link to article: <http://tinyurl.com/mh4401>

- Phenomenological study using in-depth interviews to gather rich descriptions of experiences of self-injury.
- Four themes emerged; coping strategies; staff and the organizational response – therapeutic communication, close observation and looking to the future.
- Self-injury was seen as an effective means of reducing distress

An Examination of Psychotropic Medication Side Effects: Does taking a greater number of psychotropic medications from different classes affect presentation of side effects in adults with ID? Mahan S et al., in Research in Developmental Disabilities, 31, 6, 1561-1569

Link to article: <http://tinyurl.com/mh44002>

- 80 adults diagnosed with learning disabilities took part in study to look at whether number of psychotropic medications taken by an individual with learning disabilities across classes influences side effects.
- Study found a significant main effect regarding number of psychotropic medication classes prescribed. Four of the nine *Matson Evaluation of Drug Side-effects (MEDS)* domains had different mean scores for number of psychotropic medication classes.
- In MEDS domains such as 'Central Nervous System-General', 'Parkinsonism/Dyskinesia' and 'Behavioral/Akathisia' participants in no psychotropic medication group had lower mean scores than those in one and two psychotropic medication groups.
- 'Cardiovascular and Hematologic Effects' and 'Skin, Allergies and Temperature' were MEDS domains in which there were different scores between participants taking one psychotropic medication as compared with two psychotropic medications from different classes.

Advocacy and Empowerment

Leadership development of individuals with developmental disabilities in the self-advocacy movement, Caldwell, J in Journal of Intellectual Disability Research, 54: 1004–1014

Link to article: <http://tinyurl.com/adv4401>

- Qualitative interviews conducted with 13 leaders in self-advocacy movement in USA to explore life stories. Grounded theory led to identification of major themes and factors associated with leadership development.
- Themes identified: disability oppression and resistance; environmental supports and relationships; leadership skills; advanced leadership opportunities.

Autism

Effectiveness of a Novel Community-Based Early Intervention Model for Children With Autistic Spectrum Disorder, Smith I et al., in American Journal on Intellectual and Developmental Disabilities, 115, 6, 504-523.

Link to article: <http://tinyurl.com/aut4401>

- Using the Nova Scotia early intensive behavior intervention model—NS EIBI 45 children (33 males, mean baseline age 50 months) were followed for 12 months.
- Mean gains of 14.9 months were observed on expressive and 19.5 months on receptive language measures were observed for children with IQ of 50 or more at baseline.
- 6.1 months on receptive language measures and 8.4 months on receptive language measures were observed for children with IQs less than 50.



- Behaviour problems decreased over 1-year treatment for both groups.
- Autism symptoms decreased for those with IQ of 50 or more.

Education

Mothers and Fathers at Play with their Children with Down Syndrome: Influence on Child Exploratory and Symbolic Activity, De Falco S et al., in Journal of Applied Research in Intellectual Disabilities, 23: 597–605.

Link to article: <http://tinyurl.com/ed4401>

- 40 parent–child dyads participated: 20 children with Down syndrome (DS) (*mean* age 36.14 months) with mothers and separately with fathers.
- Children increased exploratory play from solitary to collaborative sessions with both parents, symbolic play increased only during joint play with fathers.
- Fathers showed a higher degree of attunement.
- Authors suggest study shows maternal and paternal contributions to DS child play skills are positive but different.

Learning Disability Policy

Reflections on using the Model of Human Occupation Screening Tool in a joint learning disability team, Hawes D & Houlder, D in The British Journal of Occupational Therapy, 73, 11, 564-567

Link to article: <http://tinyurl.com/ldp4401>

- 6-month preliminary study of the Model of Human Occupation Screening Tool (MOHOST) in a community learning disability service as a response to demands for evidence-based practice
- Study found positive results satisfying requirements for assessments and outcome measures that are reliable in their practice setting, clinically useful and flexible.
- Occupational therapists found MOHOST facilitated consistent and evidence-based practice, without compromising professional autonomy or a client-centred focus.

Person Centred Services

The perception of friendship in adults with Down syndrome, Watt, K in Journal of Intellectual Disability Research, 54: 1015–1023

Link to article: <http://tinyurl.com/pcs4401>

- 22 adults with Down syndrome (DS), 22 typical mental age (MA) matched children and 22 typical adults matched for chronological age (CA) completed a visually based Friendship scale to evaluate the perception of friendship in adults with DS
- Adults with DS scored lower on Friendship scale in comparison with CA and MA matched groups.
- Adults with DS made more errors in identifying ‘friends’ from ‘non-friends’
Adults with DS were equally able to distinguish friendly behaviours and actions from non-friendly behaviours as CA and MA matched peers.
- Adults with DS were more likely to incorrectly identify photographs depicting teacher, mother with a child as friends



Profound Intellectual and Multiple Disabilities

What makes them feel like they do? Investigating the subjective well-being in people with severe and profound disabilities, Vos P et al, in [Research in Developmental Disabilities](#), 31, 6, 1623-1632

Link to article: <http://tinyurl.com/pimd4401>

- The Mood, Interest and Pleasure Questionnaire was completed for 360 persons with severe or profound intellectual disabilities by a member of direct support staff
- Subjective well-being of persons with profound ID was found to be lower than subjective well-being of people with mild, moderate or severe ID or those without disabilities.
- Client and informant characteristics were found to have an influence on subjective well-being of those with severe and profound ID.

Supporting Family Carers

Parents' Experiences of the Provision of Community-Based Family Support and Therapy Services Utilizing the Strengths Approach and Natural Learning Environments, Carlson, G et al., in [Journal of Applied Research in Intellectual Disabilities](#), 23: 560–572

Link to article: <http://tinyurl.com/sfc4401>

- Nine parents undertook in-depth, semi-structured interviews to understand their experience of a particular service team adopting a strengths approach, utilizing natural learning environments
- Key themes included; families' initial experiences, views of their child with a disability, hopes for the future and experiences of receiving intervention from the team.
- Parents were generally positive about the adoption of a strengths approach.

Vulnerable Adults and Abuse

Adult Protection of People with Intellectual Disabilities: Incidence, Nature and Responses, Beadle Brown J et al., in [Journal of Applied Research in Intellectual Disabilities](#), 23: 573–584

Link to article: <http://tinyurl.com/vab4401>

- Analysis of 1,926 referrals relating to people with intellectual disabilities (ID) including description of nature of abuse and responses to referrals, comparisons to those relating to other client groups and comparisons between those placed locally and those placed out-of-area.
- One-third of all adult protection referrals related to people with ID, although number of referrals increased significantly.
- Majority of people lived in residential care or supported living (reflected in nature of referrals)
- Most common type of abuse was physical abuse.
- Sexual abuse was more prevalent in ID sample than in other client groups.
- People with ID more likely to have experienced follow-up action, usually through more monitoring.
- There was a different pattern of abuse seen in those placed out-of-area.

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