NHS Evidence – learning disabilities
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In this issue:

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.

Challenging Behaviour

What impact does sleep disturbance have on the behaviour of adults with Prader-Willi syndrome?

This study set out to explore the prevalence and nature of sleep disturbances in group of adults with Prader Willi syndrome (PWS) in Holland, looking at the possibility of any relationships between sleep disturbances and behavioural problems and any possible associations between sleep disturbances and gender, age, BMI, living situation, medication use and behavioural problems in adults with PWS. Individuals with Prader–Willi syndrome (PWS) are at risk of sleep disturbances, such as excessive daytime sleepiness (EDS) and sleep apnoea and behavioural problems

The authors used semi structured questionnaires, administered to the person or their main caregiver (paid or unpaid). They also used two standard measurement tools, the Epworth Sleepiness Scale (ESS) to measure the participants' general level of daytime sleepiness, and the Sleep Apnea sub-scale of the Sleep Disorders Questionnaire (SA-SDQ) to identify if sleep apnoea was clinically probable.

The study found eleven adults with PWS (15%) had a current sleep problem, mostly night waking problems.

Twenty-six (33%) suffered from severe EDS. The authors found no differences in prevalence of sleep disturbances between genetic subtypes.

Seventeen adults with deletion (i.e. 38%) and 17 adults with maternal uniparental disomy (i.e. 52%) had behavioural problems, although no significant relationships were found between sleep disturbances and behavioural problems.

The authors conclude that excessive daytime sleepiness was the most common type of sleep disturbance found in the cohort. Men and individuals with relative high BMI were more at risk for EDS. They recommend future research focus on relationships between sleep disturbances and development of behavioural and emotional problems in adults with mUPD.

Clinical implications include a recommendation that caregivers regularly look for sleep disturbances in adults with PWS using the ESS and also look for sleep disturbances when daytime behaviour becomes disorganised. Individual treatment plans for sleep disturbances in adults with PWS could consist of a treatment of extreme obesity, treatment of sleep apnoea, attention to sleep hygiene measures and treatment of (night time) behaviour problems and/or psychiatric illness.

Sleep disturbances and behavioural problems in adults with Prader–Willi syndrome, Maas A et al., in Journal of Intellectual Disability Research 54, 10, 906–917

Extended Summary: **http://tinyurl.com/ES4201**

Reviews

1. **Self-injurious behaviour in people with intellectual disability**, Oliver C & Richards C in Current Opinion in Psychiatry: 23, 5, 412–416

Link to article: http://tinyurl.com/cb42001

- Critical review of peer-reviewed published studies of relevance to self-injurious behaviour in people with intellectual disability (ID) and autism spectrum disorders (ASD).
- Recent literature describes systematic evaluation of efficacy of aripiprazole and parent training combined with risperidone.
- Meta-analyses of behavioural interventions provide evidence of efficacy and related research describes beneficial modification to behavioural assessment procedures.
- Prevalence literature provides data on individual characteristics associated with persistence and presence of self-injury which might be considered as risk markers.
- Pain behaviour appears to be associated with self-injury, with implications for theories of the involvement of endorphins and as a causal factor.
- Authors conclude that research findings demonstrate multiple influences on self-injurious behaviour to be taken into account in assessment, formulation, and intervention process.

Single studies

2. **A Study of Post-Institutionalized Men With Severe Intellectual Disabilities and Challenging Behavior**, Hubert J & Hollins S, in Journal of Policy and Practice in Intellectual Disabilities, 7: 189–195

Link to article: http://tinyurl.com/cb42002

- Ethnographic study using participant observation designed to help understand post-deinstitutionalization experiences and needs of a group of 20 men with severe intellectual disabilities and challenging behaviors previously living locked ward in long stay ‘mental handicap’ hospital.
- Findings suggest the men's lives had improved in material terms in their new residences, but there were limitations on other significant changes in their lives.
- All still experienced social exclusion and denial of individual identity and autonomy.
- There were few fundamental changes in professional and social attitudes toward them.
- Authors conclude that evidence still exists, that individual human and civil rights of some adults with intellectual disabilities continue to be ignored even after entry back into the community.

3. **Challenging behaviours should not be considered depressive equivalents in individuals with intellectual disabilities. II. A replication study,** Sturmey P et al, in Research in Developmental Disabilities, 31, 4, 1002-1007

Link to article: http://tinyurl.com/cb42003

- Authors suggest that research proposing behavioural equivalents for depression has been contradictory.
- Study assessed relationship between a measure of depression and several proposed behavioural equivalents of depression in 693 adults (most with severe or profound intellectual disability) living in large residential setting.
- Frequency of language-based measures of depression was very low.
- A scale to assess depression was constructed based on an item analysis of a larger pool of items. Little or no relationship between proposed behavioural equivalents and depression was found.
- Authors conclude that support was found for behavioural equivalents of depression and they suggest caution when attempting to use maladaptive behaviours as evidence of depression in people with severe or profound intellectual disabilities.

4. **Mania and behavioural equivalents: A preliminary study,** Sturmey P et al., in Research in Developmental Disabilities 31, 5, 1008-10141014

Link to article: http://tinyurl.com/cb42004

- Relationship between a measure of mania and possible behavioural equivalents was assessed in 693 adults, most with severe or profound ID, living in a large residential setting.
- Mania subscale of the DASH-II was used.

- Many behavioural items acceptably correlated with mania items.
- Authors conclude that there may be some challenging behaviours related to mania in individuals with ID.
- Factor analysis noted decreased need for sleep, restlessness, agitation, and irritability as items associated with mania.

Autism

Reviews

1. **The co-occurrence of nonaffective psychosis and the pervasive developmental disorders: A systematic review,** Padgett F et al., in Journal of Intellectual and Developmental Disability, 35, 3 187-198

Link to article: http://tinyurl.com/aut4201

- Historical overview relating to the co-occurrence of pervasive developmental disorders (PDD) and nonaffective psychosis.
- Methodology and estimated rates of psychosis occurring in PDD varied dramatically.
- Authors could draw few conclusions due to level of heterogeneity and selection bias in populations studied.
- There were indications from literature that rates of co-morbid PDD were elevated in adolescents affected by juvenile-onset psychosis but methodology was insufficiently robust to estimate pooled prevalence.
- Authors conclude that some evidence exists for elevated rates of co-morbid PDD in individuals with childhood-onset psychosis.

2. **Using Participant Data to Extend the Evidence Base for Intensive Behavioral Intervention for Children With Autism**, Eldevik S et al., in American Journal on Intellectual and Developmental Disabilities, 115, 5, 381-405.

Link to article: http://tinyurl.com/aut4202

- Individual participant data from 16 group design studies on behavioural intervention for children with autism.
- 309 children received behavioural intervention, 39 received comparison interventions, 105 were in control group.
- 29.8% of children who underwent behavioural intervention achieved reliable change in IQ compared with 2.6% and 8.7% for comparison and control groups.
- Reliable change in adaptive behaviour was achieved for 20.6% versus 5.7% and 5.1%, respectively.
- Results equated to a number needed to treat of 5 for IQ and 7 for adaptive behaviour and absolute risk reduction of 23% and 16%, respectively.
- Intensity of intervention predicted gains in both IQ and adaptive behaviour.

3. **Mental health of adults with autism spectrum disorders and intellectual disability,** Underwood L et al., in Current Opinion in Psychiatry, 23, 5, 421-426

Link to article: http://tinyurl.com/aut4203

- Critical review of studies since March 2009 about mental health of adults with intellectual disability (ID) who have autism spectrum disorders (ASD)
- Recent studies do not support hypothesis that adults with ID and ASD are more vulnerable to psychiatric disorders than those without ASD.
- Severity of intellectual disability, adaptive behaviour skills and social skills were factors found to be associated with poorer mental health.

- Authors conclude that evidence base on mental health of adults with ID and ASD is small but rapidly increasing. Studies had relatively small sample sizes difficulties remain in accurately assessing ASD and psychopathology in adults with ID.

Single Studies

4. **Behaviour problems: Differences among intellectually disabled adults with co-morbid autism spectrum disorders and epilepsy,** Smith K & Matson J in Research in Developmental Disabilities, 31, 5, 1062-1069

Link to article: **http://tinyurl.com/aut4204**

- Assessment of behaviour problems among adults with intellectual disabilities (ID), autism spectrum disorders (ASD), and epilepsy residing at state-run facilities were made with the ASD–behaviour problems-adult version battery.
- 100 participants with ID matched and compared across four equal groups comprising 25 participants with ID, 25 participants with epilepsy, 25 participants with ASD, and 25 participants with combined ASD and epilepsy.
- Controlled for age, gender, race, level of ID, and hearing and visual impairments, significant differences were found among the four groups,
- No significant differences were found on self-injury subscale and disruptive behaviour subscale.
- Trend analysis demonstrated individuals with ID expressing combined co-morbid ASD and epilepsy were significantly more impaired than control group (ID only) or groups containing a single co-morbid factor with ID (ASD or epilepsy only) on these four subscales.

Learning Disability Policy

Reviews

1. **Public policy in intellectual and developmental disability**, Cumella S., in Current Opinion in Psychiatry, 23, 5, 417–420

Link to article: **http://tinyurl.com/ldp4201**

- Review of research into public policy affecting people with intellectual and developmental disabilities, published in 2009 and early 2010.
- Authors suggest a growing body of international policy relating to intellectual disability, usually expressed as general moral objectives, which may however neglect the importance of protecting people with intellectual disabilities from exploitation and violence.
- They argue that proxy purchasing of services by public agencies may steer people with ID into limited services which may treat their clients in a childlike way, failing to promote choice, problems which may arise from the difficulty experienced by staff in reconciling agency commitments to empowerment with the reality of their clients' limited capacity for making informed and rational choices.
- Authors conclude that public policy affecting the lives of people with ID is underdeveloped as an area of scholarship and there is a need for more critical analysis, drawing on a broader range of academic disciplines.

2. **Economic evidence in intellectual disabilities: a review,** Romeo R & Molosankwe I, in Current Opinion in Psychiatry, 23 5 427–431

Link to article: **http://tinyurl.com/ldp4202**

- Review of recent publications of economic studies in intellectual disability. Between January 2006 and February 2010, 10 economic studies were found.
- There is a lack of good quality information on resource and cost implications of various treatments and support for people with intellectual disabilities.
- Economic evaluation techniques can be used to inform decision making.

- Analyses assessing a wide range of outcomes alongside costs were most widely used evaluation method in the review.

Single studies

3. **Referrals to a learning disability social work team 1996 to 2005**, Morrison, A et al., in British Journal of Learning Disabilities,38: 168–174.

Link to article: **http://tinyurl.com/ldp4203**

- Referrals to North Belfast Learning Disability Social Work Team between 1 January 1996 and 31 December 2005 were studied.
- Documentary analysis of 252 referrals during 10-year period included referral books, social work files and the electronic client-based system Soscare.
- Increases in referrals with recorded autism and in those aged 18–25, and high levels of recorded behavioural difficulties were found.
- Low levels of recorded visual impairment, hearing impairment and mental health problems were identified.
- 21% of referrals were likely to have been diagnosed with a learning disability at age 16 or over.
- Child referrals showed a broad spectrum of identified need whereas adult referrals were predominantly identified as needing daytime occupation.
- Team caseload increased from 364 to 489 over the period.
- Authors recommend greater focus on health status in social work assessments, a review of case management practice and greater inclusion of 'newly diagnosed' adolescents and adults in service planning.

Health

Reviews

1. **Motivational correlates of physical activity in persons with an intellectual disability: a systematic literature review**, Hutzler, Y. and Korsensky, in Journal of Intellectual Disability Research, 54: 767–786.

Link to article: **http://tinyurl.com/hlth42001**

- Systematic analysis of literature covering articles from 1980 to 2009.

  Inclusion criteria based on terms referring to participants, psychosocial correlates and type of activity.
- 23 articles satisfied inclusion criteria, and were divided into four categories of studies:
  - (1) cross-sectional designs,
  - (2) experimental prospective one-group designs,
  - (3) longitudinal comparative intervention designs,
  - (4) Qualitative designs.
- Level of quality regarding intervention studies was assessed using four different scales and on average depicted a moderate level of evidence.
- Exercise and sport-related activities appeared to contribute to well-being.
- Improved physical fitness and elevated skill level gained during exercise and sport activities appeared to serve as mediators for increased perceptions of self-efficacy and social competence.
- Peer modeling and video and audio reinforcement appear to be important modalities in maintaining compliance to exercise programmes.

Single studies

2. **Electronic Health Record Analysis of the Primary Care of Adults With Intellectual and Other Developmental Disabilities**, Tyler, Jr., C. Et al., in Journal of Policy and Practice in Intellectual Disabilities, 7: 204–210.

Link to article: http://tinyurl.com/hlth42002

- Case-control Electronic Health Record EHR analysis of adults with intellectual and other developmental disabilities (IDD) receiving primary care in Cleveland, Ohio, USA between 2005 and 2008.
- Comparison cohort matched by age, sex, race, and insurance also specified.
- Demographic, health, and health service characteristics of the two cohorts were compared.
- IDD cohort consisted of 1,267 individuals (mean age: 39 years; 54% male). Age, sex, racial, and health insurance characteristics were similar in the 2,534 individuals in comparison cohort.
- Individuals with IDD were significantly more likely to carry co-morbid diagnoses of epilepsy, constipation, osteoporosis, obesity, and hyperlipidemia, but significantly less likely to bear co-morbid diagnoses of hypertension, diabetes, osteoarthritis, heart failure, coronary heart disease, and chronic obstructive pulmonary disease.
- Individuals with IDD were more likely to be labeled obese.
- Genetic consultation rates were higher in IDD cohort.

3. **Side Effects of Minocycline Treatment in Patients With Fragile X Syndrome and Exploration of Outcome Measures** Utari A et al., in American Journal on Intellectual and Developmental Disabilities115, 5, 433-443.

Link to article: http://tinyurl.com/hlth42003

- Review and preliminary survey to document side effects and potential outcome measures for minocycline use in treatment of individuals with fragile X syndrome.
- 50 patients with fragile X syndrome who received minocycline for at least 2 weeks surveyed - most common reported side effect was gastrointestinal difficulty, including loss of appetite.
- Families reported improvement in language and behavioral areas.
- Authors emphasise need for randomized clinical trials to determine the efficacy of minocycline in fragile X syndrome.

4. **Staff responses to age-related health changes in people with an intellectual disability in group homes,** Webber R et al., in Disability & Society, 26, 6, 657-671

Link to article: http://tinyurl.com/hlth42004

- 10 group home supervisors working in disability sector were interviewed
- Several factors relating to whether a resident could stay 'at home' or would need to be moved to residential aged care (nursing home) were identified including:
    - nature and extent of group home resources,
    - group home staff comfort with residents' health changes,
    - staff skill at navigating intersection between disability and ageing sectors,
    - Supervisor’s philosophy of care.
- Authors suggest that despite growing concern for the rights of people with disability, questions about the older person's choice of residence and participation in decision making about what was best for them, were almost nonexistent.

5. **Hospital experiences of older people with intellectual disability: Responses of group home staff and family members,** Webber R et al., in Journal of Intellectual and Developmental Disability, 35, 3, 155-164

Link to article: **http://tinyurl.com/hlth42005**

- Grounded dimensional analysis study tracking group home residents who were tracked prospectively over a 3-year period. Interviews were conducted with family, group home, and aged care staff and managers, and some residents.
- Findings highlighted difficulty people with ID experience in hospital settings and extensive strategies undertaken by family members and group home staff to improve hospital experiences.
- Ageing of family members and staffing implications for group homes complicated efforts to improve hospital experiences.
- Authors conclude that current absence of systems to accommodate special needs of people with ID in hospital settings has significant consequences for group homes, family members, hospital staff, and residents.

6. **A Pilot Study Analyzing Mortality of Adults With Developmental Disabilities Residing in Nursing Homes in Connecticut**, Kerens, G et al., in Journal of Policy and Practice in Intellectual Disabilities, 7: 177–181.

Link to article: **http://tinyurl.com/hlth42006**

- Review of mortality cases for persons with intellectual disabilities (ID) in Connecticut (USA) revealed that majority of deaths in residential settings occurred in nursing homes.
- Preliminary study examining charts of small number of deaths in nursing homes was carried out to elicit understanding of circumstances resulting in nursing home residency for people with ID.
- Data revealed many individuals admitted to nursing homes at an earlier age than for nondisabled general population.
- People with ID stayed longer and died later than general population of nondisabled individuals admitted to nursing homes.
- About half of sample received case management on at least an annual basis; a third had no documented case management.
- Lack of appropriate alternate residential settings, lack of support services for families, and lack of case management resources for adults with ID residing in nursing homes in Connecticut are all apparent from the findings.

7. **Hospitalisation rates for ambulatory care sensitive conditions for persons with and without an intellectual disability-a population perspective,** Balogh, R et al., in Journal of Intellectual Disability Research, 54: 820–832.

Link to article: **http://tinyurl.com/hlth42007**

- Study to compare hospitalisation rates for ambulatory care sensitive conditions between persons with and without an intellectual disability (ID) in a publicly insured population.
- Persons with an ID were identified among general population of a Canadian province between 1999 and 2003.
- Rates of hospitalisations for ambulatory care sensitive conditions for persons with and without ID were calculated and compared.
- Hospitalisation rates for specific conditions were compared, controlling for differences in disease prevalence where possible.
- Study found persons with ID were consistently hospitalised for ambulatory care sensitive conditions at a higher rate than persons without an ID.
- Hospitalisation rates for epilepsy were 54 times higher for those with an ID and for schizophrenic disorders 15 times higher when compared with those without an ID
- Authors conclude that the large discrepancy in rates of hospitalisation between persons with and without an ID is an indicator of inadequate primary care for.

8. **Why some adults with intellectual disability consult their general practitioner more than others**, Turk, V et al., in Journal of Intellectual Disability Research, 54: 833–842

Link to article: http://tinyurl.com/hlth42008

- Secondary analysis of data obtained from a stratified randomised sample of adults with intellectual disabilities (ID) participating in a cluster randomised trial of hand held health records was carried out.
- The number of GP consultations was obtained retrospectively for the year preceding initial health interviews from GP records.
- 201 adults with ID and/or their carers from 40 practices participated.
- GP consultation data extracted for 187 AWIDs.
- Overall consulting levels were low - 3.2 per annum for women and 2.2 for men.
- Increased age, gender (women) and type of carer (paid) were all significantly associated with increased consultations.
- Carers reporting health problems, medications reported by adults with ID, medications recorded in GP records, and pain reported by adults with ID were significant factors affecting consultations to GP practices after adjustment for age and type of carer.
- Authors conclude that consultation rates were lower than expected, affected by age, gender and type of carer.
- Authors suggest the need for targeted interventions to improve attendance and promote health.

9. **Standard care and telecare services: comparing the effectiveness of two service systems with consumers with intellectual disabilities,** Taber-Doughty, T et al., in Journal of Intellectual Disability Research, 54: 843–859.

Link to article: http://tinyurl.com/hlth42009

- Onsite standard care and remote telecare supports were provided to adults with intellectual disabilities (ID) living in community settings and evaluated using an alternating treatment design with baseline and follow-up conditions in a single-case study.
- Investigators compared prompting effectiveness provided by onsite standard care staff and a remote telecare provider.
- Both types of supports resulted in consumers completing tasks.
- Results indicated consumers achieved slightly more independence when prompted by telecare support provider. Telecare supports also resulted in greater duration for task completion per consumer.
- Authors urge caution should when interpreting the results of the study due to the small number of participants and make suggestions for future investigations.

10. **Sensory Impairment in Adults With Intellectual Disabilities—An Exploration of the Awareness and Practices of Social Care Providers**, Newsam, H., et al., in Journal of Policy and Practice in Intellectual Disabilities, 7: 211–220.

Link to article: http://tinyurl.com/hlth42010

- Semi-structured interviews carried out with 17 social care staff to explore awareness of issues relating to sensory impairment (SI).
- Topics included the identification of needs, process of screening, impact of SI on quality of life, consequences of failing to identify needs, frequency of checks, barriers to effective identification, diagnosis and management of SI, advice seeking, and adaptations to practice.
- Thematic analysis highlighted responsibility, communication, further deterioration, and lack of accountability as dominant themes.
- Indications suggest these both precipitate and perpetuate problems in identification and management of SI.
- High expressed responsibility that might motivate best practice is undermined by a lack of accountability, and highlighted a gap in service provision that may result in the sensory health needs of this population being unmet.

11. **Obesity and obesity-related secondary conditions in adolescents with intellectual/developmental disabilities**, Rimmer, J. H., et al., in Journal of Intellectual Disability Research, 54: 787–794.

Link to full text: http://tinyurl.com/hlth42011

- 461 parents of adolescents with intellectual and developmental disabilities (IDD) across 49 US states completed a web-based survey relating to their child's health status and these results were compared with published data for youth without disabilities.
- Adolescents with autism and Down syndrome were two to three times more likely to be obese than adolescents in the general population.
- Secondary health conditions were higher in obese adolescents with IDD compared with healthy weight adolescents with IDD
- Authors conclude that the problem of obesity is as great in youths with IDD as in those without disabilities.
- Obese youth with IDD have a high number of obesity-related secondary conditions predisposing them to greater health problems.

12. **Identifying facilitators and barriers to physical activity for adults with Down syndrome**, Mahy, J et al., in Journal of Intellectual Disability Research, 54: 795–805

Link to article: http://tinyurl.com/hlth42012

- Semi-structured interviews conducted with 18 participants (3 men, 15 women), six of whom were adults with Down syndrome, 12 of who, were supporters, to elicit views about what factors facilitate physical activity and what factors are barriers to activity.
- Facilitators to physical activity were identified as:
  - (1) support from others;
  - (2) that physical activity was fun or had interesting purpose;
  - (3) routine and familiarity.
- Barriers were identified as:
  - (1) lack of support;
  - (2) not wanting to engage in physical activity;
  - (3) medical and physiological factors.
- Authors conclude that support people play a key role as facilitators and barriers in the participation by adults with Down syndrome in physical activity.

Communication

Reviews

1. **Twenty Years of Communication Intervention Research With Individuals Who Have Severe Intellectual and Developmental Disabilities**, Snell M et al., in American Journal on Intellectual and Developmental Disabilities, 115,. 5, 364-380.

Link to article: http://tinyurl.com/comm42001

- Literature review to evaluate current state of evidence supporting communication interventions for individuals with severe intellectual and developmental disabilities.
- 116 articles published between 1987 and 2007 in refereed journals meeting three criteria:
  (a) described a communication intervention,
  (b) involved one or more participants with severe intellectual and developmental disabilities
  (c) addressed one or more areas of communication performance.
- Treatment fidelity or assessment of basic aspects of intervention effects were not reported in many studies.
- Evidence reviewed indicates 96% of studies reported positive changes in some aspects of communication.
- Authors suggest that these findings support provision of communication intervention to persons with severe intellectual and developmental disabilities.

Single studies

2. **Effective communication training interventions for paid carers supporting adults with learning disabilities**, Kyle S et al., in British Journal of Learning Disabilities, 38, 210–216

Link to article: **http://tinyurl.com/comm42002**

- A communication self-efficacy measure relevant to carers supporting adults with learning disabilities was developed and piloted using a pre–post intervention study design.
- 26 paid carers completed the Glasgow-Communication Efficacy Scale (G-CES) before and after participating in a communication training intervention.
- Carer communication efficacy increased after taking part in the training.

Education

Reviews

1. **A review of research on procedures for teaching safety skills to persons with developmental disabilities,** Dixon D et al., in Research in Developmental Disabilities 31, 5, 985-994

Link to article: **http://tinyurl.com/ed42001**

- Review of literature on teaching safety skills to persons with developmental disabilities (e.g. knowing how to cross the street or what to do in case of a house fire.)
- Studies reviewed have varying degrees of success and demonstrate varying degrees of generalization, but authors suggest the general finding has been that prompting, reinforcement, and role-playing are effective teaching procedures across a variety of participants, skills, and settings.

Single Studies

2. **Self-concept of children with intellectual disability in mainstream settings,** Huck S et al., in Journal of intellectual and Developmental Disability**,** 35, 3 , 141-154

Link to article: **http://tinyurl.com/ed42002**

- Perceived competence and acceptance of 17 children with intellectual disability (ID), included in mainstream classes, assessed using Pictorial Scale of Perceived Competence and Social Acceptance for Young Children (PSPCSA).
- Findings compared with independently rated academic work samples and measures of social status, and measures of perceived competence and acceptance reported for other populations of individuals with and without disability.
- Study findings suggest perceived competence and acceptance were positive and comparable to previously reported results for individuals with disability and young children without disability.
- Children's perceived cognitive competence was not consistent with ratings of their work samples but their perceived peer acceptance was more consistent with peer ratings of social status.
- Authors conclude that children with intellectual disability remained positive at an age when self-concept is likely to be negatively impacted by comparisons with higher performing peers.

Supporting Family Carers

Reviews

1. **Chronic stress and health among parents of children with intellectual and developmental disabilities,** Miodrag N & Hodapp R., in Current Opinion in Psychiatry, 23, 5, 407-411,

Link to article: **http://tinyurl.com/sfc42001**

- Review of recent studies connecting chronic stress to health outcomes in parents of children with intellectual and developmental disabilities (I/DD).
- Analysis of studies suggests that only recently have parental physical health problems been linked to aspects of the child with I/DD.
- The authors conclude that chronic stressors can wear down the body, particularly cardiovascular, immune, and gastrointestinal systems. Child characteristics, especially for older parents or for parents of children with certain conditions (e.g. spina bifida), may adversely affect parental health.
- They suggest a need for more research to explore stress-health connections among parents of children with I/DD, as well as the clinical and policy implications of such findings.

Person Centred Services

Single studies

1. **Science and Pseudoscience in Developmental Disabilities: Guidelines for Social Workers,** Thyer B & Pignotti M, in Journal of Social Work in Disability & Rehabilitation, 9, 2&3, 110-129

Link to article: **http://tinyurl.com/pcs42001**

- Authors set out to identify the nature of the evidence base for the broad range of empirically supported treatments that have been shown to be useful in promoting educational attainments, social and vocational skills, and self-care, and in reducing behavioural problems in adults with a developmental disability
- They suggest that a large number of pseudoscientific or bogus therapies continue to be offered to this population and their families.
- The authors review the characteristics of such treatments and provide several examples of unsupported or harmful interventions offered by contemporary social workers and other human service professionals

2. **Understanding Who Moved When**, Martin, L. and Ashworth M in Journal of Policy and Practice in Intellectual Disabilities, 7: 167–176.

Link to article: **http://tinyurl.com/pcs42002**

- Study examining the timing of individuals' transitions from long stay institutions in Ontario Canada, to the community and the characteristics of those individuals who experienced a change in the timing of their move.
- 40% of individuals experienced a change in their transition year.
- Age, bladder incontinence, and number of medical diagnoses were associated with increased likelihood of moving earlier than anticipated,
- Family contact, presence of strong and supportive relationship with family, psychiatric diagnoses, destructive behavior, and aggression were associated with higher likelihood of moving later.

Advocacy & Empowerment

Single studies

1. **Being a member of a self-advocacy group: experiences of intellectually disabled people**, Gilmartin, A. and Slevin, E.. in British Journal of Learning Disabilities, 38: 152–159.

Link to article: **http://tinyurl.com/adv4201**

- Phenomenological methodology exploration of the lived experiences of 13 people who belonged to three self-advocacy groups in day centres in the west of Ireland.
- Changes affected by self-advocacy group membership occurred in the day centres the self-advocating participants attended.
- Being a member was found to enhance the personal lives of the participants.
- Empowerment occurred for the participants' at an individual and collective level.
- Authors conclude that the benefits identified for group members suggests that opportunities should be provided for adults with ID not attending day services to join self-advocacy groups.

Mental Health

Single Studies

1. **The emerging role of the Registered Intermediary with the vulnerable witness and offender: facilitating communication with the police and members of the judiciary**, O'Mahony, B, in British Journal of Learning Disabilities, 38: 232–237.

Link to article: **http://tinyurl.com/mh42001**

- Intermediaries were introduced for adults with intellectual disabilities (ID) being interviewed by the police as a witness or as a suspect by the Youth Justice and Criminal Evidence Act 1999 as one of the special measures available to help facilitate communication between the police, the courts and the vulnerable witness. This mixed methods approach study explored the recent use of intermediaries with defendants.
- The study found that intermediaries were very positive about the need for vulnerable defendants to have support.
- Intermediaries highlighted a need for additional training as well as raising concerns about how their role was viewed by the courts when they were assisting defendants.

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