



NHS Evidence – learning disabilities Evidence Bulletin 036 March 2010



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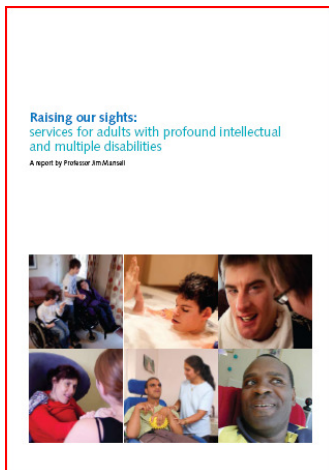
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Welcome to the March 2010 evidence update

We have the usual mix of learning disabilities evidence for you this month, with extended summaries about hand-held records and information about financial decision making, as well as the latest reviews and studies from all of the important databases and journals.

Raising Our Sights: Services for adults with profound intellectual and multiple disabilities



A report by Professor Jim Mansell

Link to full text: <http://tinyurl.com/ybgzdgs>

The review defines this group as people with severely limited understanding (intelligence quotient estimated to be under 20) with multiple disabilities, which may include impairments of vision, hearing and movement as well as other problems like epilepsy and autism. Many will have complex health needs, difficulty communicating; and some may have, in addition, problems of challenging behaviour such as self-injury. Because of this, they will have high support needs. Mansell points out though that people with profound intellectual and multiple disabilities can form relationships, make choices and enjoy activities.

The report suggests an estimated 16,000 adults with profound intellectual and multiple disabilities in England with estimates suggesting this number is likely to rise to 22,000 in 2026,

Mansell suggests that despite undeniable need, families report being met with prejudice, discrimination and low expectations.

The report sets out the elements of good services, starting with the absolute need to be individualised and person centred, working with families as 'experts',

The review found no research on the cost-effectiveness of services specifically for adults with profound intellectual and multiple disabilities, although the cost of care packages ranged from £62,952 to £179,000 a year.

In addition to working with families, the review recognises that there will be people who do not have a family able to engage with services, and Mansell suggests a need for a focus on supporting advocates to meaningfully represent people with profound intellectual and multiple disabilities.

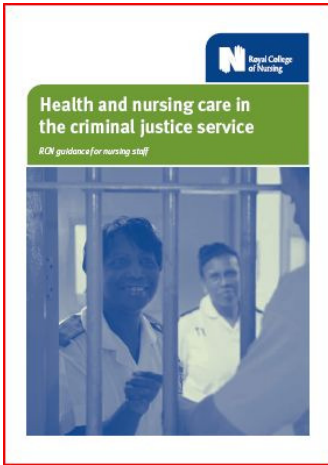
The key role of assistive technology is also highlighted in the report. e.g. use of adapted microswitches electric wheelchairs adapted to follow a track with motion sensors or other microswitches tailored to the disabled person's skills which can have a great impact on a person's quality of life.

Overall, there are 33 recommendations for change, focusing on overcoming the obstacles to providing good quality, cost effective support to this relatively small group of people within the population. Including the need for continued leadership from Government, appropriate responses from public bodies in terms of shaping public places for good access, and some specific requirements on NHS bodies to pay particular attention to meeting the needs of this group, to provide health services which focus on protection of body shape, dysphagia, epilepsy and investigation and resolution of pain and distress, and to ensure that the "Board of each NHS Trust consider a report specifically focused on the adequacy of health services for adults with profound intellectual and multiple disabilities and approve an action plan to ensure adequate treatment." Mansell 2010,p24.



Health

Health and Nursing care in the criminal justice service: RCN guidance for nursing staff.



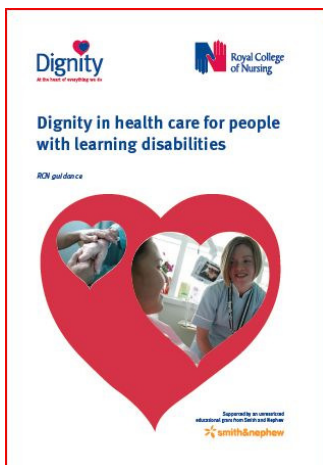
This guide replaces the 2002 Royal College of Nursing (RCN) publication, *Nursing in Prisons*, and highlights the specific health and nursing care needs of offenders.

The guide is designed primarily for nurses, health care assistants and other health care practitioners who are working in, or want to work in, health care in criminal justice service (CJS).

It is a resource to support the delivery of high quality services to people in a broad range of environments, from police custody to high security prisons. The role of health care nurses in the CJS is varied, complex and often challenging. This guide will help you to access up to date information, toolkits and sources of advice to assist you in your work. It aims to respond to the most frequent queries and concerns of nurses working within the CJS.

Link to full text: <http://tinyurl.com/hlth04001>

Dignity in healthcare for people with learning disabilities



Guidance developed by the Royal College of Nursing Learning Disability Nursing Forum aiming to improve dignity in health care for people with learning disabilities.

The guide responds to three key questions raised by a small proactive group of individuals with learning disabilities who use health care services in South East London:

- i. what does dignity mean?
- ii. what were their experiences of health services?
- iii. what could nurses do to make dignity better?

The report is structured to provide:

- i. the experiences of people with learning disabilities using health care services positive experiences areas for improvement in relation to dignity
- ii. what's needed to improve dignity
- iii. getting it right for people with learning disabilities practical ideas on what nurses can do to improve dignity
- iv. signposting
- v. sources of further information and support.

Link to full text: <http://tinyurl.com/hlth04002>

What impact did hand held records have on outcomes for adults with learning disabilities?



Use of GP services by people with learning disabilities has been shown to be lower than the general population average, despite their increased health needs. This cluster randomised controlled trial set out to assess the impact of implementing a hand held health record, called the Personal Health Profile (PHP), on GP consultations and on the health knowledge of adults with learning disabilities and/or their carers.

The Personal health Profile is a ring bound file with three sections, an introduction; eight chapters covering health issues and a section with information for carers, professionals and others. The PHP depends on participation of healthcare professionals to ensure it is updated and maintained.



Forty GP practices were randomized to the Personal Health Profile (PHP) implementation or control group. The researchers carried out interviews with 201 adults with learning disabilities and were able to follow this up with 163 interviews one year later. Adults with learning disabilities and carers were employed as research interviewers.

The authors found annual consultation rates in both groups at baseline to be low. A slightly greater increase occurred over the year in the intervention group compared with controls. Those adults with learning disabilities in the PHP group reported more health problems at follow-up.

Interestingly, 92% of those with learning disabilities using the PHP said they liked it but only 63% reported using it, with only 53% of carers reporting this. The authors found no significant increase in GP visits or usage of health services attributable to implementation of PHPs.

An Evaluation of the Implementation of Hand Held Health Records with Adults with Learning Disabilities: A Cluster Randomized Controlled Trial, Turk V et al., in Journal of Applied Research in Intellectual Disabilities, 23, 2, 100 - 111

Link to LDSC extended summary: <http://tinyurl.com/hlth04LDSC>

Reviews

1. **Major Health Risks in Aging Persons With Intellectual Disabilities: An Overview of Recent Studies** Haveman M et al, in Journal of Policy and Practice in Intellectual Disabilities, 7, 1, 59-69

Link to article: <http://tinyurl.com/hlth04003>

- Health-related literature on aging and intellectual disabilities (ID) published since 1999 examined.
- Review revealed varying differences in prevalence of health risk factors.
- Significant evidence emerging that cardiovascular disease is as prevalent among people with ID and is as common a cause of death as in the general population.
- Review showed variations in prevalence were culturally dependent.
- Digestive system problems were evident with high occurrence rates of helicobacter pylori, gastroesophageal reflux disease, and constipation.
- Review revealed growing body of work on health risk factors, such as overweight and obesity, which are often linked to the onset of a variety of diseases and impairing conditions.
- Healthier lifestyles, better nutrition and more exercise, and greater surveillance of health risks were seen as ways to improve the health status of aging adults with ID.

2. **Sleep disorders in children and adolescents with learning disabilities and their management**, Turk J in Advances in Mental Health and Learning Disabilities, 4, 1, 50-59

Link to article: <http://tinyurl.com/hlth04004>

- Review of sleep disorders in children and young people with developmental disabilities who as a group may prove refractory to standard behavioural and other psychosocial interventions usually helpful.
- Authors conclude the need for further well structured research in and for efforts to tackle frequent relative neglect by clinicians of more researched and considered approaches.

3. **Aging in Down Syndrome: Morbidity and Mortality**, Torr J et al., in Journal of Policy and Practice in Intellectual Disabilities, 7, 1, 70-81

Link to article: <http://tinyurl.com/hlth04009>

- Review of published literature for period: 1993–2008.
- Authors conclude functional decline in older adults with Down syndrome cannot be assumed to be due only to dementia of Alzheimer type (which is not inevitable in all adults with Down syndrome).
- Functional decline may be result from range of disorders, especially sensory and musculoskeletal impairments.
- The authors recommend programmatic screening, monitoring, and preventive interventions to limit secondary disabilities and premature mortality.



Single Studies

1. **Reducing health inequalities in Scotland: the involvement of people with learning disabilities as national health service reviewers**, Campbell M & Martin M in British Journal of Learning Disabilities, 38, 1,49-58

Link to article: <http://tinyurl.com/hlth04005>

- Involvement of people with learning disabilities in health service review teams is described and evaluation by health staff, carers and people with learning disabilities reported.
 - Recommendations are made to ensure the future success of this type of initiative in Scotland and elsewhere.
 - Initiative was evaluated positively and tested traditional assumptions, challenging the power imbalance in patient-provider relationships.
 - Theory and practice of including people with learning disabilities as 'expert patient' reviewers are discussed.
2. **Rehabilitation of Low Vision in Adults with Intellectual Disabilities: The Influence of Staff**, Sjoukes L et al., in Journal of Applied Research in Intellectual Disabilities, 23, 2, 186-191

Link to article: <http://tinyurl.com/hlth04006>

- Prospective study of 60 adults with recent diagnosis of low vision during 12 months after their individual intervention advice.
 - Familiarity with advice was reasonable or good in 41/60, appreciation was positive in 34/60, and implementation was reasonable to complete in 20/60 cases.
 - Familiarity, appreciation and implementation not significantly related to severity of ID or severity of visual impairment.
 - Implementation was positively correlated with familiarity but not with appreciation
 - Authors conclude that it is important to keep professional carers knowledgeable and informed to improve the quality of low vision rehabilitation.
3. **Intellectual disability and sexuality: Attitudes of disability support staff and leisure industry employees**, Gilmore L & Chambers B in Journal of Intellectual and Developmental Disability, 35, 1, 22-28

Link to article: <http://tinyurl.com/hlth04007>

- Sample of 169 disability support staff and 50 employees from leisure and service industries completed the *Attitudes to Sexuality Questionnaires (Individuals with an Intellectual Disability [ASQ-ID])*, and *Individuals from the General Population [ASQ-GP]*.
 - Support staff and leisure workers reported generally positive attitudes towards the sexuality of individuals with an ID, but men were seen as having less self-control than women.
 - Support staff were more cautious in their views about parenting.
 - Both groups considered lower level of sexual freedom to be desirable for women with an ID compared to women who are developing typically.
4. **Carer Knowledge and Experiences With Menopause in Women With Intellectual Disabilities**, Willis D et al., in Journal of Policy and Practice in Intellectual Disabilities, 7, 1, 42-48

Link to article: <http://tinyurl.com/hlth04008>

- One-to-one interviews conducted with 69 carers (7 male/62 female) from range of backgrounds, all with current responsibility for the care of one or more pre-, peri-, and/or postmenopausal women with ID.
- Carers reported difficulty in disentangling psychological and physical consequences of menopause from behaviours and symptoms arising from other causes.
- General recognition of transitional importance of menopause and widespread acknowledgment of the resilience that many women with ID show in coping with it.
- Carers emphasized need for health resources to be better tailored the women's needs and for more relevant health education training for staff.
- Authors conclude additional and new demands are placed on service provision as women with ID live longer and that increased awareness of health issues relating to menopause is needed.



5. **Papanicolaou smear screening of women with intellectual disabilities: A cross-sectional survey in Taiwan**, Lan-Ping Lin et al., in Research in Developmental Disabilities, 31, 2, 403-409

Link to article: <http://tinyurl.com/hlth04010>

- Study to identify and evaluate factors regarding utilization of Pap smears in women with ID seen in the preventive health screening program.
 - Cross-sectional survey “2009 National Survey on Preventive Health Use and Determinants among People with Disabilities” was used with study sample 508 women with ID (aged ≥15 years) in Taiwan.
 - Results showed 22.1% women with ID had ever used Pap smear screening previously. Mean age of first screening was nearly 40 years.
 - Compared to general population in Taiwan, ID women at age group <35 years were less likely to use screening and in age group ≥35 years were more likely to use Pap smears.
 - Marital status and experience of accepted tubal ligation surgery were two factors which predicted Pap smear test use in the study.
 - Married women with ID were 8.99 times more likely to use Pap smear test.
 - Women with ID who had experienced tubal ligation surgery were 10.48 times more likely to use Pap smear test.
6. **Perception and experience of primary care physicians on Pap smear screening for women with intellectual disabilities: A preliminary finding**, Jin-Ding Lin et al., in Research in Developmental Disabilities, 31, 2, 440-445

Link to article: <http://tinyurl.com/hlth04011>

- Study to establish evidence-based data to explore perceptions and experience of primary care physicians in Pap smear screening provision for women with intellectual disabilities (ID), in Taiwan.
 - Data obtained by cross-sectional survey and structured, self-administered questionnaire (12 perceptual issues).
 - 69 valid questionnaires returned (response rate 41.7%).
 - 72.5% of medical care settings provide Pap smear services and 51.5% have practical experience on conducting the tests for women with ID.
 - 90% primary care physicians expressed that women with ID need Pap smear test regularly.
 - Experienced healthcare settings in Pap smear tests for women with ID were more likely to be in public healthcare settings, feel confident in providing screening tests, have rapid screening program and have reminder follow-up system.
7. **Health and social outcomes in adults with Williams syndrome: Findings from cross-sectional and longitudinal cohorts**, Elison S et al., in Research in Developmental Disabilities, 31, 2, 587-599

Link to article: <http://tinyurl.com/hlth04012>

- Study looking at age associated changes in number of different domains of functioning in adults with Williams syndrome (WS).
 - Semi-structured interviews and standardized assessments conducted with adults with WS and their parents/carers. 92 individuals with genetic confirmation of WS (50 males, 42 females) participated in cross-sectional study (age range 19–55 years;) and 43 individuals (21 males, 22 females) were involved in a longitudinal study.
 - Cross-sectional analyses revealed no age related differences in areas of functioning investigated.
 - In longitudinal sample, significant improvements were reported in physical health, self-care and occupational skills. Social skills and adaptive behaviours had generally improved while behavioural difficulties had declined.
 - In cross-sectional and longitudinal cohorts significant correlations between adaptive functioning and IQ found.
8. **Pervasive developmental disorder behavior in adolescents with intellectual disability and co-occurring somatic chronic diseases**, Oeseburg B et al., in Research in Developmental Disabilities 31, 2, 496-501



Link to article: <http://tinyurl.com/hlth04013>

- Study to assess association between somatic chronic diseases in ID-adolescents and mild PDD behaviour.
 - Data on 1044 ID-adolescents, aged 12–18, attending secondary schools in the Netherlands collected.
 - ID-adolescents with somatic chronic diseases showed more PDD behaviour than peers without chronic diseases.
 - ID-adolescents with somatic chronic diseases in combination with pervasive development disorders (PDD) and attention deficit hyperactivity disorder (ADHD) showed more PDD behaviour than peers with only PDD/ADHD.
9. **Hypertension, hyperglycemia, and hyperlipemia among adolescents with intellectual disabilities**, Pei-Ying Lin et al., in Research in Developmental Disabilities, 31, 2, 545-550

Link to article: <http://tinyurl.com/hlth04014>

- Study to assess hypertension, hyperglycemia and hyperlipidemia prevalence of adolescents with intellectual disabilities.
 - Cross-sectional medical chart analysis of 856 students who participated in school enrolment health examinations in three special schools in Taiwan from 2005 to 2007.
 - 11.7% cases had hypertension. Biochemical analyses results showed elevated or abnormal rates of: triglyceride (9.1%), total cholesterol (1.1%), and fasting plasma glucose (0.3%).
 - Study found prevalence of hypertension and elevated triglyceride significantly higher than general population, and body mass index significantly correlated to hypertension and elevated triglyceride tests.
 - Many potential risks for metabolic syndrome in adolescents with intellectual disabilities were found to be higher than in general population.
10. **Ethical dilemmas of antenatal screening for Down's syndrome in primary care**, Douglas N, in Advances in Mental Health and Learning Disabilities, 4, 1, 20-24

Link to article: <http://tinyurl.com/hlth04015>

- Fictionalised case of Bangladeshi woman with strongly positive result for a screening test for which she has not given informed consent is examined from several different ethical standpoints. The dilemma posed by the case is resolved using a narrative ethical approach.

CHALLENGING BEHAVIOUR

Review

1. **Behavioral treatment of chronic skin-picking in individuals with developmental disabilities: A systematic review**, Lang R et al., in Research in Developmental Disabilities, 31, 2, 304-315

Link to article: <http://tinyurl.com/cb04001>

- Review of studies involving treatment of chronic skin-picking in individuals with developmental disabilities. 16 studies met inclusion criteria.
- Studies evaluated in terms of:
 - (a) participants,
 - (b) functional assessment procedures and results,
 - (c) intervention procedures,
 - (d) results of the intervention,
 - (e) certainty of evidence.
- Across 16 studies, intervention was provided to 19 participants aged 6–42 years.
- Functional assessment procedures included direct observations, analogue functional analyses, and functional assessment interviews.
- Most commonly identified function was automatic reinforcement.



- Treatment approaches included combinations of differential reinforcement, providing preferred items and activities stimuli (e.g., toys), wearing protective clothing (e.g., helmets or gloves), response interruption and redirection, punishment, and extinction. Improvements in behaviour were reported in all of the reviewed studies.

Single Studies

1. **Training Staff to Manage Challenging Behaviour**, Wietske M. et al, in Journal of Applied Research in Intellectual Disabilities, 23, 2, **192 - 196**

Link to article: <http://tinyurl.com/cb04002>

- Sessions concerning theories of challenging behaviour were combined with physical intervention training.
 - Training program proved to be effective. Staff knowledge of challenging behaviour and quality of physical intervention techniques increased significantly.
 - Scores remained above pre-test levels at follow-up. Staff members evaluated the training positively.
2. **Assessing behaviour support plans for people with intellectual disability before and after the Victorian Disability Act 2006**, Phillips L et al, in Journal of Intellectual and Developmental Disability 35, 1, 9-13

Link to article: <http://tinyurl.com/cb04003>

- Study looked at how far behaviour support plans for people with intellectual disability are inclusive of best practice criteria, making a comparison prior to and following proclamation of the Disability Act (2006) in Victoria, Australia.
 - The study found best practice criteria were inadequately included in behaviour support plans with little difference between pre- and post-Act plans.
 - Authors suggest that disability support staff are ill equipped to undertake the complex assessments, planning, and implementation associated with behaviour support strategies, despite the legislative framework that guides and directs this intervention.
3. **Challenging behavior and co-morbid psychopathology in adults with intellectual disability and autism spectrum disorders**, McCarthy J et al., Research in Developmental Disabilities, 31, 2, 362-366

Link to article: <http://tinyurl.com/cb04004>

- Investigation of relationship between challenging behaviour and co-morbid psychopathology in adults with intellectual disability (ID) and autism spectrum disorders (ASDs) ($N = 124$) compared to adults with ID only ($N = 562$).
 - All participants were first time referrals to specialist mental health services living in community settings.
 - Analyses showed ASD diagnosis was significantly associated with male gender, younger age and lower level of ID.
 - Challenging behaviour four times more likely in adults with ASD as compared to non-ASD adults.
 - In those with challenging behaviour, significant differences found in co-morbid psychopathology between ASD and non-ASD adults.
 - After controlling for level of ID, gender and age, no association found between co-morbid psychopathology and presence of challenging behaviour.
 - Authors conclude that results suggest presence of challenging behaviour is independent from co-morbid psychopathology in adults with ID and ASD.
4. **Staff reactions to challenging behaviour: An observation study**, Lambrechts G et al, in Research in Developmental Disabilities, 31, 2, 525-535

Link to article: <http://tinyurl.com/cb04005>

- Study examining sequential associations between challenging behaviour and staff reactions by means of a descriptive analysis by analysis of video recordings of reactions of 10 staff members towards challenging behaviour of clients with severe or profound intellectual disabilities who displayed self-injurious behaviour, stereotyped behaviour and/or aggressive/destructive behaviour.



- Staff members used much verbal behaviours after challenging behaviour and often immediately tried to stop the challenging behaviour.
- Staff often gave attention to challenging behaviour whereas offering or taking away material or tasks were less frequently observed reactions.
- Reactions to aggressive/destructive behaviour and self-injurious behaviour were similar.

COMMUNICATION

Single Studies

1. **Eliciting Proto-Imperatives and Proto-Declaratives in Children with Intellectual Disabilities**
Vandereet J et al, in Journal of Applied Research in Intellectual Disabilities, 23, 2, 154 – 166

Link to article: <http://tinyurl.com/comm04001>

- Twenty-eight children with intellectual disabilities participated in a standard assessment battery, consisting of formal language assessment, parent questionnaire, elicitation task for proto-imperatives, and elicitation task for proto-declaratives.
- Elicitation tasks elicited significantly more proto-imperatives than proto-declaratives; with proto-imperatives being predominantly expressed with gestures and proto-declaratives predominantly with vocalizations.
- Authors conclude that several factors need to be considered to account for observed differences in frequency and utterance forms of elicited proto-imperatives versus proto-declaratives and that results overall suggest elicitation tasks for proto-imperatives and proto-declaratives can be reliably used in children with intellectual disabilities.

2. **Relationships amongst age, language and related skills in adults with Down syndrome,**
Iacono T et al, in Research in Developmental Disabilities, 31, 2, 568-576

Link to article: <http://tinyurl.com/comm04002>

- Study using measures of receptive and expressive language from studies of younger individuals with Down syndrome (DS) exploring relationships across linguistic and associated skills, and age in young to older adults.
- Fifty-five adults (19–58 years), 10 with diagnosis of or signs of early stage Alzheimer's Disease (AD), provided data on measures of functioning associated with AD, non-verbal cognition, receptive language (which provided a measure of mental age), receptive and expressive language, and short term auditory and visual memory.
- First order correlation between measure of AD and CA was significant; but not when 10 participants with AD were removed from the analysis. Significant negative correlations obtained between CA and all other measures; small to large significant positive correlations were found amongst the other measures.
- Partial correlations conducted to remove potential effects of AD and IQ and remaining significant correlations were between auditory short term memory and all other included measures, expressive language and all other included measures, and CA and auditory short term memory and expressive language.
- Authors conclude that results indicate deterioration with age in this cross-sectional study was accounted for largely by the presence of AD.



MENTAL HEALTH

How far do people with mild to moderate learning disabilities weigh up sources of information in making financial decisions?



This study set out to look at the ability of a group of people with mild to moderate learning disabilities to weigh up financial information, given that the current Mental Capacity Act assessment includes an evaluation of the ability to 'weigh up' information. The authors had previously used a laboratory decision-making task, temporal discounting, involving a trade-off between value and delay of expected rewards, where participants with learning disabilities showed little evidence of 'weighing up' information. In this study, the authors aimed to replicate this approach, but include a more realistic financial decision-making task.

A temporal discounting task and a financial decision-making task was administered to 20 participants who used a day services along with tests of executive functioning and I. 10 staff members also underwent the tests.

The authors found that performance in both decision-making tasks was related more strongly to executive functioning than to IQ, with decisions being made on the basis of a single item of information. The study found little or no evidence of information from two sources being 'weighed' by service users in either task. The authors believe the results suggest that difficulty in 'weighing up' information could be a general problem for people with learning disabilities. The implication of this and the need to consider executive functioning in the current test of mental capacity is explored.

Evaluation of the ability of people with intellectual disabilities to 'weigh up' information in two tests of financial reasoning, Wilner P et al in *Journal of Intellectual Disability Research*, 54, 4, 380-391

LDSC Extended Summary: <http://tinyurl.com/mh04LDSC>

Reviews

1. **Caregiving and Adults With Intellectual Disabilities Affected by Dementia**, Courtenay K et al., in *Journal of Policy and Practice in Intellectual Disabilities*, 7, 1, 26-33

Link to article: <http://tinyurl.com/mh04001>

- Systematic review of literature for period 1997–2008 on current knowledge on social-psychological and pharmacological caregiving with respect to older adults with intellectual disabilities (ID) affected by dementia.
- Caregiving occurs on personal level between person and their carer and organizational and interorganizational supports have an impact on quality of care provided.
- Service organizations often had to extrapolate from evidence base of dementia care practices in general population.
- Concerns over staff burden, behavioural interventions and staff training, applications of models of care were emerging, but were not systematically studied.
- Authors noted pharmacological agents and non-pharmacological, psychosocial techniques were being used to assist carers manage behaviour, but evidence base of both non-pharmacological and pharmacological interventions was insufficient because of absence of systematic and robust studies.

Single Studies

1. **Setting up and running a loss and bereavement support group for adults with learning disabilities**, Boyden P et al., in *British Journal of Learning Disabilities*, 38, 1, 35-40

Link to article: <http://tinyurl.com/mh04002>

- Description of the setting up of a Loss and Bereavement Psychotherapy group in Birmingham consisting of five adults with mild learning disabilities, who met for 8 consecutive weeks, detailing the development of session plans and structure of the group.



- Authors encourage health professionals to consider setting up similar groups, bearing in mind reflections on practical issues highlighted within the paper.
- 2. Referrals into services for offenders with intellectual disabilities: Variables predicting community or secure provision**, Carson D et al., in Criminal Behaviour and Mental Health 20, 1, 39 – 50

Link to article: <http://tinyurl.com/mh04003>

- Case record study of 336 people referred to community services and 141 to secure provision. Information gathered on referral source, demographics, diagnosis, index behaviour, prior problem behaviours and history of abuse.
 - Comparisons revealed 19 candidate variables. Following multivariate logistic regression, six variables remained: community living at time of referral, physical aggression, being charged, referral from tertiary health care, diverse problem behaviour and IQ < 50, which correctly predicted the referral pathway for 85.7% of cases.
 - Authors conclude that an index act of physical aggression and a history of diversity of problem behaviours are predictors against the likelihood of community service referral and suggest that professionals have similar concerns about people with ID as they do about their more average offending peers. More severe levels of ID mitigated in favour of community referral.
- 3. Reliance on Carer Reports of Early Symptoms of Dementia Among Adults With Intellectual Disabilities**, Jamieson-Craig R et al., in Journal of Policy and Practice in Intellectual Disabilities 7, 1, 34 – 41

Link to article: <http://tinyurl.com/mh04004>

- Study looking at carer-reported symptoms to ascertain whether carer reports of decline in everyday function would be more effective screening method to detect possible cases of dementia than reports of memory decline in older adults with ID.
 - 154 participants reassessed along with their carers two to three years after baseline.
 - Participants who developed dementia displayed both everyday function and memory decline.
 - Overall, decline in everyday function appeared to be best indicator of new dementia cases.
 - Retrospective carer report of change in everyday function was as good as, if not better than, prospective ratings to identify dementia.
 - Authors conclude that decline in everyday function (whether prospective change from baseline or reported retrospectively by carers) appeared to be better screening method for dementia than memory decline, particularly for participants with moderate/severe ID.
- 4. The role of ethnicity in clinical psychopathology and care pathways of adults with intellectual disabilities**, Tsakanikos E et al., in Research in Developmental Disabilities, 31, 2, 410-415

Link to article: <http://tinyurl.com/mh04005>

- Study exploring whether people with intellectual disability from ethnic minority groups had higher rates of mental health problems and accessed different care pathways than their White counterparts.
 - Data collected for 806 consecutive new referrals to specialist mental health service for people with ID in South London. Referrals grouped according to ethnic origin.
 - Analyses showed an over-representation of referrals from ethnic minority groups with diagnoses of schizophrenia spectrum disorder.
 - Black participants more likely to have an autistic spectrum disorder.
 - Referrals of ethnic minority groups considerably younger than White referrals, and less likely to be in supported residences.
- 5. Psychological and other non-pharmacological interventions in services for people with learning disabilities and dementia**, Dodd K, in Advances in Mental Health and Learning Disabilities, 4, 1, 28-36

Link to article: <http://tinyurl.com/mh04006>

- Paper describing most commonly used approaches to supporting people with intellectual disabilities and dementia, including:
 - developing an understanding of dementia,
 - anxiety and stress reduction,



- life story work,
- reminiscence,
- reality orientation and validation techniques,
- helping peers to understand dementia,
- other therapeutic approaches,
- understanding behaviour and dementia care mapping and their impact on the well-being of people with learning disabilities and dementia and the people who support them.

6. Mental ill-health and care pathways in adults with intellectual disability across different residential types, Chaplin E et al., in Research in Developmental Disabilities, 31, 2, 458-463

Link to article: <http://tinyurl.com/mh04007>

- Study investigating co-morbid psychopathology and clinical characteristics of adults with ID living across different types of residential settings.
- First time referrals to specialist services in South-East London living either with their family ($N = 375$) or in supported residence ($N = 280$) or independently ($N = 95$).
- Analyses showed personality disorders were more likely to be diagnosed in people who lived independently or in supported residence, while anxiety disorders were more likely in those living with their family.
- Those who lived in independent residence had higher rates of co-morbid psychopathology.
- Younger adults more likely to live with their families while those with higher ID level were about 17 times more likely to live independently.
- Largest proportion of referrals to outpatients lived in independent residence although there were no significant differences in other care pathways.

SUPPORTING FAMILY CARERS

Review

- 1. Siblings of Adults With Developmental Disabilities: Psychosocial Outcomes, Relationships, and Future Planning**, Heller T & Keiling Arnold C, in Journal of Policy and Practice in Intellectual Disabilities, 7, 1, -16-25

Link to article: <http://tinyurl.com/sfc04001>

- Review of English-language literature on siblings of adults with intellectual and developmental disabilities, focusing on three main questions:
- what are the psychosocial outcomes of having a sibling with an intellectual and developmental disabilities on the sibling without a disability?;
- what factors relate to the nature of the sibling relationship?;
- what factors relate to future planning, including expected and future relationships when parents can no longer provide care?
- Twenty-three relevant studies were identified.
- Overall, studies present mixed, but generally positive picture of psychosocial outcomes of having sibling with a disability.
- Siblings tended to have long-lasting close relationships with siblings with a disability and anticipate taking on greater supportive roles as both grow older.

Single Studies

- 1. The time and effort in taking care for children with profound intellectual and multiple disabilities: a study on care load and support**, Tadema A & Vlaskamp C, in British Journal of Learning Disabilities, 38,1, 41 - 48

Link to article: <http://tinyurl.com/sfc04002>

- Questionnaire study to collect information about caring task and level of parental burden concerning health-related tasks and basic need tasks such as eating and drinking, dressing and sleeping.
- Level of support parents experience from friends, relatives and special services included and use of special aids and resources. 133 parents completed questionnaire.
- Most children are dependent on them for meeting all basic needs and have several health problems.



- Significant relationships found between number of times parents get up at night and level of burden, and between days a child stayed in hospital and level of parental burden.
- Authors suggest that results indicate caring task places heavy demands on parents.
- Professional support is alleviating and extremely important for parents.
- Caring task necessarily indicative for subjective burden parents experience.
- Parents of young children express higher levels of burden than parents of older children.

2. Effectiveness of a stress-relief initiative for primary caregivers of adolescents with intellectual disability, Jung Hu in Journal of Intellectual and Developmental Disability, 35, 1, 29-35

Link to article: <http://tinyurl.com/sfc04003>

- 77 primary caregivers of people with ID recruited (intervention group, $n=31$; non-intervention group, $n=46$) to study which involved participation in one stress management workshop (intervention group only) and both groups reading an education booklet on stress management.
- 22.1% of caregivers were at high risk of depressive stress and in need of mental health consultation; a prevalence nearly six times that of general population.
- Effectiveness of mental health initiatives resulted in significant reduction in depressive stress for intervention group.

3. Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome, Dabrowska A & Pisula E, in Journal of Intellectual Disability Research, 54, 3, 266-280

Link to article: <http://tinyurl.com/sfc04004>

- 162 parents examined using Holroyd's 66-item short form of Questionnaire of Resources and Stress for Families with Chronically Ill or Handicapped Members and the Coping Inventory for Stressful Situations by Endler and Parker.
 - Results indicated higher level of stress in parents of children with autism.
 - Interaction effect revealed between child diagnostic group and parent's gender for two scales of parenting stress: dependency and management and limits of family opportunities.
 - Mothers of children with autism scored higher than fathers in parental stress;
 - Authors conclude that results strongly supported earlier findings on parenting stress in parents of children with autism.
-
- same intervention but with additional involvement of community stakeholders such as parents, the police, and local schools ($n = 22$).
 - Third work centre ($n = 18$) acted as waiting list control comparison.
 - Pre-intervention, 43% of participants reported they had been bullied within preceding three months and 28% identified themselves as having bullied others.
 - Reports of being bullied decreased significantly within two intervention groups over time but not in control group.
 - No differences found between two intervention groups, and no statistically significant reduction in self-reported bullying behaviour.
 - Initial data on intervention suggest that effects might be clinically meaningful with associated Numbers Needed to Treat for reduction in exposure to bullying of 5.55.

VULNERABLE ADULTS & ABUSE

Review

- 1. Teaching abuse-protection skills to people with intellectual, disabilities: A review of the literature**, Doughty A & Kane L, in Research in Developmental Disabilities. 31. 2. 331-337

Link to article: <http://tinyurl.com/vab04001>

- Authors reviewed relevant empirical investigations since 1997.
- Six studies trained sexual-abuse-protection skills, two also included protection skills related to physical and verbal abuse.
- Each study involved participants with mild or moderate intellectual disabilities, four noted their participants' relatively efficient communication skills.



- No study included male participants, only one included participants younger than 21.
- Three studies involved in-situ training, only two assessed skill generalization.

Report

1. Disability Hate Crime: A report about crimes against disabled people

Link to article: <http://tinyurl.com/vab04002>

- Report about how to deal with a type of crime called Disability hate crime.
- Disability hate crime is a type of crime that can happen to disabled people.
- In this report we talk about disabled people.

Single study

1. Outcomes of anti-bullying intervention for adults with intellectual disabilities, McGrath L et al., in Research in Developmental Disabilities, 31, 2, 376-380

Link to article: <http://tinyurl.com/vab04003>

- Despite significant clinical interest in bullying, authors found no published research on outcomes of bullying intervention for individuals with intellectual disabilities.
- Adults with ID in three work centre settings participated in one of two interventions for perpetrators and/or victims of bullying:
- Psycho-educational intervention with a cognitive behavioural orientation ($n = 20$).

PERSON CENTRED SERVICES

Single Studies

1. Skills for support: personal assistants and people with learning disabilities, Williams V et al., in British Journal of Learning Disabilities, 38, 1, 59-67

Link to article: <http://tinyurl.com/pcs04001>

- Reports of inclusive research study using video analysis to study communication skills of personal assistants (PAs) who worked with people with learning disabilities.
- Fine detail in strategies PAs used to show respect, support choices, and give advice are revealed.
- PAs were able to step back, listen to and observe the person with learning disabilities, and use good, open body language. They gave people time, built up a close relationship and talked with people in a friendly, adult way.
- Research produced training materials to help people with learning disabilities train and support their own PAs.

2. The Effect of Active Support Interactive Training on the Daily Lives of Adults with an Intellectual Disability, Totsika V et al., in Journal of Applied Research in Intellectual Disabilities, 23, 2, 112-121

Link to article: <http://tinyurl.com/pcs04002>

- Observations and ratings of staff and resident behaviours were obtained for 21 adults with ID in residential settings, before, immediately after training sessions, and at 6 months follow-up.
- Group-level analyses indicated short-lived improvement in quality of staff support but, in general, there was an overall lack of change in staff behaviours, resident engagement and – observed and rated – challenging behaviours.
- Subgroup analyses showed significant improvement in engagement immediately after training for participants who had significantly higher aggressive behaviour ratings at beginning of study.
- Authors conclude that findings support combination of training components of AS for improvements in quality of life for people with intellectual disability.



- 3. A Five-Country Comparative Review of Accommodation Support Policies for Older People With Intellectual Disability**, Bigby C, in Journal of Policy and Practice in Intellectual Disabilities, 7, 1, 3 - 15

Link to article: <http://tinyurl.com/pcs04003>

- Article comparing development and implementation of accommodation support policies for people aging with intellectual disabilities in five liberal welfare states.
 - Limited development of policies found in this area
 - Review of peer reviewed and grey or unpublished advocacy and policy literature on aging policies for people with intellectual disability conducted covering Australia, Canada, Ireland, the UK, and the U.S.
 - Despite consistent identification of similar broad policy issues and overarching goals, little progress has been made in development of more specific policies or implementation strategies to address issues associated with accommodation support as people age.
 - Policy debates have conceptualized the problem as aging in place and the shared responsibility of the aged-care and disability sectors.
- 4. Therapeutic progressions of client and therapist throughout a course of psychodynamic therapy with a man with mild learning disabilities and anger problems**, Alim, N in Advances in Mental Health and Learning Disabilities, 4, 1, 42-49

Link to article: <http://tinyurl.com/pcs04004>

- Case study exploring 18 psychodynamic therapy sessions with an adult with mild learning disabilities and anger problems, investigating therapy outcomes and progress along a nine-stage Malan model, analysing therapeutic interactions leading to therapy progression.
- Patient's progression along Malan stages explored by thematic analysis matching therapy sessions to the model.
- Investigation of therapeutic interactions achieved by discourse analysis of those therapy sessions indicative of Malan-Stage progression.

AUTISM

Single Studies

- 1. Obtaining the views of children and young people with autism spectrum disorders about their experience of daily life and social care support**, Preece D & Jordan R, in British Journal of Learning Disabilities, 38, 1, 10-20

Link to article: <http://tinyurl.com/aut0401>

- 10 boys and 4 girls aged 7 to 18 years with autism were interviewed regarding experience and attitudes of families towards daily life and short breaks support.
 - Data collected on children's experience of day-to-day life, social workers, and short breaks services, and their wishes.
 - The children were positive about family life, (most activities reported were solitary).
 - None understood the role of social workers.
 - Those attending short breaks enjoyed some activities and peers' company but were disturbed by noise and staff discipline.
- 2. A Comparison of Adults with Intellectual Disabilities with and without ASD on Parallel Measures of Challenging Behaviour: The Behavior Problems Inventory-01 (BPI-01) and Autism Spectrum Disorders-Behavior Problems for Intellectually Disabled Adults (ASD-BPA)**, Rojahn J et al, in Journal of Applied Research in Intellectual Disabilities, 23, 2, 179-185

Link to article: <http://tinyurl.com/aut0402>

- Challenging behaviour may not be part of the diagnostic criteria for Autistic Disorder but they are frequently exhibited by children and adults with this condition. Levels of challenging behaviours are highest in individuals with an autism spectrum disorder (ASD) and co-occurring intellectual disability (ID). The sample for this study consisted of



- 57 institutionalized adults with ID who either did or did not meet criteria for an ASD on a screening instrument [*Autism Spectrum Disorders-Diagnosis for Intellectually Disabled Adults (ASD-DA)*] took part in the study.
 - Two groups were compared on two parallel measures of challenging behaviour commonly used with this population: the *Behavior Problems Inventory-01 (BPI-01)* and *Autism Spectrum Disorders-Behavior Problems for Intellectually Disabled Adults (ASD-BPA)*.
 - Individuals with ASD demonstrated higher levels of overall challenging behaviour (especially with regard to self-injurious and stereotypical behaviours).
 - Convergent validity of these two scales was demonstrated for entire sample and by group.
- 3. Understanding early communication signals in autism: a study of the perception of infants' cry** Esposito G & Venuti P, in *Journal of Intellectual Disability Research*, 54, 3, 216-223

Link to article: <http://tinyurl.com/aut0403>

- Two studies used:
 - Study 1, 50 adults (parents and non-parents) asked to judge level of distress elicited from artificially modified structural parameters of cry episode
 - Study 2, acoustic analysis applied to episodes of crying selected from retrospective home videos of 42 children with AD, TD and DD at 18 months.
 - Differences in the fundamental frequency and other structural parameters of cry lead parents
 - At 18 months of age, AD episodes of crying have higher fundamental frequency (f_0).
 - Authors suggest findings support hypothesis that acoustic characteristics of episodes of crying of children with autism, especially higher fundamental frequencies, may account for mental states of uneasiness in the listener.
- 4. Expressive language in male adolescents with fragile X syndrome with and without comorbid autism** Kover S & Abbeduto L, in *Journal of Intellectual Disability Research*, 54, 2, 246-265

Link to article: <http://tinyurl.com/aut0404>

- Spontaneous language samples collected from male adolescents with FXS without autism ($n = 20$), comorbid FXS and autism ($n = 8$), and Down syndrome ($n = 16$).
- Syntactic complexity (indexed by mean length of utterance), expressive vocabulary (indexed by lexical diversity), talkativeness, fluency and intelligibility were assessed in two contexts: conversation and narration.
- Groups matched on non-verbal IQ, non-verbal mental age and chronological age to allow the assessment of relative strengths and weaknesses across language variables.
- Males with comorbid FXS and autism were less intelligible than males with only FXS.
- No other differences between these two groups were found.
- Authors conclude that although individuals with comorbid FXS and autism may be more impaired than those with only FXS, data from the study of males with comorbid FXS and autism with low IQs suggest their relative strengths and weaknesses in spontaneous expressive language are largely comparable and not differentially affected by the context in which their talk occurs.

EDUCATION

Single Studies

- 1. Family expectations and transition experiences for young adults with severe disabilities: does syndrome matter?** Blacher J et al, in *Advances in Mental Health and Learning Disabilities*. 4, 1, 3-16

Link to article: <http://tinyurl.com/ed04001>

- Parents of 246 young adults with severe learning disability aged 18-26 took part.
- Young adults classified into four diagnostic groups: autism ($N = 30$), Down's syndrome ($N = 68$), cerebral palsy ($N = 95$) and undifferentiated learning disability group ($N = 53$).
- Parent expectations about transition and parental satisfaction and worries were assessed.
- Results indicated more community expectations of work for young adults with Down's syndrome, and more restrictive expectations for young adults with autism, including more expectations that young adults with autism would move out of the family home into a residential environment.



- Parents of young adults with autism also worried significantly more about various aspects of transition than other parent groups.

LEARNING DISABILITY POLICY

1. **The Relationship between Reciprocity and the Emotional and Behavioural Responses of Staff**, Thomas C & Rose J in, Journal of Applied Research in Intellectual Disabilities, 23, 2, 167-178

Link to article: <http://tinyurl.com/ldp04001>

- Staff working in community homes within voluntary, private and public sector for people with intellectual disabilities within an urban borough completed a self-report questionnaire including measures of reciprocity, burnout, emotion, optimism and helping behaviour.
- Support was found for association between lack of reciprocity and levels of burnout.
- Burnout found to be correlated with emotion, optimism and helping behaviour.
- Path analysis revealed significant associations between lack of reciprocity with organization and colleagues, burnout, positive affect, optimism and helping.
- Authors conclude that findings provide support for role of reciprocal relationships between care staff, the organization and work colleagues in burnout.

John Northfield
Project Lead
johnnorthfield@yahoo.co.uk

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