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Up-to-date journal abstracts on newly published research

**Down Syndrome**

**SEX DIFFERENCES IN THE GAIT KINEMATICS OF PATIENTS WITH DOWN SYNDROME: A PRELIMINARY REPORT.**

**Author(s):** ZAGO, Matteo; CONDOLUCI, Claudia; PAU, Massimiliano; GALLI, Manuela

**Source:** *Journal of Rehabilitation Medicine* Feb 2019; vol. 51 (no. 2); p. 144-146

Available at *Journal of Rehabilitation Medicine* (Stiftelsen Rehabiliteringsinformation) - from IngentaConnect - Open Access

**Abstract:** Objective: Sex-specific medicine requires understanding of the specific therapeutic needs and pathophysiology of men and women. In these terms, we investigated sex-related differences in the gait kinematics of patients with Down syndrome. Design: Retrospective observational cohort study. Subjects: A sample of 230 patients (103 females) aged 7-50 years underwent a standard gait-analysis test from 2000 to 2015. Methods: Spatiotemporal gait parameters and synthetic indexes were computed as Gait Profile Score (GPS) and pelvis/lower limbs as Gait Variable Scores. Results: Although speed, normalized step width, %stance and %swing were similar, in female patients step length was shorter and GPS was higher than in male patients, with no significant effect of age, speed and body mass index. Sex-specific features were found at the pelvis, hip and knee level (sagittal plane), and at the ankle level (transverse plane). Conclusion: Overall, in people with Down syndrome, the gait function of females tends to be more impaired than in males, with the exception of foot progression. Therapists should consider these differences when evaluating the severity of gait impairment and designing rehabilitation strategies.

**Database:** CINAHL

**Verb production by individuals with Down syndrome during narration.**

**Author(s):** Loveall, Susan J.; Channell, Marie Moore; Abbeduto, Leonard; Conners, Frances A.

**Source:** *Research in Developmental Disabilities*; Feb 2019; vol. 85 ; p. 82-91

**Abstract:** Background: Despite research identifying verb knowledge as a strong predictor of later syntactic skills in typical development, virtually no research has examined verb development in Down syndrome. Aims: The purpose of this study was to examine verb production (density, diversity, and type-token ratios) by individuals with Down syndrome in the context of story generation relative to two comparison groups - nonverbal cognitive ability level matches with typical development and chronological age matches with mixed-etiology intellectual disability. Methods and Procedures: Thirty-five participants with Down syndrome (11-21 years), 27 participants with intellectual disability (13-20 years), and 29 participants with typical
development (4-6 years) completed a narrative story generation task. Transcripts were coded and analyzed for verb production. Outcomes and Results: Examining overall verb production, participants with Down syndrome produced narratives with less verb density than participants with typical development and had smaller verb type-token ratios than participants with intellectual disability. Upon examining lexical verb production, participants with Down syndrome produced narratives with less lexical verb density than participants with typical development.

Conclusions and Implications: The results indicate that individuals with Down syndrome have a developmentally appropriate diversity of verbs in their lexicon but are not using verbs as frequently as comparison groups.

Differentially expressed gene (DEG) based protein-protein interaction (PPI) network identifies a spectrum of gene interactome, transcriptome and correlated miRNA in nondisjunction Down syndrome.

Author(s): Sriroopreddy, Ramireddy; Sajeed, Rakshanda; P, Raghuraman; C, Sudandiradoss

Source: International journal of biological macromolecules; Feb 2019; vol. 122 ; p. 1080-1089

Abstract: Down syndrome, a genetic disorder of known attribution reveals several types of brain abnormalities resulting in mental retardation, inadequacy in speech and memory. In this study, we have presented a consolidative network approach to comprehend the intricacy of the associated genes of Down syndrome. In this analysis, the differentially expressed genes (DEG's) were identified and the central networks were constructed as upregulated and downregulated. Subsequently, GNB5, CDC42, SPTAN1, GNG2, GNAT, PRKACB, SST, CD44, FGF2, PHLPP1, APP, and FYN were identified as the candidate hub genes by using topological parameters. Later, Fpclass a PPI tool identified WASP gene, a co-expression interacting partner with highest network topology. Moreover, an enhanced enrichment pathway namely Opioid signaling was obtained using ClueGo, depicting the roles of the hub genes in signaling and neuronal mechanisms. The transcriptional regulatory factors and the common miRNA connected to them were identified by using MatInspector and miRTarbase. Later, a regulatory network constructed showed that PLAG, T2FB, CREB, NEUR, and GATA were the most commonly connected transcriptional factors and hsa-miR-122-5p was the most prominent miRNA. In a nutshell, these hub genes and the enriched pathway could help understand at a molecular level and eventually used as therapeutic targets for Down syndrome.

Physical therapy in Down syndrome: systematic review and meta-analysis.

Author(s): Ruiz-González, L; Lucena-Antón, D; Salazar, A; Martín-Valero, R; Moral-Munoz, J A

Source: Journal of intellectual disability research : JIDR; Feb 2019

Abstract: BACKGROUND Down syndrome is the most common chromosomal abnormality, with a worldwide incidence of around 0.1% in live births. It is related to several conditions in which the physical therapy could take action-preventing co-morbidities. This study aims to evaluate the effectiveness of physical therapy in Down syndrome, to know and compare the effectiveness of different physical therapy interventions in this population. METHODS A systematic review and a meta-analysis of randomised controlled trials were conducted. The search was performed during June 2018 in the following databases: PubMed, Web of Science, Physiotherapy Evidence Database and Scopus. The studies were selected using predefined inclusion and exclusion criteria. The Physiotherapy Evidence Database scale evaluated the quality of the methods used in the studies. Subsequently, the data were extracted, and statistical analysis was performed when possible. RESULTS A total of 27 articles were included, of which nine contributed information to the meta-analysis. Statistical analysis showed favourable results for the strength of upper and lower limbs [standardised mean difference (SMD) = 1.46; 95% confidence interval (CI): (0.77-2.15); and SMD = 2.04; 95% CI: (1.07-3.01)] and mediolateral oscillations of balance [SMD = -3.30; 95% CI: (-5.34 to -1.26)]. CONCLUSIONS The results show the potential benefit of certain types of physical therapy interventions, specifically in strength and balance, in people with Down syndrome. There are still many aspects to clarify and new lines of research.

Behaviour

Sensory Eating Problems Scale (SEPS) for children: Psychometrics and associations with mealtime problems behaviors.

Author(s): Seiverling, Laura; Williams, Keith E.; Hendy, Helen M.; Adams, Whitney; Yusupova, Stella; Kaczor, Aleksandra

Source: Appetite; Feb 2019; vol. 133 ; p. 223-230
Abstract: The present study developed the 22-item Sensory Eating Problems Scale (SEPS) to measure sensory aspects for children surrounding eating, documented psychometrics of SEPS subscales, and examined their association with mealtime behavior problems. Study participants were 449 caretakers of children referred to feeding clinics, including children in three special needs status groups: autism spectrum disorder (ASD), other special needs, and no special needs. Caretakers completed surveys to report children's demographics, four measures of children's mealtime behavior problems, and five-point ratings for how often children showed various sensory feeding reactions. Exploratory factor analysis of the sensory feeding items identified six SEPS subscales with acceptable goodness-of-fit, internal reliability, and test-retest reliability: Food Touch Aversion, Single Food Focus, Gagging, Temperature Sensitivity, Expulsion, and Overstuffing. ANCOVAs revealed that child demographics most associated with higher SEPS subscale scores were younger age and special needs. Multiple regression analyses found that children's mealtime behavior problems were most often associated with SEPS subscales of Food Touch Aversion, Single Food Focus, Expulsion, and Overstuffing, with the set of six subscales explaining 18-44% of variance in mealtime behavior problems. Suggestions for how clinicians and researchers may find the SEPS useful for assessment and intervention are provided.

Database: CINAHL

An evaluation of a punisher assessment for decreasing automatically reinforeced problem behavior.

Author(s): Verriden, Amanda L.; Roscoe, Eileen M.
Source: Journal of Applied Behavior Analysis; Feb 2019; vol. 52 (no. 1); p. 205-226

Abstract: We extended research on the identification and evaluation of potential punishers for decreasing automatically reinforced problem behavior in four individuals with autism spectrum disorder. A punisher selection interview was conducted with lead clinicians to identify socially acceptable punishers. During the treatment evaluation, treatment phases were introduced sequentially and included noncontingent reinforcement (NCR), NCR and differential reinforcement of alternative behavior (DRA), and NCR-and-DRA with punishment. During the NCR-and-DRA with punishment phase, four to five potential punishers were evaluated using a multielement design. Dependent measures included the target problem behavior, appropriate item engagement, and emotional responding. For all participants, NCR-and-DRA was not effective and punishment was necessary. However, the most effective punisher identified in the context of NCR-and-DRA differed across participants.

Database: CINAHL

A Review of School-Based Interventions to Reduce Challenging Behavior for Adolescents with ASD.

Author(s): Rivera, Gabby; Gerow, Stephanie; Kirkpatrick, Marie
Source: Journal of Developmental & Physical Disabilities; Feb 2019; vol. 31 (no. 1); p. 1-21

Abstract: A systematic review was conducted to assess the types of school-based interventions commonly used for adolescents (10 to 21 years) to reduce challenging behavior. A total of 40 articles were identified through the database search and ancillary searches. Participant, implementer, and intervention characteristics were recorded during descriptive coding. This review found that antecedent-based interventions were most commonly used within the school setting. School personnel reported antecedent-based interventions to be acceptable and feasible within the school setting. Results of the descriptive coding found that around 70% of participants were ages 10 to 13 years old, with limited research being conducted with students older than 13; therefore, additional research is needed with this age group. Based on What Works Clearinghouse standards, 25 articles Met Standards or Met Standards with Reservations and 22 articles provided moderate to strong evidence for the efficacy of these interventions within the school setting.

Database: CINAHL

Microswitch-Cluster Technology for Promoting Occupation and Reducing Hand Biting of Six Adolescents with Fragile X Syndrome: New Evidence and Social Rating.

Author(s): Perilli, Viviana; Stasolla, Fabrizio; Caffò, Alessandro O.; Albano, Vincenza; D'Amico, Fiora
Source: Journal of Developmental & Physical Disabilities; Feb 2019; vol. 31 (no. 1); p. 115-133

Abstract: We further extended the use of microswitch-cluster technology for promoting occupational activities and reducing hand biting of six adolescents with fragile X syndrome and severe to profound developmental disabilities. The primary rehabilitative goal was to enhance the adaptive response (i.e., inserting three different objects in the three containers within a 4 s time interval). The secondary objective was to evaluate the effects of the intervention on indices of positive participation as outcome measure of the participants’ quality of life. Finally, a social validation assessment involving sixty-six external raters was
conducted. The study was carried out according to an ABB1AB1 experimental sequence for each participant. Thus, A indicated baselines, B indicated the intervention focused on promoting the adaptive response irrespective of the challenging behavior, and B1 indicated the cluster phases with the provision of positive stimulation only if the adaptive response was exhibited with the absence of the challenging behavior. A one-year follow-up was implemented. Results showed an improved performance for all the participants, which was maintained over the time. Indices of positive participation increased as well. Social raters favorably scored the use of the microswitch-cluster technology. Clinical, educational, psychological, and rehabilitative implications of the findings were critically discussed.

**Database:** CINAHL

**Factor Validation of the Staff Perceptions of Behavior and Discipline (SPBD) Survey.**

**Author(s):** Feuerborn, Laura L.; Tyre, Ashli D.; Zečević, Mladen

**Source:** Remedial & Special Education; Feb 2019; vol. 40 (no. 1); p. 32-39

**Abstract:** The implementation of schoolwide positive behavior interventions and supports (SWPBIS) requires a shift from a reliance on reactionary discipline to prevention-oriented supports, and it requires that staff adopt and regularly apply the practices throughout the building. This level of systemic change in staff thinking and practice is challenging to achieve and sustain, but data can assist teams in navigating the process. The Staff Perceptions of Behavior and Discipline (SPBD) is a needs assessment survey developed to measure staff beliefs, needs, and concerns for discipline and behavioral support practices. This tool can help teams make data-informed decisions, and target professional development to fit the needs and concerns of staff in their building. This study reexamines the internal consistency and factor structure of the SPBD using an expanded data set of 147 schools, including elementary, middle, and high schools across several geographic regions in the United States. The results corroborate the SPBD's existing factor structure over alternative factor structures and support the internal consistency of each subscale. Implications for practice and future research are provided.

**Database:** CINAHL

**Social climate and aggression in IDD services**

**Author(s):** Joanne Emma Robinson, Leam Craig,

**Journal of Intellectual Disabilities & Offending Behaviour 2019**

**Abstract:** The purpose of this paper is to adapt a social climate measure for use within a forensic intellectual and developmental disabilities (IDD) service and examine perceptions of social climate and the links with patient aggression across three levels of security. Four staff participated in a focus group to discuss how the Essen Climate Evaluation Schema (EssenCES) could be adapted for IDD patients. Subsequently, a pilot study with three patients highlighted some difficulties in administering the adapted measure. Alterations in the administration of the measure were implemented with a further ten patients residing across three levels of security. The EssenCES was adapted to include more visual prompts to assist in the patients’ completion of the measure. The frequency of aggressive incidents in each of the three settings was also collated. Statistical analysis revealed a non-significant trend where positive social climate ratings increased as the security level decreased. There was a significant difference in the frequency of aggressive incidents across the three levels of security; however, there were no significant relationships found between the questionnaire ratings and the frequency of incidents. The results lacked statistical power due to the low number of participants. Further studies with adapted social climate measures need to be conducted to assess the implications of social climate on individuals with IDD in secure forensic services. The study adapted and piloted a social climate measure for individuals in a forensic IDD service.

**Tourettes**

**Review: Physical exercise in Tourette syndrome – a systematic review.**

**Author(s):** Reilly, Colin; Grant, Michael; Bennett, Sophie; Murphy, Tara; Heyman, Isobel

**Source:** Child & Adolescent Mental Health; Feb 2019; vol. 24 (no. 1); p. 3-11

Available at [Child & Adolescent Mental Health](https://onlinelibrary.wiley.com/journal/10.1111) - from Wiley Online Library All Journals Login with Athens Account details

**Abstract:** Background: Tourette syndrome (TS) is a common neuropsychiatric disorder which, in addition to the core symptoms of motor and vocal tics, includes a high association with co-existing mental health disorders. Physical exercise is increasingly being recommended as part of management for children and young people with mental health problems. However, there is a lack of guidance regarding the role of physical exercise in the management of TS in children. Methods: EMBASE, MEDLINE, PsycINFO,
SportDiscus, Google scholar and Cochrane register of controlled trials (CENTRAL) databases were searched. Studies investigating interventions aimed at reducing core symptoms of TS and comorbidities and exploring the relationship between physical exercise and tic severity were included. Results: Seven studies were identified. Five focused on physical exercise interventions and two were observational studies investigating the relationship between tic severity and physical activity. There was some evidence indicating that physical exercise reduces tic severity in the short term and some evidence regarding the benefit of physical exercise on associated co-occurring symptoms, such as anxiety. However, none of the intervention studies involved randomisation and interventions varied in terms of content and duration. Conclusions: There was some evidence of a short-term improvement in tic expression as a result of physical exercise interventions, but there is a lack of methodologically robust studies. Thus, conclusions about the impact of exercise on TS symptoms or comorbidities cannot be drawn at this stage. There is a clear need for well-designed methodologically robust studies, including prospective observational studies and randomised controlled designs.

Database: CINAHL

The psychology of Tourette disorder: Revisiting the past and moving toward a cognitively-oriented future.

Author(s): Gagné, Jean-Philippe

Source: Clinical psychology review; Feb 2019; vol. 67 ; p. 11-21

Abstract: Tourette syndrome is a neurodevelopmental disorder characterized by chronic tics (i.e., repetitive and stereotyped movements and vocalizations) and premonitory urges (i.e., aversive sensations preceding tics that are alleviated once a tic is performed). Research supports that dysfunctional neurobiological and psychological processes interact and contribute to the development and maintenance of tics. However, psychological theories of Tourette syndrome and accompanying research have mainly focused on the emotional states (e.g., anxiety and frustration) and behavioural principles (i.e., operant conditioning) that play a role in tic exacerbation. This selective review summarizes key discoveries pertaining to the emotional and behavioural aspects of Tourette syndrome but also proposes a more comprehensive, cognitively-oriented conceptualization of the disorder. Specifically, it is proposed that maladaptive beliefs about discomfort and about one's ability to cope with discomfort underlie negative appraisals of unpleasant sensory experiences in individuals with Tourette syndrome. It is further suggested that these beliefs lead individuals to perceive premonitory urges in a catastrophic manner and thereby enhance tic frequency. Concrete research avenues to empirically examine these hypotheses are outlined and clinical implications for the field of cognitive-behaviour therapy are discussed.

Database: Medline

Tic disorders revisited: Introduction of the term "tic spectrum disorders"

Author(s): Müller-Vahl, Kirsten R.; Sambrani, Tanvi; Jakubovski, Ewgeni

Source: European Child & Adolescent Psychiatry; Jan 2019

Abstract: Although the DSM-5 chronic motor tic disorder (CMTD) and Tourette syndrome (TS) are distinct diagnostic categories, there is no genetic or phenotypic evidence that supports this diagnostic categorization. The aim of this study was to compare patients with both diagnoses along a number of clinical characteristics to provide further diagnostic clarity. Our sample consisted of 1018 patients (including adult and child patients) suffering from chronic tic disorders. Tic severity was assessed via Shapiro Tourette Syndrome Severity Scale (STSS). Lifetime prevalence of other comorbid conditions was assessed in a semi-structured clinical interview. The data were gained through retrospective chart analysis. The two groups did not differ significantly in any of the clinical or demographic variables. Patients only differed in tic severity, with CMTD patients (n = 40) having lower mean tic severity (STSS = 2.0 vs. 2.8; p < 0.001), prevalence of complex motor tics (27.5% vs. 55.9%; p < 0.01), copropraxia (0% vs. 16.2%; p < 0.01) and echopraxia (10.0% vs. 23.8%; p < 0.05), and a markedly lower comorbidity score (1.9 vs. 2.7; p < 0.001) as compared to TS patients (n = 978). Our results suggest that both disorders exist along a symptom severity continuum of which TS constitutes a more severe and CMTD a less severe form. We therefore suggest the introduction of the term "tic spectrum disorders", instead of using different diagnostic categories.

Database: PsycINFO

General

Epigenetics of fragile X syndrome and fragile X-related disorders.

Author(s): Kraan, Claudine M; Godler, David E; Amor, David J

Source: Developmental Medicine & Child Neurology; Feb 2019; vol. 61 (no. 2); p. 121-127
Abstract: The fragile X mental retardation 1 gene (FMR1)-related disorder fragile X syndrome (FXS) is the most common heritable form of cognitive impairment and the second most common cause of comorbid autism. FXS usually results when a premutation trinucleotide CGG repeat in the 5′ untranslated region of the FMR1 gene (CGG 55-200) expands over generations to a full mutation allele (CGG >200). This expansion is associated with silencing of the FMR1 promoter via an epigenetic mechanism that involves DNA methylation of the CGG repeat and the surrounding regulatory regions. Decrease in FMR1 transcription is associated with loss of the FMR1 protein that is needed for typical brain development. The past decade has seen major advances in our understanding of the genetic and epigenetic processes that underlie FXS. Here we review these advances and their implications for diagnosis and treatment for individuals who have FMR1-related disorders. WHAT THIS PAPER ADDS: Improved analysis of DNA methylation allows better epigenetic evaluation of the fragile X gene. New testing techniques have unmasked interindividual variation among children with fragile X syndrome. New testing methods have also detected additional cases of fragile X.

Database: CINAHL

Effectiveness of interventions to increase physical activity in individuals with intellectual disabilities: a systematic review of randomised controlled trials.

Author(s): Hassan, N. M.; Landorf, K. B.; Shields, N.; Munteanu, S. E.

Source: Journal of Intellectual Disability Research; Feb 2019; vol. 63 (no. 2); p. 168-191

Abstract: Background: People with intellectual disabilities (ID) often do not meet recommended guidelines for physical activity. The aim of this study was to systematically review available evidence that evaluated the effectiveness of interventions to increase physical activity in individuals with ID. Method: Five electronic databases (MEDLINE, CINAHL, EMBASE, SPORTDiscus and Cochrane Central Register of Controlled Trials) were searched from inception of the database to July 2017 to identify randomised controlled trials that evaluated the effectiveness of interventions to improve physical activity among people with ID. Trials were included if they measured at least one objective measure of physical activity. Quality appraisal was completed by two independent reviewers using the Cochrane Risk of Bias Tool. The magnitude of treatment effect was estimated for each intervention by calculating the standardised mean difference (SMD) and associated 95% confidence interval. Results: Nine randomised controlled trials (976 participants, 501 women, age range 9 months to 83 years) were included. Four trials evaluated unimodal interventions and five trials evaluated multimodal health promotion programmes based on using supportive environments to enable sustained behavioural changes in physical activity. None of the trials were rated as high risk of bias as all had at least one item on the Cochrane Risk of Bias Tool that was considered to be high risk. No trials were able to implement participant blinding. Three trials found statistically significant beneficial effects of interventions for increasing physical activity. Results showed that a 10-week progressive resistance training programme led to maintenance of physical activity levels at 24 weeks in adolescents with Down syndrome (SMD 0.78, 95% CI 0.17 to 1.40). Additionally, a 12- to 16-month multicomponent diet and physical activity programme produced improvement in physical activity at programme completion in adults with ID (reported effect size of 0.29). Finally, an 8-month physical activity and fitness programme increased physical activity at 8 months in adults with ID (SMD 0.91, 95% CI 0.20 to 1.60). Findings regarding other interventions were inconclusive with small effects that were not statistically significant. Conclusions: There is inconsistent evidence of the effects of interventions for improving physical activity levels in individuals with ID. A progressive resistance training programme was found to maintain physical activity levels in adolescents with Down syndrome, while a multicomponent diet and physical activity programme and a physical activity and fitness programme were found to improve physical activity levels in adults with ID. Future trials using rigorous research designs are required to confirm these findings and establish whether other interventions designed to increase physical activity in people with ID are effective.

Database: CINAHL

Transforming care in England

Author(s): Jean O’Hara, (National Learning Disabilities Programme, King’s Health Partners, London, United Kingdom Of Great Britain And Northern Ireland)

Advances in Mental Health and Intellectual Disabilities, Vol. 13 Issue: 1,

Abstract: When the National Health Service in the UK was set up in 1948, the colonies or institutions which were built originally in the nineteenth century to segregate people with learning disabilities from the rest of society, became “hospitals” in which people were “nursed” and their problems defined in medical terms. We now know how damaging institutional life was for many people. Because of their size, location and regimented routines, institutional services made people dependent, powerless and lacking in choice,
privacy or social networks. They were often treated inhumanely, and sometimes with deliberate cruelty or abuse (Sperlinger, 1997). Although since the 1980s many long-stay institutions have closed with a move to new community service provision, many of the attitudes and behaviours and some practices remain as legacies of the past. Much has advanced in public health, in the management and prevention of infectious diseases, in the delivery of antenatal, prenatal and postnatal care. Premature and low birth weight babies have a significantly higher survival rate, and society now cares for children with multiple disabilities and complex needs. The average life expectancy for an adult with learning disabilities has also risen although we know they die on average 13–20 years earlier than someone without learning disabilities, often from causes that are preventable and avoidable. “Transforming Care” is a three-year NHS England funded programme (2016–2019), in response to the perceived slow pace of change following the exposure of abusive practices at a non-NHS assessment and treatment unit (Winterbourne View) for people with learning disabilities and/or autism. “A hospital is not a home”. At the heart of the Transforming Care Programme is co-production, giving people with learning disabilities (and those with autism) and their families a voice that is listened to, addressing health inequalities through a rights-based approach and building capacity and person-centred support in the community to reduce reliance on inappropriate inpatient provision. This special issue is a collection of papers, written by clinicians, practitioners, commissioners and others who are working at a national level, alongside experts by experience and family carers, to transform care. It may not be of the same style as previous issues, but it captures the uniqueness of our journal, with its original focus on translating policy into practice and sharing practice-based evidence. NHS England uses the term “learning disabilities” rather than “intellectual disabilities”, so we have allowed for this terminology to be interchangeable in this special issue. Whaley and colleagues remind us that the words we choose to use can either oppress and diminish or empower and humanise. They present a framework for looking at the power of, and around, people with learning disabilities who have mental health issues or display behaviour that can challenge services. Sanderson, in his paper, describes the potential a personalised approach and personal health budgets could have in promoting choice and control over one’s care. He argues they can not only improve health and care outcomes but reduce the total spend across the system. In October NHS England (2015) published a new national service model (Building the Right Support) and signalled its intention to close the last remaining free-standing learning disability hospital in the country. Turner’s case study in this special issue comes from the North East of the country and illustrates the culture change and local leadership required to make things happen: how every aspect of the jigsaw can come together if we work in partnership, as one team, to create the conditions within which the person can be discharged from a mental health or specialist learning disability hospital, and supported to have and live an ordinary life in the community. There is understandable anxiety given the current financial austerity and particularly the funding challenges in social care. It is precisely at such times that we need to innovate, hear what people with learning disabilities and their families want, and make the best use of the resources we have in a creative way that achieves meaningful outcomes and healthier lives.

Public Health England’s analysis show 17 per cent of adults with learning disabilities known to primary care services and living in the community, will be receiving antipsychotic medication, and this compares to less than 1 per cent of the population without learning disabilities. This is a shocking statistic and an issue known about for decades. Two papers by Branford and colleagues on Stop Overmedicating People gives us the background and implementation of a national call to action. It is an approach that has galvanised people with learning disabilities, family carers and voluntary organisations as well as healthcare professionals and researchers. Whether this will result in a meaningful reduction in use or better-informed reviews, or improvements in quality of life and patient safety, remains to be evaluated. The NHS marked its 70th birthday in June 2018, and it was important we celebrated its many successes and the incredible achievements in public health, basic sciences, neuro-imaging and translational research. It was a time to reiterate its universality and commitment to free healthcare at the point of need. It is also right we recognise the experiences of the past, health inequalities, the legacy of institutions and “forgotten lives”. Deb’s review of Professor Nick Bouras’ memoirs (a psychiatrist’s chronological from deinstitutionalisation to community care) charts the dramatic changes that have occurred in our recent past; the clinical developments, research challenges, successes and frustrations working within systems that may not at times even have a shared vision. Our challenge now is to shift the balance of power from hospital to community, from clinician to patient, from executive boards to front-line staff and from engagement to co-production. But it is not just a health issue. We have a long way to go as a society if we are to truly support people with learning disabilities to have a life rather than a service. Ultimately that is what Transforming Care is all about.

**Shifting the balance of power**

**Author(s):** Jo Whaley, Di Domenico, Jane Alltimes,

*Advances in Mental Health and Intellectual Disabilities, Vol. 13 Issue: 1,*

**Abstract:** This purpose of this paper is to examine the role of engagement and empowerment in “Transforming Care”, for people with a learning disability. The aim is to shift the balance of power so that people are able to live ordinary lives in the community, in the home they choose, close to people they love. It shares ideas to support people to take control over their own lives and to influence the system, so that it works with people, rather than “doing to” people. The paper examines barriers and enablers to people having their rights as citizens. So that people have as much choice and control as they are comfortable with to live an ordinary life (bearing in mind any legal restrictions). The paper includes people’s involvement in system/service redesign. It critiques traditional views of looking at language, participation and power. The authors have used the language throughout which people have told us they prefer as a descriptor. The authors present a framework for looking at the power of, and around, people with a learning disability who have mental health issues or have displayed behaviour that can challenge services. This paper offers advice on how to address power imbalances at individual level and at organisational/system level. It looks at the language we use, the information we share and how we work with experts by experience to ensure we can transform care and support and enable people to live ordinary lives as citizens.

**Ensuring a personalised approach**

**Author(s):** James Sanderson, Nicola Hawdon,

*Advances in Mental Health and Intellectual Disabilities, Vol. 13 Issue: 1,*

**Abstract:** The purpose of this paper is to outline how personal health budgets and a universal, integrated model of support, can positively transform the way in which individuals with a learning disability experience their health and support needs. The review recognises that Integrated Personal Commissioning, as a policy approach, provides the framework to offer personalised care, and enables people to live an independent, happy, healthy and meaningful life. Evidence suggests that a personalised and integrated approach to both health and social care not only offers better outcomes on all levels for the individual, but also benefits the system as a whole. The study reveals that a personalised care leads to people to have choices and control over decisions that affect in better health and wellbeing outcomes for people.

**North Cumbria and North East Transforming Care, transforming lives case study**

**Author(s):** Ursula Turner,

*Advances in Mental Health and Intellectual Disabilities, Vol. 13 Issue: 1,*

**Abstract:** The purpose of this paper is to describe how, as part of a national initiative led by NHS England and key partners, it is transforming lives by helping people with a learning disability, autism or both to live more independent and better quality lives in their own home rather than spending many years in hospital unnecessarily. The methodology applied was to capture the real experience of a person with a learning disability, autism or both who successfully moved from long-term hospital care to home. This was achieved through developing a narrative story by capturing their experiences in their own words and the words of the individual’s support team who made this life changing event possible. This story shows how with the right planning and support, people with a learning disability can live in their own homes, gain their independence and be supported to take risks. This is an original case study that has not been published previously and has been written for the sole purpose of this journal.

**Stopping over-medication of people with intellectual disability, Autism or both (STOMP) in England part 1 – history and background of STOMP**

**Author(s):** David Branford, David Gerrard, Nigget Saleem, Carl Shaw, Anne Webster,

**Abstract:** The programme – Stopping the over-medication of people with an intellectual disability, Autism or Both (STOMP) is a three-year programme supported by NHS England. Concern about the overuse of antipsychotic drugs has been a constant theme since the 1970s. However, despite a multitude of guidelines the practice continues. The report into the events at Winterbourne View not only raised concerns about the overuse of antipsychotic drugs but of antidepressants and multiple psychotropic drug use. The purpose of this paper is twofold: Part 1 is to present the history and background to the use of psychotropic drugs in intellectual disabilities, autism or both; and Part 2 presents the progress with the STOMP programme. The review tracks the various concerns, guidelines and attempts to tackle the issue of over medication of people with intellectual disability autism or both. The review identifies that despite the many studies and guidelines associated with the prescribing of psychotropic drugs for people with an intellectual disability,
autism or both the practice is common. Programmes that minimise the use of psychotropic drugs involve a full use of the multidisciplinary team and an availability of alternative methods of managing challenging behaviours. STOMP is part of an English national agenda – Transforming care. The English Government and leading organisations across the health and care system are committed to transforming care for people with intellectual disabilities, autism or both who have a mental illness or whose behaviour challenges services. This review identifies many studies, programmes and guidelines associated with psychotropic drug use for people with an intellectual disability, autism or both.

**Stopping over-medication of people with an intellectual disability, autism or both (STOMP) in England part 2 – the story so far**

**Author(s):** David Branford, David Gerrard, Nigget Saleem, Carl Shaw, Anne Webster,

**Abstract:** The STOMP programme – stopping the over-medication of people with an intellectual disability, autism or both is a three-year programme supported by NHS England. Concern about the overuse of antipsychotic drugs has been a constant theme since the 1970s. However, despite a multitude of guidelines the practice continues. The report into the events at Winterbourne View not only raised concerns about the overuse of antipsychotic drugs but of antidepressants. Part 1 presented the historical background to the use of psychotropic drugs for people with an intellectual disability, autism or both. The purpose of this paper (Part 2) is to present the approach adopted to reduce over-medication (the “Call to Action”) and the progress so far at the half way stage. The “Call to Action” methodology is described in a Manchester University report – mobilising and organising for large-scale change in healthcare “The Right Prescription: A Call to Action on the use of antipsychotic drugs for people with dementia”. Their research suggested that a social mobilising and organising approach to change operates could provide a mechanism for bringing about change where other approaches had failed. The adoption of the “Call to Action” methodology has resulted in widespread acknowledgement across intellectual disability practice that overuse of psychotropic medication and poor review was resulting in over-medication. Many individual local programmes are underway (some are described in this paper) however to what extent the overall use of psychotropic drugs has changed is yet to be evaluated. STOMP is part of an English national agenda – transforming care. The government and leading organisations across the health and care system are committed to transforming care for people with intellectual disabilities autism or both who have a mental illness or whose behaviour challenges services. This paper describes a new approach to stopping the over-medication of people with an intellectual disability, autism or both.

**Food selectivity in a diverse sample of young children with and without intellectual disabilities.**

**Author(s):** Bandini, Linda G.; Curtin, Carol; Eliasziw, Misha; Phillips, Sarah; Jay, Laura; Maslin, Melissa; Must, Aviva

**Source:** Appetite; Feb 2019; vol. 133 ; p. 433-440

**Abstract:** Children with developmental concerns are more likely to be referred to feeding clinics for food selectivity than typically developing (TD) children. However, there is limited research on food selectivity in children with intellectual disabilities (ID). Fifty-nine TD children and 56 children with ID ages 3-8 years participated in the Children’s Mealtime Study to compare food selectivity, conceptualized as food refusal and narrow food repertoire, among TD children and children with ID. Parents completed a 119-item food-frequency questionnaire. Food refusal rate was calculated as the number of foods the child refused of those offered. Food repertoire, comprising the number of unique foods eaten, was determined from a 3-day food record. Compared to TD children, among children with ID the food refusal rate was significantly higher (28.5% vs. 15.7%) and mean food repertoire significantly narrower (20.7 vs. 24.2 unique foods) (p < 0.01). Approximately 10% of children with ID and approximately 4% of TD children reported eating no fruit on any of the three days of food intake recording, and approximately 10% of children with ID compared to approximately 2% of TD children reported no vegetable intake on any of the three days. In further analyses, we examined the two measures of food selectivity among children with both ID and probable autism spectrum disorder (ASD) (by the Autism Spectrum Rating Scale) compared to children with ID only and to TD children. Food selectivity appeared to be primarily attributable to those children who also had a probable diagnosis of ASD. These findings support the need for screening for food selectivity of children with ID, particularly those who also have ASD. Children who exhibit food selectivity should be referred for further evaluation and intervention.

**Subjection of people with learning disabilities in the UK: Commentary on indifference of a devalued group**

**Author(s):** Bob Gates

**Source:** British Journal of Learning Disabilities March 2019 Volume47, Issue1
Welcome to the first issue of BJLD for 2019, a wide range of papers are presented that includes issues of symptoms of autism spectrum conditions (ASC) in children with mucopolysaccharidosis, respite care for people with intellectual disabilities and their families in Ireland, experiences of people with intellectual disabilities in Ireland when moving home using an inclusive research approach, a transnational discourse between partners in Egypt and the UK on definition and features of ASC of children and young people in Egypt, a dialogic approach to working inclusively with two young people with intellectual disabilities and hearing voices groups (HVGs). There is also a paper from Australia to determine whether communication partners of children and adults with developmental disabilities can learn and retain a basic Key Word Skill (KWS) vocabulary, and finally one from the UK concerning attitudes amongst support staff towards sexuality and adults with learning disabilities.

Before I introduce these papers, I would ask your indulgence and your time for but a brief few paragraphs whilst I attempt to outline my very deep concerns about the low value that seemingly continues to be placed upon some people in the UK; those with learning disabilities. As you read this editorial, I have no doubt there are those who think my concerns are exaggerated, and there will be those who think them underplayed. But as someone who has worked for nearly fifty years in the field of learning disabilities, I cannot but help make comment on what I see as the continuing subjection of people with learning disabilities resulting for some in everyday struggles for their families and carers. Despite moves to raise awareness of the challenges faced by this group, there seems an indifference to so many aspects of some of their lives. Yet surely, we as a society have a collective responsibility to ensure that all citizens are able to enjoy equity and equality, but this seems to allude this group in so many ways: fiscally, educationally, in employment, their health and even compromise the very integrity of their human rights. There are many examples I could use to support the general theme of my editorial but I have chosen, for the sake of brevity, to focus on five.

Here in the UK, over the last 2 years we have had to endure acres of newsprint, hours–days even, of debate which have been aired on our television and our radios, and delivered to our tablets and smartphones, and all of which have been devoted to “Brexit”; a relatively new word to enter the UK vernacular referring to the nature of the United Kingdom’s exit from the European Union. For friends and colleagues outside of the UK, it is difficult to imagine the distorted sense of presence this has had on the daily lives of our population. Yet in the back ground to this never- ending debate, many domestic matters, and particularly those in health and social care, seem to have gone unnoticed. And nowhere is this more evident than in the lives of some people with learning disabilities, their families and carers. The continuing impact of austerity and a vacuum of specific learning disability policy blights the lives of some of our citizens with learning disabilities, and this directly impacts on their families and carers in deleterious ways. I am not entirely sure that this is a distinctly unique feature of the UK, and other countries seem to have similar challenges in asserting the integrity of rights for people with learning (Developmental) disabilities (Disability Justice, 2019); but this editorial is confined to issues closer to home.

Consider the following as illustrative of my line of thinking: financial issues, people with learning disabilities residing in inappropriate residential settings, distress caused by inappropriate educational provision, health inequity and inequality, avoidable deaths in our NHS hospitals, a seemingly endless pursuit for equality in employment or, for those unable to work, meaningful day time activity.

A fascinating book published in 2018 by Neil Carpenter based on his work as a volunteer advocate for Cornwall Advocacy clearly shows how adults with learning disabilities have been affected by UK government austerity measures since 2010 (Carpenter, 2018). It focussed on five men with learning disabilities who live in Cornwall and compared their income and spending with national and county averages. He presents compelling argument as to extent to which they have been “left behind” and leaves us in little doubt as to the harmful impact of current fiscal policy in the UK. His book examines their quality of life within a context of ever declining support given them. When these men’s spending was compared with the Minimum Income Standard of the Joseph Rowntree Foundation, and the UK and Cornwall medians, the results were disturbing. Their own spending averages were 48% of the UK median, 55% of the Cornwall median and 71% of the Minimum Income Standard; their income was below the relative poverty threshold. All of these men have had their support hours at home, or their day centre attendance cut, and two of the five men have had benefits cut. One has failed to have his Disability Living Allowance transferred to a Personal Independence Payment. Seemingly, their quality of life has suffered. Carpenter reports most of these men lack friends, and that loneliness is a real problem. And for all of the men portrayed their lives seemingly fall short of the definition of “well- being” identified in the Care Act 2014. Carpenter asserts that there are a significant number of adults with learning disabilities in the UK who have been affected by the current governments continued austerity measures. His book exposes a disturbing reality and describes this in authentic and compelling detail, albeit the lives of five men, but more generally
asserts that some people with learning disabilities are austerity's victims, and he calls for a fight against this injustice.

Next consider those people with learning disabilities detained in Assessment and Treatment services. From 2011, numerous reports along with work programmes have attempted to prevent another scandal such as that of Winterbourne View (Flynn, 2012). These have included NHS England's Transforming Care agenda introduced in 2011, which developed new procedures aimed at reducing admissions to hospitals like Winterbourne View (NHS England, 2015). But by April of last year, their own figures still continued to show that more than 2,000 people with learning disabilities and, or, autism remained in such services. Although some 130 people were discharged in April, 105 others were admitted! Perhaps an uncomfortable truth here is that the NHS continues to lose its specialist NHS workforce, particularly learning disability nursing, on an unprecedented scale, and that Local Authorities are not able to accommodate the often complex care packages needed to support some people with learning disabilities in their local communities.

What of educational provision? A recent annual inspectorate report by Ofsted stated;

Children and young people identified as needing SEND (special educational needs and disability) support but who do not have an education, health and care plan often have a much poorer experience of the education system than their peers. In the local authorities we inspected, leaders were not clear how their actions were improving outcomes for these children and young people. Some parents reported that they had been asked to keep their children at home because leaders said that they could not meet their children’s needs. This is unacceptable. (Ofsted, 2017, pp. 9)

It is known that some of these children are informally excluded, often with parents being asked by school personnel to educate them at home—because they are unable to support them. Formal exclusions of SEND children with challenging behaviour were reported as high in a number of areas in the country. They also found that those children whose special needs were not severe enough to require an education, health and care (EHC) plan was found to have a worse time in school than those with an EHC plan.

Consider next the health inequality iniquity phenomena and the avoidable deaths experienced by people with learning disabilities. It has been unequivocally established, and for some time, that people with learning disabilities receive poor care whilst in acute hospitals (Heslop et al., 2013; Mencap 2007; Mencap 2012; Michael, 2008). It is thought that as many as 1, 200 people with learning disabilities die each year, avoidable deaths, often through a lack of training for staff (House of Commons, 2018; Mencap, 2018). And despite continued calls for better training for all NHS staff, such atrocities on the scale of a national scandal continue (Mencap, 2018).

Even the specialist services offered people by the NHS are no guarantee of their safety. A sad example of this was the failure to ensure the safety, leading to the preventable death, of Connor Sparrowhawk whilst in specialist NHS care in England which has brought into sharp focus the need to address quality, safety and sustainability of specialist NHS staff (NHS England, 2015).

Finally, briefly consider the seemingly endless search for equality in employment or meaningful day time occupation. Mencap has suggested that 8 out of 10 working age people with a learning disabilities have mild to moderate learning disabilities yet less than 2 in every 10 of them are employed (Mencap, 2016). And it is suggested that only 6 in 100 are in work of those with severe learning disabilities are in work (Mencap, 2016). Indeed, as a class of potential workers it was estimated in 2008 that 83% were unemployed (Emerson and Hatton, 2008). Typically, they face many barriers in obtaining employment, and often lack support to get and maintain employment and are often prejudiced by a lack of understanding as to what they are able to achieve at work. And if you are not able to work, what of day services, and the opportunity of meaningful day time activities? In 2015, Learning Disability Today reported on the results of a survey in one London borough. It was found that despite platitudes concerning safeguarding local services for people with learning disabilities, services had been affected by austerity measures, and high levels of anxiety about future trends were expressed by service users, carers and support workers believing that such cuts would have a negative effect on people with learning disabilities. Fear was expressed that they might become isolated, and that family carers would find it difficult to cope (Learning Disability Today, 2015).

Living in the 21st Century in a country that boasts to be the 5th largest economy in the world, how is any of what I have recorded here in this editorial acceptable? Perhaps in this New Year, there needs to be a new dawn, a rebirth of a stronger advocacy movement for people with learning disabilities. Our governments, and our health and social care institutions, are failing some in this group of people and their families. It would seem that it is now the responsibility of advocates, parent groups and those collective advocacy organisations with national resource, who amongst all us should be shouting the loudest, to collectively voice our concern and outrage as to the continuing subjection of this group of people along with the indifference as to what some must endure on a daily basis. I must leave this aspect of my editorial here for
fear of saying what is in my heart as well as presenting these uncomfortable truths. This editorial is a reflection of my understanding of what I believe has, and is happening to some people with learning disabilities, but I would point out that this understanding is grounded in multiple sources of evidence, and from numerous sources including inspectorates, serious case reviews, parents, and people with learning disabilities, politicians and former ministers, and researchers from a wide variety of academic and professional backgrounds.

Let me now turn to this issue of BJLD. The first paper of 2019 by Wolfenden et al. presents a fascinating paper on symptoms of autism spectrum disorder (ASC) in children with mucopolysaccharidosis type III (MPS III). Questionnaires measuring the two core domains of ASC (social responsiveness and repetitive behaviour) were completed by 17 parents of children with MPS III. Their results indicate that scores consistent with ASC were reported by all parents on a measure of social responsiveness, but that lower scores were reported for repetitive behaviour. Their findings perhaps provide support for the provision of additional interventions, focusing on the social and communication difficulties that children with MPS III may face across all phases of their disorder.

In the next paper, Nicholson et al., point out that respite care is an essential support for people with intellectual disabilities and their families; however, there is limited evidence examining different models of respite care. Their research examined quality of life amongst adults with intellectual disabilities using three different models of respite services in Ireland. Using a quasi-experimental research method, they sought to determine differences in quality of life across the three respite care groups using two measures: a self-reported quality of life scale and a quality of life questionnaire filled out by a keyworker. Eighty-two people with mild/moderate intellectual disabilities and eighty-one keyworkers took part in the study. Concerning the three distinct models of respite services that were assessed, these included the following: traditional—residential; personalised—residential respite; and personalised—non-residential respite services. No differences emerged between the groups on self-reported quality of life; however, the groups differed on a proxy measure of quality of life with respect to rights, emotional well-being, personal development and interpersonal relationships. They conclude their data offer initial exploration of self-and proxy-reported quality of life amongst people with intellectual disabilities in receipt of novel models of respite care in Ireland.

Remaining in Ireland for a short while, Salmon et al., point out that supporting people with intellectual disabilities to live well in communities they choose is deinstitutionalisation’s central aim and endorsed by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006). Their study focused on the experiences of people with intellectual disabilities in Ireland moving home using an inclusive research approach. Participants in the study included 19 men and 16 women (total n = 35) with ages ranging from 22 to 77 years. Structured interviews attended to the experience of moving home and the supports accessed during and after the transition to community living. Thematic analysis yielded four themes: “expressing choice” in the moving process; “feeling connected or isolated when moving”; “accessing supports during and after the move”; and finally, participants' reflections on “experiencing vulnerability and feeling safe” whilst resettling. They conclude that this is the first study about people with intellectual disabilities moving home to be collaboratively designed and completed by an inclusive research team. Although much is understood about the long-term benefits of engaging in meaningful choices about housing and supports, concerns remain about the extent to which the will and preferences of people with intellectual disabilities in Ireland are respected when moving home.

Next Gabriel et al., outline, through transnational discourse between partners in Egypt and the UK, an overview of the literature on the definition and features of Autistic Spectrum Conditions (ASC) with associated learning needs and health conditions as applied to children and young people in Egypt. As a low-to-middle-income country, Egypt has poor and underdeveloped health, education and social services to support children with ASC, and little research has investigated this phenomenon. This paper adds to contemporary discussion, through shared knowledge and practice in the educational curriculum, of children with ASC in Egypt.

Next Lloyd et al., present a paper reporting on the use of a dialogic approach to working inclusively with two young people with intellectual disabilities as part of a “Research Reference Committee” for a project that examined how adults with intellectual disabilities and their families plan for their future. Their paper presents an overview of the role of a “Research Reference Committee” written by the research team to provide the context for reporting. They discuss and reflect on how they used “mediated talk” when working with these young people with intellectual disabilities to develop strategies that enabled them to contribute to the reference committee. The third section of the paper was co-written with the third and fourth authors listed on the paper. The structure follows their decisions about how they wanted to write this section in ways that allowed them to tell their stories of participation as narratives, using their own words. In the discussion, the challenges of co-authorship are acknowledged and considered as well as the benefits of...
using an iterative dialogical approach to enable the active participation of these young people in a reference committee, and as a method of co-authoring that allows a broader dissemination of the voices of people with intellectual disabilities in research outputs.

Roche- Morris and Cheetham from London present a paper concerning hearing voices groups (HVGs). They assert these are an effective strategy to support for people who hear voices in the general population; however, they state their application and adaptation for people with learning disabilities are scarce. Their paper evaluates a pilot HVG for people with learning disabilities. The pilot included five people who attended a group which ran weekly for 6 weeks. They undertook measures of psychological functioning and quality of life both before and after the group. They undertook to explore participants’ understanding of their voice hearing experiences along with any attendant stigma associated with voice hearing both before and after the group experience. They found high attendance rates along with positive satisfaction ratings. They report that participants said they had a better understanding of voice hearing and endorsed the value of positive social support. They conclude that quantitative outcome measures should be reviewed when conducting HVGs. Also whereas the 6-week group was associated with positive feedback, they suggest it might have benefited by an increase the number of sessions offered and point to the need to involve carers. They suggest the importance of bridging gaps between services available for those who hear voices in the general population learning disabilities.

In the penultimate paper, Smidt et al., from Australia point to the need for children and adults with developmental disability to be offered aided or unaided alternative and augmentative communication (AAC). Key word sign (KWS) involves using natural gesture and sign language to support the key words in spoken utterances. The purpose of this study was to determine whether communication partners of children and adults with developmental disabilities can learn and retain a basic KWS vocabulary. In their study, communication partners attended a one-day training workshop where they were taught 100 signs. Measures of sign recognition and production were taken prior to the training, immediately after the training on the day and at 6 and 12 weeks later. These participants were able to learn signs during the workshop and demonstrate receptive and expressive knowledge of KWS. However, sign knowledge decreased after 6 and 12 weeks. Participants noted having to be tested again after several weeks motivated them to practise and served as a follow-up. They conclude their work provides evidence that KWS training enables participants to learn and retain signs, but that there is need for ongoing training and support, even for communication partners who regularly sign.

Finally, Maguire and colleagues from Surrey, back in England, state that whereas there might be positive attitudes amongst support staff towards sexuality, adults with learning disabilities report being dissatisfied with the support they receive. Their research explores support workers’ understanding of their role in supporting the sexuality of adults with learning disabilities. Six support workers from supported living services were interviewed about their role in this area. Data were analysed using interpretative phenomenological analysis, and from this, three themes emerged which suggest support workers held conflicting beliefs and emotions about their role in supporting sexuality for the people they support. This ambivalence could result in support workers distancing themselves from an active role in supporting sexuality for the people they support. This study concludes that support workers may inadvertently express an understanding of their role that could be consistent with negative and limiting discourses about the sexuality of adults with learning disabilities. Their findings suggest a continuing need for sexuality training that focusses on reflective practice.

I sincerely hope that readers find something of interest in this issue, and that these papers, as with papers previously published in BJLD, continue to contribute to contemporaneous debate on some of the important issues they raise for this important, but often overlooked, section of our communities. It is important that we collectively work towards promoting people with learning disabilities, their families and carers ever closer towards full citizenship.

Our Homes: An inclusive study about what moving house is like for people with intellectual disabilities in Ireland

Author(s): Nancy Salmon

Source: British Journal of Learning Disabilities March 2019 Volume47, Issue1

Supporting people with intellectual disabilities to live well in communities they choose is deinstitutionalisation’s central aim and endorsed by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006). This study focused on the experiences of people with intellectual disabilities in Ireland when moving home using an inclusive research approach. This inclusive research project employed a qualitative approach. Participants included 19 men and 16 women (total n = 35) with ages ranging from 22 to 77 years. Structured interviews attended to the experience of moving home and the supports accessed during and after the transition to community living. Thematic analysis
yielded four themes: “expressing choice” in the moving process; “feeling connected or isolated when moving”; “accessing supports during and after the move”; and finally, participants' reflections on “experiencing vulnerability and feeling safe” while resettling. This is the first study about people with intellectual disabilities moving home to be collaboratively designed and completed by an inclusive research team. Although much is understood about the long-term benefits of engaging in meaningful choices about housing and supports, concerns remain about the extent to which the will and preferences of people with intellectual disabilities in Ireland are respected when moving home.


“You hear voices too?”: A hearing voices group for people with learning disabilities in a community mental health setting

Author(s): Aisling Roche- Morris

Source: British Journal of Learning Disabilities March 2019 Volume47, Issue1

We ran a group for people with learning disabilities who hear voices that nobody else can hear. During the group, people talked about what it is like to hear voices nobody else can hear and how they cope. We interviewed people before and after the group. We asked them about what their voices say, how they felt about their voices and why they thought they heard voices. We also asked them about their quality of life and if they liked the group. People told us that they liked the group and found it helpful to talk to other people who hear voices. Some people said they felt better after the group.

Abstract: Hearing voices groups (HVGs) are effective avenues of support for people who hear voices in the general population yet their application and adaptation for people with learning disabilities who hear voices are scarce. This paper is an evaluation of a pilot HVG for people with learning disabilities. Five people attended the group which ran once weekly for 6 weeks. Measures of psychological functioning and quality of life were collected before and after the group. Participants’ understanding of their voice hearing experiences and the stigma associated with voice hearing were explored at the pre- and post-group stage. High attendance rates and positive satisfaction ratings suggested the group was acceptable to clients. Participants said they had increased understanding of voice hearing and endorsed the positive value of social support. The use of quantitative outcome measures should be reviewed when conducting HVGs. Although the 6-week group was associated with positive feedback, there might be benefit in extending the number of sessions offered as well as involving carers. Bridging the gap between services available for those who hear voices in the general population compared to people with a learning disability is essential.


Support workers' understanding of their role supporting the sexuality of people with learning disabilities

Author(s): Karla Maguire

Source: British Journal of Learning Disabilities March 2019 Volume47, Issue1

We asked support workers what they thought about their role supporting sexuality. They said they want to try to support sexuality and relationships but also have to keep people safe. They said they have lots of things to consider which makes it difficult.

We think support workers need more training and advice to help them talk about some of their worries and difficulties supporting sexuality.

Abstract: Despite positive attitudes amongst support staff towards sexuality, adults with learning disabilities report being dissatisfied with the support they receive. This research aimed to explore support workers' understanding of their role supporting the sexuality of adults with learning disabilities. Six support workers from supported living services were interviewed about their role. Data were analysed using interpretative phenomenological analysis. Three themes emerged which were understood as suggesting that support workers held conflicting beliefs and emotions about their role supporting sexuality. This was interpreted as creating an ambivalence that could result in support workers distancing themselves from an active role in supporting sexuality. This study concluded that support workers may inadvertently express an understanding of their role that may be consistent with negative and limiting discourses about the sexuality of adults with learning disabilities. The findings suggest a continuing need for sexuality training with a focus on reflective practice.


A review of the frequency and nature of adaptations to cognitive behavioural therapy for adults with Intellectual Disabilities
Author(s): Laura Surley

Abstract: There is increasing evidence that cognitive behavioural therapy (CBT) can be effective for people with intellectual disabilities. The aim of this review was to report the nature and frequency of adaptations reported in studies of CBT for people with intellectual disabilities. This review updated and extended a previous review by (Whitehouse et al. 2006, J Appl Res Intellect Disabil, 19, 55), which used a framework of adaptations developed by (Hurley et al., 1998, J Dev Phys Disabil, 10, 365). Adaptations included simplification, language, activities, developmental level, use of directive style, flexible methods, involve caregivers, transference/countertransference and disability/rehabilitation approaches. A search identified peer-reviewed papers that reported individual CBT informed psychological interventions for people with an Intellectual Disability. The search identified 23 studies which met the inclusion criteria for review. Studies reported the majority of the categories of adaptation described by (Hurley et al., 1998, J Dev Phys Disabil, 10, 365). The results suggest that the framework of adaptations needs further development to increase sensitivity in identifying and categorizing adaptations of CBT. Increased, systematic reporting of adaptations to studies of CBT with people with intellectual disabilities is recommended.


Athens login required

Self-concept research with school-aged youth with intellectual disabilities: A systematic review

Author(s): Christophe Maïano

Abstract: Research on the self-concept of youth with intellectual disabilities has not been summarized in more than four decades. The present systematic review addresses this gap. A systematic literature search was performed in nine databases and 21 studies, published between 1979 and 2017, met our inclusion criteria. Significant differences between the self-concepts of youth with intellectual disabilities and typically developing (TD) youth were found in: (a) cognitive-academic self-concept in disfavour of youth with intellectual disabilities; (b) global self-concept and cognitive-academic self-concept in disfavour of children with intellectual disabilities; and (c) global, behavioural, and cognitive-academic self-concept in disfavour of youth with intellectual disabilities schooled in a special class. Additionally, except for age, intellectual functioning and school placement, no significant relations were found between the self-concept dimensions and academic achievement and sex. Studies on self-concept research with school-aged youth with intellectual disabilities have several weaknesses that need to be advanced in future research.


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An evaluation of mainstream type 2 diabetes educational programmes in relation to the needs of people with intellectual disabilities: A systematic review of the literature

Author(s): Andrew Maine

Abstract: Risk reduction and self-management programs for type 2 diabetes (T2D) are commonplace. However, little is known about their appropriateness for people with intellectual disabilities (ID). This review evaluates successful components and theoretical basis of interventions and preventions in relation to the needs of people with ID with or at risk of T2D. Characteristics of 23 randomised controlled trialled T2D educational programs were systematically assessed alongside the needs of people with ID, and evaluated in terms of study design and theoretical application. Successful components of programs align to the needs of people with ID. Further adaptations are required to ensure accessibility of materials and social support to enable reflection on illness perceptions and self-efficacy, as underpinned by Self-regulation and Social-cognitive theories. Support is provided for further trials of self-management and preventative adaptations under development. Impact may be enhanced through preventions aimed at younger groups in educational settings.


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Validating GO4KIDDS as a brief measure of adaptive skills in special education settings for children with severe intellectual disability

Author(s): Xinyu Pan
**Source:** Journal of Applied Research in Intellectual Disabilities Volume32, Issue2 March 2019

**Abstract:** Adaptive skills measures tend to be lengthy. The GO4KIDD (Great Outcomes for Kids Impacted by Severe Developmental Disabilities; (Journal of Applied Research in Intellectual Disabilities, 58, 2015 and 594)) Brief Adaptive Behaviour Scale was developed to provide a brief assessment of adaptive skills. Our study aimed to examine the psychometric properties of GO4KIDD Brief Adaptive Scale in a large sample of children in special education. Teachers reported on 361 students with severe to profound intellectual disability. The scale's factor structure was examined through principal components analysis (PCA), while its convergent validity was examined in relation to the Vineland (VABS- II; Vineland- II adaptive behavior scales, Circle Pines, MN, AGS and 2005). The PCA indicated a single component measuring overall adaptive skills, which had excellent internal consistency (alpha = 0.93), and convergent validity (Pearson’s r = 0.81). Teacher- reported scores on GO4KIDD Brief Behaviour Scale can provide a reliable and valid composite of adaptive skills in children with severe to profound intellectual disability. The scale will be useful to researchers and teachers who need a brief descriptive assessment of adaptive functioning.


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Invariance of parent ratings of attention deficit hyperactivity disorder symptoms for children with and without intellectual disability

**Author(s):** Victor B. Arias

**Source:** Journal of Applied Research in Intellectual Disabilities Volume32, Issue2 March 2019

**Abstract** Although attention deficit hyperactivity disorder (ADHD) is considered a valid diagnosis for children with intellectual disability, no studies have evaluated the invariance of ADHD symptom ratings across children with and without intellectual disability. Parents completed ratings on the ADHD symptoms for 189 children with intellectual disability and for 474 children without intellectual disability. Differential item functioning analysis was used to determine the equivalence of the ADHD symptoms across the two groups. The symptoms loses things, talks too much, and blurts out answers showed significant bias against children with intellectual disability. The prevalence of ADHD in children with intellectual disability was 18% (according to the symptom criterion), and 7.4% when the academic and/or social impairment criterion was also considered. Most of the ADHD symptoms can be valid for the assessment of ADHD in children with mild and moderate intellectual disability. ADHD symptoms may be used in further studies to establish base rates of the disorder in the intellectual disability population.


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Approaches to communication assessment with children and adults with profound intellectual and multiple disabilities

**Author(s):** Darren Chadwick

**Source:** Journal of Applied Research in Intellectual Disabilities Volume32, Issue2 March 2019

**Abstract** Communication assessment of people with profound intellectual and multiple disabilities (PIMD) has seldom been investigated. Here, we explore approaches and decision making in undertaking communication assessments in this group of people. A questionnaire was sent to UK practitioners. The questionnaire elicited information about assessment approaches used and rationales for assessment choices. Fifty- five speech and language therapists (SLTs) responded. Findings revealed that the Preverbal Communication Schedule, the Affective Communication Assessment and the Checklist of Communication Competence were the most frequently used published assessments. Both published and unpublished assessments were often used. Rationales for assessment choice related to assessment utility, sensitivity to detail and change and their applicability to people with PIMD. Underpinning evidence for assessments was seldom mentioned demonstrating the need for more empirical support for assessments used. Variability in practice and the eclectic use of a range of assessments was evident, underpinned by practice- focused evidence based on tacit knowledge.


**Effects of a self- management training for people with intellectual disabilities**

**Author(s):** Janice Sandjojo

**Source:** Journal of Applied Research in Intellectual Disabilities Volume32, Issue2 March 2019
Abstract To help people with intellectual disabilities lead a more independent life, it is important to promote their self-management. This study evaluated the effectiveness of a self-management training for people with intellectual disabilities directed at independent functioning in daily life. In the training, 17 people with intellectual disabilities worked on personal self-management goals covering a wide range of everyday affairs. Primary outcome measures focused on goal attainment, independence and support needs. Moreover, outcomes regarding psychopathological behaviour and quality of life were explored. Data were collected before and at the start of the training, and 3, 6, 9 and 12 months later. The training contributed to the attainment of self-management goals and to the reduction in support needs (p < 0.01). There were no changes in independence, psychopathological behaviour and quality of life. Results indicate that the training supports people with intellectual disabilities to self-manage their daily affairs.


Living with support: Experiences of people with mild intellectual disability

Author(s): Sanne A. H. Giesbers


Abstract To enhance social inclusion of people with intellectual disability, policy is aimed at increasing informal support networks. Nevertheless, staff continue to play a vital role in their support networks. Six individuals with mild intellectual disability, living in community-based settings, were interviewed following a semi-structured format. In-depth accounts of participants' support experiences were established using Interpretative Phenomenological Analysis. Three main themes were identified: relationships with staff placed within a personal history, relationships with staff within an organisational context, and staff support and interviewees' place in the world. Relationships with staff were often one of the closest and most significant social relationships participants had. As living in the community had not necessarily led to meaningful inclusion for participants, the findings point at the important role of staff in supporting and facilitating friendships and close relationships of people with intellectual disability.

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